EAPC 2017
15th World Congress of the European Association for Palliative Care
Progressing Palliative Care

18 – 20 May 2017
Madrid, Spain

www.eapc-2017.org

EAPC
European Association for Palliative Care
www.eapcnet.eu

SECPAL
Spanish Society of Palliative Care
www.secpal.com
Abstracts
EAPC President’s Welcome

Dear Friends,

Welcome to the wonderful city of Madrid! Bienvenidos a Madrid!

On behalf of the EAPC Board of Directors, I am delighted to welcome you to the IFEMA Congress centre and to the 15th EAPC World Congress. This Congress, as others, is the result of two years of planning, organisation, meetings, reflection, decision-making and finally, here we are! I am in no doubt that the 2017 Congress will demonstrate how, in so many ways, we are ‘progressing palliative care’.

The choice of title is important. Both as an organisation and as a discipline, we are making progress. As I am sure you will experience over the three days of Congress, we continue to shape the global palliative care landscape in terms of research, education and clinical practice. This Congress is our opportunity to share and celebrate our work, to greet old friends and make new, but ultimately to remember that our time together in Madrid demonstrates that, in a myriad of ways, we share one goal: to promote the optimal care of patients and families living with chronic, life-limiting and life-threatening disease. And we should never forget that we do that well.

The multidisciplinary nature of palliative care is the strength of our identity. I am particularly pleased that this Congress will honour the essential work of volunteers as a key component of that multidisciplinary team through launching a new EAPC charter on volunteerism. My particular thanks to Leena Peltaari, Ros Scott and EAPC Board Member Catherine Walshe for bringing this important work to this point.

As always, there are many people to thank. Not least is the Scientific Committee, ably led by Professor Dr. Christoph Ostgathe as Chair, and his team in Erlangen, Dr. Franziska Herbst and Ms. Andrea Scotti. Thank you all for your contribution, vision, leadership and tenacity in bringing this Congress to us. Equally important is the Local Organising Committee under the direction of Dr. Alberto Alonso Babarro and Mr. Carlos Alonso and SECPAL, without whom this Congress would not have been possible. Les damos las gracias por hacer posible este Congreso en España.

Y a nuestros colegas españoles ... Deseo dar una bienvenida especial a todos nuestros delegados de España y agradecerles la invitación a su hermoso país.

And of course, thanks to the EAPC Head Office Team, Dr Julie Ling, Dr Amelia Giordano and Ms Eleanor Blake for their continuing work to support this Congress.

The theologian and philosopher, Henri Nouwen exhorts us to ‘be sure that you make a difference in the world’. I hope that your time in Madrid helps you appreciate how you make that difference.

I wish you a wonderful Congress and an enjoyable visit to this most wonderful city.

Professor Philip J Larkin
President, European Association for Palliative Care
Welcome from the Chairs of the Scientific and Local Organising Committee

Dear Congress Participant,

On behalf of the EAPC Board and the organising committees we are delighted to welcome you to Madrid and the 15th World Congress of the European Association for Palliative Care. Throughout the world, palliative care is growing in strategic importance to healthcare delivery. In some countries, however, the development of quality-driven systems to meet the increasing need for best possible care for patients with advanced diseases and their families remains underdeveloped. Therefore, the title chosen for this congress is ‘Progressing Palliative Care’. ‘Progress’ stands for the better transition of evolving evidence into practice, timely integration of palliative care into general care, further service development with adequate access to specialised care and the openness to new technologies in our field.

The congress provides the opportunity for you to discuss advances in the field of palliative care, to debate how access to palliative care is developing globally, to assess the integration of palliative care across healthcare systems and ultimately to affirm, develop and change our multi-professional practice. Societal involvement in palliative care continues to be critical to broadening the development and the vision and scope of palliative care. The launch, at this congress, of the ‘Voice of Volunteering’ – the EAPC Madrid Charter on Volunteering in Hospice and Palliative Care – recognises the impact that volunteers have on patients, families and the wider hospice and palliative care community. In particular, the charter acknowledges the role that volunteers make to the patient and family experience.

From the first EAPC congress in Paris in 1988 to Copenhagen in 2015, the EAPC World Congresses have developed and evolved and continue to provide a platform for all of those working in palliative care. More than 2,500 delegates representing a range of disciplines from many countries in Europe and from further afield will attend this EAPC World congress. This makes it the ideal forum for the exchange of new information, the discussion of new research results, and the provision of up-to-date education and training. Additionally, attending the EAPC World Congress also provides a unique opportunity to network and meet with colleagues, clinicians, caregivers, researchers and educators in palliative care from across the globe to exchange knowledge and to share experiences.

Madrid is honoured and proud to host the EAPC World Congress and wishes a warm welcome to the global palliative care community. The cosmopolitan capital of Spain is an open and thriving metropolis, which has embraced change whilst maintaining strong Spanish tradition. Madrid is a beautiful city with many world-class attractions and it is the only capital city in the world that has six World Heritage Cities only one hour by car from the city centre. We hope you will find time to take advantage of the climate, food, and culture that Madrid provides.

We are delighted that HRH Queen Letizia of Spain is the President of Honour for the EAPC conference 2017.

Professor Dr. Christoph Ostgathe  
Chair of the Scientific Committee

Dr. Alberto Alonso Babarro  
Chair of the Local Organising Committee
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PL01

Progressing Palliative Care: Current Perspectives and Future Directions

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No abstract available
Beyond Cancer: Challenges and Opportunities for Early Palliative Care Engagement

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Palliative care should be provided to patients with advanced stages of disease irrespective of diagnoses. However, the majority of patients receiving palliative care suffer from cancer. Patients with non-malignant diagnoses, such as cardio-respiratory, kidney or liver failure or dementia, have similar symptom burden and palliative care needs as cancer patients but often earlier in the disease trajectory. Prognosis in non-oncological patients is more challenging, with repeated crises, such as acute exacerbations or acute decompensation in organ failure or more lingering decline in dementia and frailty. Traditional palliative care models as developed in cancer patients might not be appropriate for these patient groups and might not be a good use of resources. Palliative care provision should be based on need rather than diagnoses or prognoses. Therefore, models of evaluating patients’ needs regularly need to be developed, with indicators and pathways to aid in deciding when to consider palliative care provision. Depending on the underlying disease, various models of palliative care provision are imaginable. These vary from strengthening of generalist palliative care and integrated care models in primary and home-based care to more specialist palliative care services for specific diseases, such as heart failure or COPD. Also, symptom-specific services, such as breathlessness services, might provide an opportunity for early integration of palliative care in these patient groups. If palliative care should be provided to all patients with advanced disease who are in need, clinicians, researchers, funders and policy makers need to challenge the traditional models and perceptions of palliative care and develop new ways to optimise outcome for these patients.
Challenges for Palliative Care in Changing Societies

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This presentation summarises the ongoing evolution of palliative care’s involvement in the social dimensions of care – tracing this care from efforts by professionals, then volunteers from hospice, to volunteers in the community, and finally to civil actions in towns and cities. Civil actions are part of a ‘public health’ approach to palliative care – they promote prevention, harm reduction and early intervention strategies designed to address the co-morbidities of dying, ageing, caregiving, and grief. Core parts of these actions include community development, public education, social ecology, health promotion, and policy development. These actions occur within local government, workplaces or schools, or within religious or cultural organizations. Most of these social actions are generated by what are now called “Compassionate Cities”. Each city commits to a 13-point Charter guiding them to particular areas of social support in broad areas of end-of-life care. The international development of these city-wide approaches are described.
From Bed to Bench and Back: Finding Evidence to Support our Clinical Practice

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Bedside care is familiar to every palliative care practitioner. We observe and listen to our patients in order to give them the best possible personalized care. However, sometimes we make observations that do not make sense or challenge our professional perceptions and practice. This talk will start by presenting some fascinating examples of how bedside observations have triggered research that in turn has given new perspectives on clinical practice – from bed to bench and back.

Evidence in palliative medicine has mostly come from clinical research: registry studies, health services research, and observational and interventional studies directly involving patients or family members. Bench research refers to basic science research mostly performed in a laboratory. The concept of ‘bench to bed’ often relates to research directed at finding out one particular piece of a scientific puzzle, using modern ‘-omics’ techniques that analyze the function and structure of proteins or genetic material. This approach is linked to the current concept of ‘personalized medicine’ or ‘precision medicine’, which aims to select the most appropriate therapies based on a patient’s genetic makeup or other molecular or cellular characteristics.

This talk will try to outline the basics of ‘precision medicine’ and discuss its relevance for palliative care, both the limited applicability at present and more promising future prospects. The emphasis will be placed on some practical examples of ‘bench to bed’ translations.

Leading experts in palliative care and oncology have argued that ‘personalized medicine’ in its new meaning may overshadow the individually tailored, whole-person care that is fundamental for the palliative care approach (Cherny et al, JNCI 2014). Palliative care must face the challenge of applying basic science results to clinical practice while at the same time affirming its culture and philosophy.
FLORIANI LECTURE: PROGRESSING PALLIATIVE CARE IN LOW AND MIDDLE INCOME COUNTRIES

DE LIMA L.
IAHPC, Executive Director, Houston, TX, United States

In May 2014, the World Health Assembly (WHA) adopted a palliative care (PC) resolution, which outlines clear recommendations to the UN member states, such as including PC in national health policies and in the undergraduate curricula for healthcare professionals. It also highlights the critical need for countries to ensure that there is an adequate supply of essential PC medicines, especially those needed to alleviate pain.

This WHA resolution carries great challenges: Every year over 20 million patients (of which 6% are children) need PC at the end of life. However, in 2011, approximately three million patients received PC, and only one in ten people in need of PC is currently receiving it. Most of the world’s population, especially those living in Low and Middle Income Countries (LMICs), has little or no access to pain control and palliative care.

The purpose of this plenary is to present a summary of the status of PC development in LMICs.

The main objectives of this presentation are to:
1. Provide information on the status of PC in LMICs
2. Present the challenges that LMICs face and possible ways to overcome them
3. Identify some success stories from LMICs, and look at how they may serve as examples to other countries of the world
4. Explore ways in which civil society and academia could collaborate to continue advancing PC efforts

There are ways in which the inequities can be overcome and they all require awareness and understanding of the political, social, economic and ethical issues relevant to this situation: Universal health coverage must include PC; healthcare workers need to be educated; and PC needs to be recognized as an essential priority for funding in health.

After this presentation, participants will have a better understanding as to how the global PC community can help in progressing PC in LMICs and the ways in which mutual collaboration may be beneficial for the development of PC globally.
Filling the Gap between People, Management and Technology in Palliative Care

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No abstract available
Social Inequalities in Admission to Specialist Palliative Care. A Nationwide Study from the Danish Palliative Care Database

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Background: Socioeconomic position (SEP) has repeatedly been found to be associated with admittance to healthcare facilities, but studies investigating its influence on access to specialised palliative care (SPC) are few and limited.

Aim: To investigate whether cancer patients’ SEP is associated with their admittance to SPC (hospital palliative care team/unit and/or hospice).

Method: A register-based study with data from the Danish Palliative Care Database, The Danish Cancer Registry and national registers at Statistics Denmark (2010–12). SEP was measured by education and family income. The associations were investigated using logistic regression analysis adjusting for sex, age, cancer diagnosis, cohabiting status and geographic region.

Results: In the study population (N=44,480), 6% had missing data about education or income. Primary school was the highest attained education level for 45%; 6% had a long academic education. Admittance to SPC increased with increasing education level; persons with a long academic education were more likely to be admitted to SPC than those having completed primary school only (OR=1.68; CI 1.50–1.88). The results were similar when subdivided into hospital-based palliative care team/unit and hospice; OR=1.47; CI 1.30–1.67; OR=1.72 1.51–1.96, respectively. In relation to income, admittance to SPC increased with increasing income: persons in the highest quartile of income were more likely admitted to SPC compared to the lowest quartile (OR 1.43; CI 1.34–1.52). This association was stronger for hospice (OR= 1.67; CI 1.54–1.80) than for hospital-based palliative care team/unit (OR= 1.18; CI 1.10–1.26).

Conclusion: This nationwide register-based study indicated that admittance to SPC was clearly associated with education and income. We hypothesise that persons with lower SEP do not have the same resources to communicate their needs and to search knowledge about SPC. We believe that the observed associations indicate inequity and should be corrected.
A Phase III, Multi-site, Randomised, Double Blind, Placebo Controlled Parallel Arm Study of Daily Extended Release (ER) Morphine for Chronic Breathlessness

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Introduction: Phase II studies and meta-analyses support using regular low-dose oral morphine to safely reduce chronic breathlessness when underlying causes are treated optimally.

Aim: To determine efficacy and safety of ER morphine for relieving chronic breathlessness and predictors of response.

Methods: Opioid-naïve participants with modified Medical Research Council scores (mMRC) 2–4 despite optimal treatment of the underlying cause(s) were randomised to double-blinded placebo or 20mg ER morphine daily for 7 days. The primary outcome was reduction in breathlessness intensity (0–100mm visual analogue scale; a clinically meaningful reduction is >5.5mm). Secondary endpoints were adverse events.

Results: 282 participants (mean age 73.7, SD 9.5; 162 [57%] with COPD) were randomised in 12 sites in Australia. There was no difference in average breathlessness over the previous 24 hours, but worst breathlessness in people with COPD and mMRC 3 or 4 was significantly reduced in the intervention arm (response rate 54% vs 33%; p=0.035). Using an adjusted mixed model with daily scores, worst breathlessness improved on morphine compared to placebo (4.57mm; 95% CI, 0.31 to 8.83; p=0.036); in patients with COPD (6.30 mm; 95% CI, 1.36 to 11.24; p=0.012); and COPD with mMRC 3,4 (11.47mm; 95%CI, 5.21 to 17.73; p < 0.001). Withdrawals were similar between arms (time to event, event rate). Constipation and drowsiness were more frequent on morphine. There were no treatment-emergent episodes of respiratory depression.

Conclusion: People with COPD and more severe chronic breathlessness gain symptomatic benefit safely from daily ER morphine.
Best Abstract/Mejor Abstract

Building Primary Level Palliative Care Capacity through Education across Canada: The Pallium Canada Experience

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Background: Since 2001, Pallium Canada (a non-profit, government-funded organization) has been providing PalCare education for healthcare professionals across Canada. The last two years have seen significant scaling up and outreach.

Goals: Diffuse the Palliative Care Approach among non-palliative care specialists and carers, and accelerate the integration of PalCare in Canada.

Intervention: The Learning Essential Approaches to Palliative Care (LEAP) 1 to 2-day courses are interprofessional and competency-based. There are several versions for different settings; from community to emergency services, nursing homes and hospitals. Some are disease-specific (e.g., LEAP Renal). There are classroom, online and blended options. Quality Improvement is integrated. They are supported by several products; The Pallium Portal (online learning management system for course and learner registration and downloads), a Facilitator Training Program and Pallium Pocketbook and APP. Subject matter experts from across Canada develop the courses using an iterative process that includes peer review.

Results: From April 2014 to March 2015, 43 courses were held across Canada (897 learners). This increased to 205 in 2015/2016 (7,867 learners). From November 2014 to March 2016, 3,555 nurses, 1,707 physicians, 72 pharmacists, 1,271 paramedics and 195 social workers participated. There are 510 certified facilitators across Canada. Key partnerships include: the Ontario Renal Network and Nova Scotia Emergency Services. Over 30,000 books have been distributed. 89–98\% of participants recommend the courses to colleagues. Impact on knowledge, attitudes, comfort levels and commitment to change will be reported, as will the scalability model.

Lessons learned: It is possible to launch a national education initiative. The scalability model and impact on outcomes such as knowledge, attitudes and changes in practice will be presented. The next steps involve developing Compassionate Schools and Carers programs.
EAPC Researcher Award Plenary: Winner of the Post-Doctoral Award

Palliative Care for People with Intellectual Disabilities: An International Perspective

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People with intellectual disabilities make up 2% of the population. When they develop palliative care needs, the challenges for carers, professionals and service providers are enormous.

For the past 15 years, I have focused on researching this area. What is it like for people with intellectual disabilities, and their families and carers, when they reach the end of life? Why is accessing palliative care so difficult for them? What are the issues? How can we do better – whether it is listening to their needs, or helping them understand what is happening, or assessing symptoms in people who communicate differently, or making end-of-life decisions, or finding ways to collaborate and organise services? Some of these questions need to be answered by people with intellectual disabilities themselves, and I have worked with them as informants, advisors and co-researchers – occasionally breaking the rules of research in order to make it accessible!

There is a growing international focus on the palliative care needs of people with intellectual disabilities. We set up the EAPC Taskforce on Intellectual Disabilities which developed consensus norms and best practice guidance, published as a White Paper in 2015. Another international project involved developing an agenda for research priorities for palliative care of people with intellectual disabilities in Europe. It is important to investigate the challenges in achieving best practice and find ways of addressing them. Much work is still to be done.

I am honoured and delighted to have won the EAPC post-doctoral researcher award, and look forward to sharing my research experience and findings.

Amanda Cresswell, my co-researcher with intellectual disabilities, will support me during my talk.
Dignity and Other Lessons from Portuguese Clinical Research

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For the past seven years, I have been conducting research on several aspects of end-of-life psychosocial experience, mainly dignity, but also depression, anxiety, desire for death and demoralization.

The concept of dignity was always one of the central aspects of medicine. To think about the dignity is an imperative of modern medicine.

Dignity Therapy (DT) is a brief psychotherapeutic intervention, which provides patients an opportunity to convey memories, important disclosures and prepare a legacy. We conducted the first Portuguese randomized controlled trial, with the aim of studying the effect of DT on several psychosocial variables. Our results were the first ever to show the efficacy of DT in several psychosocial variables in highly distressed terminally-ill patients.

Many other clinical research opportunities have emerged along this period.

Desire for death and demoralization within the context of palliative care have become prominent medical issues. Our group conducted the first Portuguese studies on the prevalence of desire for death and demoralization and its clinical correlates.

Many lessons have been drawn from this path, mainly on the fields of dignity and the precious need for dignity conserving care.

Clinical research has elaborated a profound change in my personal world view. This change can be conveyed via some simple principles:

- Be humble – nothing is more important than people’s needs and wishes.
- Be watchful and curious – research opportunities are all around us.
- Adapt clinical research to people’s needs – simple research can be the best research.
- Don’t get overexcited and isolated from reality with data and numbers.
- Surround yourself with honest and morally good people.
- All research “belongs” to patients: without their commitment and generosity, no study would be possible.
- Dignity should be the value, not a value.
- Finally, nothing can ever happen without the support of those that are attached to you through love – family.
Cross-National Comparisons Today and in the Future

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Cross-national research is widely established in health services and health policy research, including the fields of palliative and end-of-life care. It is a way for us to reach important insights about end-of-life care practices in different countries. Cross-national comparisons also serve to generate hypotheses about links between health care policy and care delivered to patients. Although much of cross-national research to date permits limited inference about the causes of observed differences between countries, over the past years it has led to empirical evidence that should inspire a response. This includes careful thought about and in-depth investigations of how particular countries organize palliative and end-of-life care.

This lecture will present: (1) the purpose, possibilities, and limitations of cross-national research as it has been conducted in palliative and end-of-life care to date; (2) important insight gained from cross-national comparisons; (3) how findings from cross-national comparisons can and should be used and followed up in research and policy-making; and (4) an overview of the questions that cross-national comparisons in palliative and end-of-life care should seek to answer in the coming decade. The speaker will illustrate and elaborate on these points through examples of her own cross-national population-based research on specialist palliative care use, the quality of dying in care homes, hospital admissions at the end of life, and place of death. Ultimately, this lecture will present arguments for upholding cross-national comparisons as an essential element of research in palliative and end-of-life care.
Parallel Sessions

PS01 Successful Innovation Strategies in Latin America in the Implementation of the WHA Palliative Care Resolution / Estrategias de innovación en Latinoamérica para la implementación de la Resolución de Cuidados Paliativos de la Asamblea Mundial de la Salud

PS02 Palliative Care: Complexity, Economics and Health Policy

PS03 Volunteer Delivered Interventions: What Are the Issues in Understanding and Measuring Outcome and Effect?

PS04 New Developments in Spiritual Care

PS05 Advances in Pain Management / Avances en el tratamiento del dolor

PS06 Advances in Neurological Palliative Care

PS07 Education and Specialisation in Europe and Beyond

PS08 Innovations in Psychological Interventions

PS09 Integrated Palliative Care Services: A Matter of Life and Death (InSup-C) / Servicios integrados de cuidados paliativos. Una cuestión de vida y muerte (InSup-C)

PS10 Thrombosis and Anticoagulants in Palliative Care

PS11 EAPC Research Network Session on Research Methodology

PS12 The Role of Palliative Care Social Work in Europe

PS13 Optimal Advance Care Planning / Optimización de la Planificación Anticipada de Cuidados

PS14 MRSA – Multiresistant Pathogens in End-of-Life Care

PS15 Palliative Care in Long Term Care Facilities in Europe: State of the Art (EU-funded PACE project)

PS16 Update on Paediatric Palliative Care

PS17 Maruzza Foundation – Palliative Care for Older People: Understanding Frailty / Cuidados paliativos para personas mayores. Comprendiendo la fragilidad

PS18 Palliative Care for People with Heart Failure

PS19 Recognising and Responding to a Spectrum of Bereavement Needs

PS20 Primary and Community Care
ITES (Transforming the System Initiative): A Plan to Promote the Undergraduate Teaching of Palliative Care in Latin-American Medical and Nursing Schools

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Introduction: All health professionals should be able to provide adequate assistance at the end of life; the WHO considers education one of the crucial aspects to implement Palliative Care (PC) in a country.

The International Association for Hospice and Palliative Care (IAHPC), the FEMEBA Foundation (Argentina) and the University of Aachen (Germany) developed the ITES to promote the teaching of PC in undergraduate medical and nursing schools in Latin America.

Method: The ITES began in Colombia, and was developed in the following stages:
1. A visit to six universities to meet with deans, curriculum committees, teachers and students to know their perception and interest in PC (March 2014).
2. A workshop to determine in consensus the competences in PC in the undergraduate of physicians and nurses (November 2014).
3. A workshop to display teaching models of PC and review technical aspects of teaching (December 2015).

Results: In stage 1 the interest in the project became evident.

In stage 2 thirty-six people representing 16 medical and 6 nursing schools participated in a workshop to discuss and define through a consensus process, the PC competences for undergraduate level in both disciplines.

In stage 3 different technical aspects of teaching were evaluated and work was done in groups to design undergraduate classes using the competences agreed in the second stage and the previously technical aspects analyzed.

The ITES generated interest, willingness to participate and enthusiasm among the participants. It motivated different universities to modify their curricula: at present 18 already did it using the competences identified, and others are in the planning process.

Conclusions: ITES helps each country to model this discipline curricula discipline according to the needs of patients and resources. ITES will be replicated in other countries of the Region: the development of stages 2 and 3 has been scheduled in Argentina in April 2017.
Projecto Lucy: Innovation in the Financing and Provision of Palliative Care Services

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Introduction: In Colombia, 200,000 people die a year. The New Health Foundation (NHF) is a non-profit organization in Spain, dedicated to the promotion and implementation of palliative care systems, via implementation methodologies of excellence (NEWPALEX), that have shown effectiveness, improvement in palliative care and cost optimization. In 2014, NHF in collaboration with prestigious institutions and organizations such as the IAHPC, launched the Lucy project to promote palliative care in Colombia.

Aims: To develop and implement a new national organizational model for end-of-life care.

Method: Creation of programs and resources for palliative care within care providers, redesigning financial models for services by insurers, stimulate the training of professionals and generate social awareness.

Results:

1) New political framework: Proposal for a national palliative care strategy with the National Cancer Institute in 2015. In 2016 NHF collaborated with the Cuenta de Alto Coste, an institution of major national authority, to establish a national model of mandatory compliance for every insurance company in the country.

2) Improve the service offerings through a new management model: Based on the cost analysis of more than 20,000 terminal patients in Colombia and demonstration of the economic impact from its implementation, the Lucy project, according to the NEWPALEX® Method, created a management model for the country’s public and private insurers and service providers, that has proven to be tremendously efficient for the former and very economically profitable for the latter. Currently the model has been implemented in various insurance organizations that exceed the 15 million insured affiliates in the country.

3) Social awareness: Projects to create compassionate cities (Proyecto Todos Contigo) have been put in place for the purpose of involving citizens in providing care at the end of life in various cities including: Cali, Medellin, and now Bogota, Cundinamarca.
How to Measure and Monitor Progress? Palliative Care Macro Indicators of the Latin American Association for Palliative Care

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Background: Recently the ALCP developed a set of indicators to monitor the development of palliative care, which may be applicable to the development of regional and national strategies.

Aim: The aim of this paper is to evaluate the efficacy and applicability of the indicators.

Methods: The indicators are based on the WHO Palliative Care Public Health Model (indicators in each category): Policy (1); Education (3); Service Provision (3); and Opioids (3). Using data collected in 2011–2012 through the ALCP Atlas for Palliative Care in 19 countries of the region, each indicator was applied and analysed. An index was constructed adding the standard score (z-score) of each indicator. Multiple regression analysis was conducted to evaluate whether the indicators were predictive for palliative care development.

Results: Costa Rica registered the highest score (8.5). Summation of z-value scores for Costa Rica, Chile, Argentina and Uruguay were higher than 4.0 (75th percentile). Guatemala, Dominican Republic, Honduras and Bolivia had –4.0 or less (25th percentile). Analysis of three indicators was not possible: percentage of nursing schools which include palliative care in their undergraduate curricula and number of pharmacies dispensing opioids per capita (information not available). Existence of palliative care in the primary care level was eliminated as it registered a positive response in all countries with no variance.

Conclusion: The ALCP indicators are a useful tool to assess the level of development of PC and for follow-up monitoring. It may be applicable to all regions of the world. Additional studies are needed to evaluate the specificity of each indicator.
PS02 | Palliative Care: Complexity, Economics and Health Policy

Complexity and Costs in Palliative Care: What Patient-level Characteristics Drive Resource Use?

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The hospice movement has provided a model of excellent care for those with advanced disease. However, there are marked inequities in provision. Those who are older or with non-cancer conditions, for instance, are less likely to receive hospice or palliative care. There are also major geographical variations in provision resulting in often poor match between the needs of a patient/family, the resources provided to meet those needs, and the improvement in symptoms/quality of life achieved. This presentation will report evidence for a systematic approach (a case-mix classification) to accurately capture the complex needs of patients with advanced disease, to better understand and quantify those needs, and to fairly allocate resources to meet them.
Measuring Palliative Care’s Effect on Healthcare Costs

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The economics of palliative care is a subject of growing attention among researchers and policymakers. This lecture will summarise key points about economic evidence to date in the field of palliative care, and highlight priorities for future economics and policy research. The lecture will also aim to provide practical insights for researchers who are interested in addressing these priorities in their own work.
Health Policy Reformation through Engagement of Dying Patients and their Families

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Delivery and financing of palliative care are generally regarded as fragmented and suboptimal. Access to palliative care is inadequate and public knowledge of palliative care is limited. Although integrated, coordinated and comprehensive programs have been introduced two decades earlier, their adoption and spread have been limited. Palliative care continues to evolve opportunistically and relies on charity, local champions and uncertain revenue streams. In Canada, a health policy reform initiative called Palliative Care Matters (PCM, www.palliativecarematters.ca) was launched. Building on a consensus development conference model, the role of patients, family and public as experts was acknowledged. Building on twenty years of largely unaddressed national palliative care recommendations, we hypothesized that enhancing the role of patients and families was necessary to effectively translate evidence and influence policy. PCM created an visible interface between scientific experts, patients, family, public, healthcare providers and policy makers. A coalition of CEOs from fourteen governmental and national organizations were created to maximize and sustain policy formation. Eight scientific experts and a twelve member lay panel carefully considered systematic reviews and a national opinion poll answering six questions. A two-and-a-half-day conference culminated in a consensus statement containing twenty recommendations. Informed by knowledge and lived experiences it is notable that the recommendations were drafted independently by the lay panel. Governments and key stakeholders have been asked to provide contextual information, including economics, so that the recommendations can be operationalized. A robust evaluation framework measuring engagement, policy formulation, implementation and outcomes has been deployed. Lessons learned and progress will be reported including baseline metrics, media, social media and uptake by governments and stakeholders.
Research with Volunteers in Poland: Understanding Outcomes from the Perspectives of Repeated National Surveys

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Volunteers have played crucial role in creating hospice movement in Poland (In Solidarity. Hospice-Palliative Care in Poland, Gdansk 2015). Since 2007, when the nationwide initiative called ’I like helping’ had started, volunteering has been recognized anew. All hospice-palliative care centers in Poland had been invited to the series of initiatives regarding development of volunteering and improvement of volunteer’s coordination. At the end of three years program, with more than 100 centers involved, different local initiatives have been created. The nationwide program brought new volunteers to hospice-palliative care, trained and empowered coordinators, establishing them in the caring teams, as confirmed by action research (Social and educational functions of hospice-palliative care. Action research 2002–2010, Gdansk 2012). Five years after this research initiative, in front of the demographic changes and migration trends in Poland, new model of training for volunteer coordinators or managers is needed. New research would show level of willingness of local communities to respond to the growing needs and present level of support for hospice-palliative care.

Aims: What is the situation of volunteering and its coordination in the five years after the completion of the project in hospices compared with centers that have not joined the project I like helping.

Methods: survey among volunteers, coordinators and leaders of centers, participating in the project and those that have not joined the project

Results: 2012 results showed significant improvement in: quality of care, financial stability, cooperation with schools, and local communities among those participating in the project. To what extent these differences will be seen in five years after empowering volunteers?

Conclusion: Comparison will show endurance of the process of empowerment of coordination of volunteers and hp care volunteering in local communities in Poland, and new management challenges.
Volunteer originated, led or delivered services and interventions are increasingly common within palliative and end-of-life care. Volunteers are known to have different roles and functions across services, contexts and countries. The importance of volunteers and understanding and guiding their work is recognised by the EAPC with their volunteering taskforce. Research and service evaluation is a vital component of delivering and improving services, but this requires a clear understanding of what outcomes could be expected from such services/interventions and how to measure and understand outcomes and their impact. Whilst there has been much attention paid to outcomes in palliative and end of life care recently, attention has tended to focus primarily on clinical outcomes, which may not be appropriate for expected outcomes associated with a volunteer provided service/intervention. Delegates to this session will learn about the choices made by different researchers when studying volunteer services. They will gain a greater understanding of the issues to be considered in outcome assessment (both quantitative and qualitative) for volunteer led studies. The strengths and weaknesses of different tools or approaches will be considered, and speakers will contextualise this discussion with reference to their own current research with volunteer led, managed or delivered services or interventions. Delegates will be able to use this information to aid their own design and or interpretation of studies both for the purposes of research and service evaluation. Invited speakers are from different countries (UK, Ireland, Poland) and contexts, with experience of working with and conducting research in partnership with volunteers in statutory and voluntary/charity contexts.
**Juggling Stories and Statistics: A Critical Reflection of Outcomes in the INSPIRE Trial Designed to Evaluate a Volunteer Led Model of Practical and Social Support for People Living at Home with Palliative Care Needs in Ireland**

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**Background:** The INSPIRE trial aims to evaluate the effectiveness of volunteer-led models of social care and practical support for people living at home during their last year of life, with a focus on Milford Care Centre’s Compassionate Communities Good Neighbour Partnership. INSPIRE is aligned to the MRC Framework for Complex Interventions and includes a feasibility RCT (n=80).

**Aim:** This presentation explores and challenges the assumptions made by the lead researcher as she attempts to understand and measure the outcome and effect of volunteer-led community mobilisation for people with palliative care needs.

**Method:** The lead researcher’s assumptions were explored using Fook and Gardner’s (2007) theory and process of critical reflection adapted for n=1.

**Results:** Three critical incidents are shared, together with identification of key constructs and assumptions, noting where and how they fit together. These were often in conflict with the original research hypotheses and study design, yet exploring these interpretations and constructions formed the real learning from INSPIRE.

**Conclusion:** Fook’s model generated the capacity to explore and tolerate uncertainty during this exploratory study, as the researcher tussled with the power of the story vs. the need for robust quantitative data.
Aims: Spiritual care is still the least developed dimension of palliative care. The EAPC Taskforce on Spiritual Care aims to further “evidence-based spiritual care”, and identified the need to perform a recent comprehensive review of the relevant literature to support research in the priority areas of the Taskforce, covering the English, Dutch, German, Spanish and Portuguese language.

The research questions of this systematic review are:
1– What are the activities concerning spiritual care in palliative care?
2– Which healthcare professionals provide spiritual care?
3– What are the outcomes of spiritual care in palliative care?

The aim of this systematic review is to map the existing knowledge on spiritual care in palliative care.

Methods: A systematic review was conducted. Literature was collected from the databases PubMed, CINAHL, ATLA, PsychINFO, ERIC, IBSS, Web of Science, EMBASE, PiCarta, DIMDI, Ethmed, PSYNDEX and MEDPILOT, SciELO, RCAAP, Bireme and LILACS. The inclusion criteria:
1– peer-reviewed article that describes original research,
2– provides information on spiritual care in palliative care,
3– study is traceable
4– is published between 2010 and 2016.

Two independent reviewers assessed titles and abstracts, and subsequently the full texts independently. Data were extracted using a charting table, which comprises PCC, study characteristics and the elements concerning the objective of this review.

Results: Preliminary results will be presented, including a flowchart illustrating the article selection process, the charting table with study details that comprise the elements to the objective of the review. Also, templates will present the data to the three research questions.

Conclusions: The results will provide a base for identifying gaps in existing knowledge as well as for listing suggestions to improve spiritual care in palliative care, concerning it research, education, implementation in clinical practice and policy.
Aim: To provide guidance on spiritual care education for all palliative care professionals.

Target group:
- Professionals involved in teaching or training palliative care and spiritual care
- Stakeholders, leaders and decision makers responsible for training and education provided to all professionals involved in palliative care
- National and local curricula development groups.

Scope: The white paper on spiritual care education in palliative care provides a framework with recommendations for spiritual care training and education at a general palliative care level (Gamondi et. al. 2013). According to the white paper on palliative care competencies all palliative care professionals should be able to:
   - Demonstrate the reflective capacity to consider the importance of spiritual and existential dimensions in their own lives
   - Integrate the patients’ and families’ spiritual, existential and religious needs in the care plan, respecting their choice not to focus on this aspect of care if they so wish
   - Provide opportunities for patients and families to express the spiritual and/or existential dimensions of their lives in a supportive and respectful manner
   - Be conscious of the boundaries that may need to be respected in terms of cultural taboos, values and choices.

This white paper on spiritual care education describes these four domains in detail providing poignant examples from existing curricula, consensus papers, and evidence based research in this field.

Proceedings: A paper will be written by the steering group members. The draft will be discussed with experts from EAPC Spiritual Care RG and revised based on the feedback from these experts. The revised draft will be circulated to the national member associations of EAPC and their curricula development groups. The final version will be submitted to the board of directors of EAPC for adoption as an official position paper of EAPC.
Background: Interest to study spiritual care (SC) raises. The EAPC contributes to establish rigorous development frameworks through its Spirituality Taskforce.

Aims: To inform of SC Implementation initiatives. To publicize results from the Implementation subgroup activity to explore and recognize clinicians and others working in palliative care SC understanding. Study the impact of professional and sociodemographic characteristics.

Methods: SC profile was raised in EAPC conferences by its Spirituality Taskforce. The Implementation Subgroup set out to scope SC, including a survey designed from different disciplines and cultural backgrounds. Once piloted, it was disseminated online to clinicians and others in palliative care, sourced via a circular email to all EAPC members, social media, and “snowballing” (colleague to colleague). Quantitative data analysed using descriptive statistics; free-text responses thematically. Hypothesised relationships between respondents’ characteristics and emergent themes tested. Conferences aided results dissemination and discussion.

Results: Colleagues feedback encourages coordinated implementation. The survey shows that SC represents variety: from assessment to therapy and planning. It yielded 452 responses – 68% female, 35% aged 46–55 – from across the world. 66% of them engaged in spiritual – including religious – practices. Most, regardless of own faiths and spiritual activities, addressed similarities and differences between religion and spirituality. Other themes included engaging in conversations with patients and families; collective or individual prayer; provision of religious, pastoral or counselling services; music, art, or complementary therapies. 28% followed formal guidelines.

Conclusion: Strict Implementation and culturally sensitive spiritual activity need careful attention. Professionals have varying understandings re SC scope, not all follow guidelines. Internationally agreed definition and scoping could improve SC provision and development.
What Should we Know as Clinicians about Opioid Interactions?

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Patients with advanced cancer need multiple drugs from several pharmacological classes to control symptoms of progressing severe disease. In addition many patient receive anti-cancer treatment and take medications for the management of concurrent diseases. Due to the complexity of their disease patients with advanced cancer are often treated by physicians from more than one medical specialty, including clinical oncologist and palliative care physicians. Consequently, cancer patients with advanced disease are at high risk for complications caused by drug induced adverse effects and drug drug interactions (DDIs).

DDIs can be either pharmacokinetic or pharmacodynamic. Pharmacokinetic DDIs are caused by that a drug inhibits or increases the activity of an enzyme responsible for opioid metabolism. One example is rifampicin which increases the degradation of oxycodone thereby minimising oxycodone efficacy. Pharmacodynamic interactions is that a drug cause some of the similar actions as an opioid. One example being benzodiazepines which like opioids cause sedation. Pharmacodynamic interactions can also be caused by drugs with opposite effects such as opioids and naloxone.

Because DDIs may influence pain management physicians should be aware of potential DDIs related to opioid therapy.
Do We Need Step 2 of the WHO Pain Ladder – An EAPC Research Network Study

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The need for step 2 of the WHO analgesic ladder has been questioned, but more evidence is needed. A pilot study supported a multicentre RCT: patients “worst pain” and “average pain” scores were lower with the 2 step than the 3 step (p=0.003 and p=0.03 respectively). Patients in the 2 step arm achieved pain control more quickly than those in the three step arm; median of 5 days versus 11 days. In the 3 step arm of the pilot study hospital admissions were more common due to poor pain control.

Multicentre RCT

Primary objective: Establish if a 2 step approach to cancer pain relief can achieve stable pain control more quickly but without increased side-effects compared to the standard 3 step approach of the WHO ladder.

Secondary objective: Establish if a 2 step approach to cancer pain relief has improved health economics compared to the standard 3 step approach of the WHO ladder.

Design: An international, multicentre, open randomised parallel group trial comparing a two step approach for cancer pain relief with the standard three step approach of the WHO ladder in patients with cancer pain requiring step 2 analgesia (weak opioid).

Duration of trial was 20 days from randomisation.

Other treatments influencing analgesia: stable before study entry.

All patients received standard background care: 150 patients over 36 months.

Primary Outcome: Time to achieving stable pain control, where stable pain control is defined as the first day of three consecutive days with average pain score ≤3 using scores from the Patient Diary and patient assessments.

Secondary Outcomes:

Mean of daily average pain scores from the Patient Diary
% days with average pain score ≥ 6 from the Patient Diary
% days with worst pain score ≥6 from the Patient Diary
Pain intensity, pain relief, and pain interference scores at day 10 and 20 from the BPI
Distress score at day 10 and 20 from the NCCN Distress Thermometer.

Study results will be presented.
Radiotherapy for Pain and Bone Metastasis

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Radiotherapy can be broadly divided into external radiotherapy (normally delivered by a linear accelerator) radiotherapy given by radioactive isotopes (iodine$^{131}$, strontium$^{89}$ and radium$^{223}$) or brachytherapy.

Radiotherapy is used both with a curative and palliative intent. Bone metastasis is the most prevalent indication for palliative radiotherapy, while brain metastasis and spinal cord compression are also prevalent conditions in need of palliative radiotherapy.

Bone metastasis is often diagnosed due to local pain. Supplementary images are needed before radiotherapy can be offered to the patients. Bone scintigraphy and often supplemented (not always) with regular x-rays, CT, scans and MRI are often the diagnostic procedures.

The painful area verified by imaging is often the target volume. Standard therapy is 8G x 1. Side effects of the treatment are often mild and up to 75% of the patients experience pain control within few days or up to 2–4 weeks.

Brain metastasis can be treated with whole brain radiation, with stereotactic radiotherapy, that is often given as one or a few fractions delivered to the area of the brain where the metastasis is located. In some cases patients can be treated with neurosurgery often supplemented by post-operative radiotherapy.

Spinal cord compression is clinically often presented as back pain with or without neurological symptoms like irradiating pain and reduced strength in the extremities. The defined diagnosis is often based upon an MRI. Treatment will often start with high dose corticosteroids. Thereafter one need to consider to offer patients radiotherapy and/or neurosurgery.
**What Neurologists Would Like from Palliative Care**

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**Background:** Many people with neurological disease need palliative care. The role of palliative care for those with progressive disease – such as amyotrophic lateral sclerosis, and other neurodegenerative disorders, multiple sclerosis and primary malignant brain tumours – has already been delineated, although prognosis and thus the timing of palliative care involvement will vary.

The European Association of Palliative Care Taskforce, in collaboration with the Scientific Panel on Palliative Care in Neurology of the European Academy of Neurology has recently published an evidence-based consensus review based on the available literature on palliative and end-of-life care for patients with progressive neurological disease, and their families (Eur J Neurol 2016;23:30).

**Results of review and recommendations:** Overall there is limited evidence to support the recommendations but there is increasing evidence that palliative care and a multidisciplinary approach to care do lead to improved symptoms and quality of life of patients and their families. The main areas in which consensus was found and recommendations could be made are in the early integration of palliative care, breaking of bad news, involvement of the wider multidisciplinary team, communication with patients and families including advance care planning, symptom management, end-of-life care, carer support and training, and education for all professionals involved in the care of these patients and families. Neurology teams often receive little education how to break bad news and in palliative care principles.

**Conclusions:** There is a continuing need to develop the evidence base and ensure that palliative care is included in guidelines about the care of people with neurological disease. This is already the case for ALS, but needs to be done for other neurological conditions as well. There is a pressing need for increased collaboration between neurology and palliative care.
The NICE Guideline on MND/ALS – How Can it Be Used across Europe?

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In the UK the National Institute for Health and Care Excellence (NICE) has produced guidance on the care of people with MND / ALS, using a rigorous process of a comprehensive literature search and synthesis of the data using GRADE methodology (www.nice.org.uk/guidance/NG42).

The guideline includes:

- Recognition and referral – encouraging awareness of MND / ALS and speedy referral
- Information and support at diagnosis – the diagnosis should be given by a neurologist with expertise and knowledge of MND / ALS
- Organisation of care – a clinic based Multidisciplinary Team to co-ordinate care with regular assessment and management of all areas of care
- Psychological care – support should be provided
- Social care – a specialised practitioner should be able to discuss these needs
- Planning for end-of-life care – all professionals should be open to discuss end-of-life care, including advance care planning
- Provision of equipment – the need aids should be assessed regularly and equipment provided speedily
- Nutrition – regular assessment and consideration of gastrostomy
- Communication – assessment of all communication needs and ensuring equipment can be integrated with other equipment
- Saliva management – careful assessment and management is needed
- Cough effectiveness – cough augmentation techniques should be offered
- Non-invasive ventilation – respiratory assessment should be undertaken at all stages of the disease progression and NIV offered when appropriate. Support should be provided for people stopping NIV, at their request
- Cognitive assessment – should be undertaken at diagnosis if there are concerns about cognition or behaviour.

Conclusions: Although these guidelines have been produced within the UK, they are based upon international best evidence and so are applicable across Europe, with awareness of differences due to local health and social care systems. They aim to improve quality of life, and death, for people with MND/ALS and their families.
The first international guideline on the topic of palliative care in neurological diseases was coordinated by the EAN/EAPC task force (D. Oliver et al.) and published in 2016 in the Eur J Neurol. The aim was to start a “development of palliative care for patients with chronic and progressive neurological disease” something which was not common attitude when the group started some years earlier. For this, we pulled together available evidence in a semi-structured way, and came to clear conclusions not specific for any neurological diagnosis regarding e.g. the beginning of palliative care, triggers for specialized palliative care, advance care planning, family and carer support, care in the dying phase and bereavement.

In the meantime, several international disease groups have now also started to work on guidelines, now with a more rigorous methodology (e.g. systematic reviews) due to more work power available. For instance, currently, a guideline “Palliative care in adult glioma patients” (coordinated by M Taphoorn, De Hague und A Pace, Rome) is being developed; similarly, in the multiple sclerosis community, a guideline “Palliative Care for People with severe Multiple Sclerosis” (coordinated by A. Solari, Milano) is being developed, with support by the EAN and ECTRIMS.

Drawing on the experience of the National Guideline program in Germany, it will be discussed how
(1) it could be avoided that in different guidelines there will be different recommendations,
(2) how the structure and relation between a “generic” and “disease specific” guidline could look like, and
(3) how recommendations from oncological palliative care guidelines could be transferred to be relevant for patients with neurological diseases.
Specialty Training Improves Quality of Care

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The status of official Palliative Medicine (PM) training for physicians in Europe has been thoroughly mapped and analysed in recent years by an EAPC dedicated Task Force lead by University of Navarra (Spain) and Accademia delle Scienze di Medicina Palliativa, Bologna (Italy). Results of a pan-European WHO region (53 countries) expert survey have been published in Supplement of the EAPC Atlas of Palliative Care in Europe and on the Journal of Pain and Symptom Management. Showing a comparative analysis about the main features and peculiarities of training programs in PM lead to the understanding of a non homogeneous system often tailored upon country palliative care and health services organizations. Recent data show that in Europe the process is still in the works, and in countries in which programs exist already they are under constantly improvement. Moreover, the European trend is to keep launching official educational programs in other countries. This session aims at updating the issue which raised the issue of understanding the of the education provided to physician all over Europe.
Palliative Medicine is a rapidly evolving speciality that often challenges practitioners’ clinical expertise and professional development. The number of patients with palliative care needs will increase, with the WHO projecting that the proportion of the European population over the age of 65 will rise from a current 16.3% to 27.8%. In response, the WHO has called for Palliative Care to be “integrated as a routine element of all undergraduate medical ... training”. A Taskforce (IMEP – International Medical Education in Palliative Care) from the EAPC Steering Group on Medical Education and Training developed EORTC structured translations of validated assessment tools in French, German, Spanish and Italian. The translated assessment tools were piloted within local institutions to establish the feasibility of collecting meaningful data on the effect of undergraduate training programmes. In addition to the work of the EAPC taskforce, MD students from Aachen University, and PhD students in collaboration with the University of Liverpool had developed further translation and assessment of the tools in China, India, Brazil, Argentina, South Africa, Nigeria, Armenia and Georgia. The “Global IMEP Initiative” seeks to: 1) pilot an electronic version of the assessment tools; 2) Coalesce existing data; and 3) engage wider international collaboration to establish baselines on the preparedness of newly qualified doctors to practice palliative care. Data from established baseline will assist in the further assessment and promotion of the integration of training in palliative medicine across Europe and beyond.
Providing High Quality Palliative Care without Having a Specialized Training

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Palliative care (PC) has been part of Spanish Public Health care services since a new Law was launched in 2002. Some years later, a national plan was published in which each region committed itself to achieving some mandatory objectives, however, 15 years later, the authorities have not yet implemented the accreditation system for PC doctors and nurses. What a barrier!

Government and PC professionals have always agreed not to launch a full specialty. Since 2004, SECPAL has tried to convince them to launch a subspecialty, with the support of many related scientific societies. In 2004 and 2011, two sudden changes of government stopped an almost definitive agreement, bad luck!

Recently, Spanish government has not opted for specialization nor subspecialization. A third level accreditation, the diploma, which was accepted by SECPAL only as a temporary emergency solution, is currently under way. However, this process runs very slowly. Maybe some kind of leaders palliophobia? bad luck again!

So, the quality of the provision of PC depends on the selection procedures. But this does not happen in the same way in all regions, nor in all institutions,

Some good news... There are at least 9 universities teaching high-quality Master Degrees in PC. Each year about 200 persons complete these studies that enable them to perform comprehensive quality PC. Some health institutions take into account this in their selection procedures and others do not. In Madrid, for example, the government requires physicians to have at least 1,400 hours of initial training and 50 hours of continuous training per year. In other regions, however, no preparation is required to be part of the PC teams.

Parliament is currently debating the promulgation of a general palliative care Law with the agreement of most political parties. Healthcare professionals are hopeful that this Act will give new impetus to the expected professional accreditation. New opportunities are coming?
Available data from countries across Europe show that people tend to avoid end-of-life care discussions, including practical aspects such as writing a will or sharing their wishes for funeral service.

Thinkaboutdeath.org is an online tool developed with the aim to facilitate thinking and discussing the end-of-life care preferences. It enables the visitor to complete a list of last wishes, from easier topics (such as preferences for music during funeral/memorial service) to more difficult (such as fears related to death and dying), which can be shared via social networks and email.

The original website, published in Czech as http://mojesmrt.cz in September 2014, has been visited by more than 180 000 users since the launch, with more than 80 000 people engaging in the development of the list of last wishes and 3150 successfully completed the whole task. User data analysis showed that this form of an online tool can be used not only by young people (primary target group were young adults between 18–34 years of age) but also by other age groups, with 52 % users being older than 35 and 20 % older than 55.

The EAPC granted its auspices for development of English version of the application, which will be available to a wider international community.
Integrated Psychological Intervention in Palliative Home Care – The DOMUS Study

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**Background:** Patients and their informal caregivers have numerous psychological and psychosocial needs during palliative care. Many patients wish to receive care and die at home. Few home-based specialized palliative care (SPC) interventions systematically integrate psychological support. A randomized controlled trial (RCT) of home-based SPC called DOMUS was developed which included a psychological intervention integrated in the SPC as part of interdisciplinary care.

**Aim:** We aimed to develop a systematic and needs-based psychological intervention with focus on existential concerns. We also wanted to test its acceptability and feasibility by assessing uptake and utilization.

**Methods:** A manual for a needs-based psychological support intervention was developed based on existential-phenomenological therapy. The intervention aimed to alleviate distress in patients and caregivers and enhance patients’ chances of receiving care at home. A pilot test was performed and enrollment in the overall DOMUS RCT and uptake of the psychological intervention component were examined from the outset.

**Results:** An intervention manual was prepared describing the principles of the systematic needs-assessment, the therapeutic approach, and the course of sessions. The manual was pilot-tested and enrollment in the RCT and uptake of the psychological intervention indicated that it was acceptable to patient and caregivers and feasible. Few percent chose to withdraw early from the psychological intervention, and no patients who had dropped out of the overall RCT named the psychological intervention as the cause.

**Conclusion and discussion:** We concluded that psychological intervention can be systematically integrated into SPC. The overwhelming majority of patients and caregivers found the psychological intervention component of the RCT acceptable, and that it was feasible to conduct in this population. The DOMUS RCT will provide results of a novel model of multidisciplinary SPC.
Psychotherapeutic interventions have been shown to significantly reduce symptoms of anxiety and depression and enhance quality of life in patients with cancer. However, a substantial number of patients do not receive psycho-oncological interventions tailored to their individual situation although many studies indicate high levels of emotional and psychosocial distress in patients with advanced cancer. Given the lack of reliable data on the efficacy of psycho-oncological interventions in palliative care settings, a brief, manualized individual psychotherapy for patients with advanced cancer: Managing Cancer and Living Meaningfully (CALM) was developed by Rodin and Colleagues (2014). CALM aims to reduce depression and death anxiety, to strengthen communication with healthcare providers, and to enhance hope and meaning in life. We adapted the intervention for German cancer care settings and used a single-blinded randomized-controlled trial design with two treatment conditions: intervention group (IG, CALM) and control group (CG). Patients in the CG received a usual non-manualized supportive psycho-oncological intervention (SPI). Adult patients with a malignant solid tumor who have tumor stages of III or IV (UICC) were randomized between the IG and CG and assessed at baseline (t₀), and assessed after three (t₁) and after 6 months (t₂). We used validated measures for depression, distress, quality of life and related constructs. Results will be presented showing baseline psychological depression and the course of depression and distress in both intervention arms over time. Possible therapeutic effects and perceived efficacy of CALM will be discussed.

Opening Doors for Integrated Palliative Care: What Needs to Be Done?

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Aims: Many patients with advanced disease experience unnecessary and often burdensome hospital transfers and interventions, with possible overburdening of family caregivers. It seems difficult to ensure that patients with palliative care needs receive appropriate care at the right time, in the right place, by the right caregiver. This is the essence of integrated palliative care. In this presentation we will explore examples of integrated palliative care in Europe.

Methods: A European Commission funded research project InsupC (www.insup-c.eu, grant no. 305555) has been carried out from 2013–2016. In this project 22 initiatives were investigated that were delivering integrated palliative care in five European countries: the Netherlands, Germany, the UK, Belgium, and Hungary. Multiple embedded case study methodology was used to examine the perspectives of patients (n=156), family caregivers (n=88) and health professionals (n=133).

Results: The analyses of the European guidelines showed that mentioning of the referral criteria for palliative care is often lacking. This explains another finding of the study, namely that palliative care services are often called in too late. Based on the case studies, best practice elements for integrated palliative care appeared to be:
1) multidimensional ‘whole patient’ treatment,
2) development of integrated care pathways,
3) provider arrangements to position palliative care in the chain of care,
4) a regional contact point where palliative care knowledge and expertise can be obtained,
5) societal accountability and visibility,
6) sustainable long term development (resources),
7) accessibility for all patients in need, not only in cancer.

Conclusions: In the project, it was possible to identify best practice elements for integrated palliative care. However, contextual variation was important to make local integration work in practice. Inspiring practices have been highlighted in a book and in an online learning course.
Integrated Palliative Care: Evidence from International Research in Europe

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Introduction: Integrated care concerns care at the right time at the right place at the right moment, by the right caregiver. During the past years, the EU FP7 InsupC project has investigated integrated palliative care initiatives across five European countries. In this presentation, we explore the way forward for integrated palliative care and identify recommendations.

Methods: To organise a policy workshop in Brussels, September, 2016. At this workshop, three presentations were given about the InsupC results, one addressing a patient level, one addressing an organisational level, and one more directed at a policy level. Participants split into 4 groups to discuss the findings and make recommendations. The recommendations were collated and sent out to policy group members for ranking about importance using transparent expert consultation technique. A similar list of recommendations was sent to participants of an online course on the project.

Results: Over 500 people contributed to rankings of the recommendations about what integrated palliative care should encompass. During this presentation, these results will be presented and discussed in the light of the recent WHO resolution on integrated care (2016). The latter has identified a framework for integrated people-centered health services with five strategies.

The most important recommendations were: 1) Integrated palliative care should encompass different dimensions of care including physical, psychological and spiritual aspects and 2) Palliative care regulations and policies should be extended to apply to non-cancer patients as well (COPD, heart failure and dementia).

Conclusion: Integrated care has become an important area of clinical and organizational development in healthcare. Palliative care, by nature, concerns integrated care, but how this can be achieved in practice is not always clear. Policy recommendations will hopefully boost developments and contribute to improved quality of palliative care.
PS09 | Integrated Palliative Care Services: A Matter of Life and Death (InSup-C) / Servicios integrados de cuidados paliativos. Una cuestión de vida y muerte (InSup-C)

Integrated Palliative Care: The American Model

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Aims: This session will provide an overview of the state of palliative care in the US, including the benefits of early introduction of palliative care; the education, implementation, and policy barriers to greater implementation of palliative care; and work to overcome those barriers.

Methods: Based on literature review, advancement of palliative care integration across the US health care system requires policy, education, and practice changes. Gaps in education are being addressed, including both provider and workforce training and certification and patient and clinician education to change the perception of palliative care as limited to end-of-life. Education efforts are focusing on supporting interdisciplinary teams, ensuring advance care planning and setting goals of care, and increased pain and symptom management expertise. US policy changes, the move from fee-for-service reimbursement to value-based payment models, and the formation of integrated delivery systems are enhancing the adoption of palliative care services across the continuum as a cost-effective service that reduces hospitalizations and increases patient and family satisfaction and quality of care.

Results: Integrated palliative care is recognized as supporting the US Institute for Healthcare Improvement’s Triple Aim initiative to enhance the patient experience (including quality and satisfaction), improve population health, and reduce the per capita cost of care. Over the past decade, the availability of inpatient palliative care in the US has dramatically increased. Integration across community-based settings in the home, long-term care, and office practices is the new frontier.

Conclusion: Overcoming the barriers to palliative care requires substantial culture change. This session will describe the opportunities for overcoming barriers and facilitating integrated palliative care for seriously ill patients across the continuum—now and into the future.
Cancer Associated Thrombosis: A Problem We Can no Longer Ignore

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Venous thromboembolism (VTE) is a common occurrence in the cancer setting and the risk of VTE increases with disease progression as does the risk of bleeding. However, the management of cancer associated thrombosis (CAT) falls between several specialties, none of whom have designated responsibility for the ongoing management of CAT.

Whilst there is strong data supporting the management of CAT in the six months, the populations recruited to such study are unrepresentative of the patients commonly seen by palliative care professionals. Furthermore, palliative care teams see a larger proportion of patients with challenging clinical scenarios that fall outside the current evidence base including recurrent VTE, thrombocytopenia and bleeding.

This talk will outline the current data when it applies to palliative care as well as reviewing the management of complex CAT cases seen in the advanced cancer setting. It will present real world data outlining the scope of CAT cases likely to be encountered by palliative care teams. Finally, it will challenge the audience to consider whether palliative and supportive care teams may, of all teams, be best equipped to manage this evolving sub-speciality.
Thromboprophylaxis in Hospice

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This session will look at the current evidence available regarding the use of thromboprophylaxis for patients in the hospice setting.

Should all thromboprophylaxis be stopped when patients are transferred to Hospice from Hospital? Should all patients in hospice be on thromboprophylaxis? What is known and what do we need to find out to answer such questions.
Cancer patients have a higher risk of cancer-associated thrombosis (CAT) and those with CAT carry higher risk of recurrence, bleeding and mortality as compared to non-cancer patients. The LMWH are recommended for CAT secondary prevention. The direct oral anticoagulants (DOAC) have been approved for the treatment of VTE. They are characterized by a rapid onset of action, have renal elimination, no food interactions and limited drug-drug interactions, as compared to vitamin K antagonists (VKAs). They are administered in fixed doses without laboratory monitoring and dose modification. DOACs are not devoted of risk for serious bleeding and their prescription should be restricted to their approved indications. DOACs are contraindicated in patients with severe renal or liver insufficiency. In patients with moderate renal insufficiency the dose should be adapted. Evaluation of hepatic and renal function before treatment initiation is recommended. DOACs present some significant interactions with drugs frequently used in cancer patients, which might influence their pharmacokinetics, compromising their efficacy and safety.

In this context, despite the simplicity of treatment with DOACs and the advantages over VKAs, the risk of bleeding is not negligible. The limited data available today show that the management of bleeding in DOAC-treated patients does not pose a greater challenge than that in patients without cancer. Specific antidotes in management of bleeding complications and development of coagulation assays for their plasma levels will further boost the confidence in the DOACs.

DOACs provide an appealing alternative to LMWH for CAT, but they should not be routinely used for such patients because their efficacy is unproven. The analysis of the available data reinforces the request for the design of new Phase III clinical trials for the assessment of the efficacy and safety of DOACs in specific populations of patients with cancer.
A Randomized Clinical Trial of Accelerated Transition from Oncological Treatment to Palliative Care at Home (the DOMUS Study)

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Background: Specialized Palliative Care (SPC) focuses on improving care for patients with incurable diseases and their families, which includes the opportunity to make their own choice of place of care and ultimately place of death.

Aim: The DOMUS study investigates whether an accelerated transition from oncological treatment to SPC enriched a psychological intervention at home for patients with incurable cancer results in more patients reaching their preferred place of care and death.

Method: DOMUS is a RCT with an allocation ratio of 1:1. The planned sample size is 340 adult in- and outpatients with incurable cancer, with no or limited antineoplastic treatment options treated at a comprehensive cancer center. Patients are randomly assigned either to:
   a) standard care plus SPC enriched with a standardized psychological intervention for patients and caregivers at home or
   b) standard care alone.

The patients are followed for six month and quality of life, several symptoms, psychological and treatment variables are assessed.

Results: 340 patients have been included in the trial and follow-up will close at the 1 of Marts 2070. Background data and trajectories of intervention and control arms are well-balanced.

Discussion: The patients included in DOMUS were similar in age, sex, disease stage, and type of cancer compared to previous RCTs assessing SPC. The baseline findings indicate that the included population is the target group for SPC interventions, which aim at managing and preventing function deterioration and symptom development. The study can provide needed evidence of a research area with very few RCT’s and has both national and international relevance.

The intervention provides a model of how SPC can be integrated into an oncology treatment trajectory. The clinical as well as the organizational and cost-benefit analyses may provide the basis for making decisions about the organization SPC in the future.
Cancer cachexia is multifactorial syndrome defined by characterised by an on-going muscle loss (with or without fat loss) that cannot be fully reversed by nutritional support and leads to progressive functional impairment. Research has been slow in cancer cachexia due to a combination of limited pharmaceutical funding, lack of consensus in regulatory endpoints and the complexity of its pathophysiology. It is argued that to optimally treat cancer cachexia all components (anorexia, the systemic inflammatory response and physical function) should be targeted; termed multimodal intervention.

The MENAC trial (Multimodal Exercise, Nutrition, Anti-inflammatories in Cachexia) is now underway following a successful pilot study. The pilot study will be discussed as will key design considerations in cachexia trials in patients with advanced cancer. The challenge of defining accepted but also clinically meaningful endpoints and patient related outcome measures in cachexia trial design, will be presented, as will the “real-world” challenges of delivering a complex intervention for cachexia.
A major concern in today’s oncology is the complexity of treatment that increases costs. A main contributor to the latter is use of chemotherapy (including targeted therapy and immunotherapy) during end of life (EoL: last 12 months of life). Intensive chemotherapy in EoL has uncertain efficacy, may result in frequent hospitalizations and less time at home. Also, patients with incurable disease who receive intensive treatment at EoL have worse quality of life (QoL). A systematic palliative care (PC) approach that focuses on optimal symptom-management and maintenance of QoL of patients and family is often introduced too late in the disease trajectory. Studies indicate that early introduction of PC in patients with unfavourable prognosis may improve QoL and prolong survival. These and related findings have made international stakeholders advocate a stronger integration of oncology and PC for patients with incurable cancer.

The present project is a national multicentre cluster-randomized trial in 12 oncology departments in all 4 health regions in Norway. The project tests the efficacy of a complex tripod intervention that integrates oncology and PC for cancer patients with a life-expectancy < 12 months who receive chemotherapy and includes: A) implementation of standardized care pathways, B) systematic electronic assessment of symptoms and C) an education program for oncologists/PC physicians. The PC pathway focuses on the patient’s journey through the PC trajectory including EoL care in order to improve quality of care and reduce the variability in clinical practice and costs. The intervention aims at empowering physicians, patients and relatives and promoting shared decision-making. The primary end point is use of chemotherapy the last 3 months of life; secondary end points are patient reported outcome measures, patients’ satisfaction with information, and relatives’ QoL. Inclusion of patients starts in the beginning of 2017 and the study will be finalised in 2019.
The Palliative Care Social Workers’ (PCSW) performance is based on specific knowledge, skills, empirical diagnosis and social policy concerns. Their roles are crucial to improving well-being in patients’ and families’ life. Recently the European Association for Palliative Care (EAPC) Task Force for Social Work in Palliative Care published the ten core social worker competencies: 1) Application of the principles of PC to social work practice; 2) Assessment; 3) Decision-making; 4) Care planning and delivery; 5) Advocacy; 6) Information-sharing; 7) Evaluation; 8) Interdisciplinary team-working; 9) Education; and 10) Research and Reflective practices. Based on this key competencies, we will discuss different PCSW education, attitudes, knowledge and skills through the Europe. Topics as the assessment, evaluation, information-sharing and the interdisciplinary team-working have been encouraged by the EAPC Social Work Task Force as standards for PCSW in the Europe. However, a pragmatic view of different cultural environments may justify the barriers to implementing good practices.
Parents Experiences of when an Adult Child is Seriously Ill – They Are Still your Child

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**Background:** In Europe there is an ageing population. This can cause that older person’s likelihood can be confronted with family member’s serious illness. Older parents in a growing aged population is at the risk that they may have to follow their adult child in a severe illness and even to their death.

**Aim:** To investigate how a parent to an adult child with a severe illness experienced the situation according to social life, existential thoughts and need for support.

**Methods:** A qualitative design with data collected by in-depth interviews to gain a deeper understanding.

**Result:** The result showed that a common sense was that it is a very special experience to have an adult child with a severe illness. There were five areas that was highlighted; The existential experience that had underlying areas; Life took a wrong way, Difficult to see the child as sick and The increased worrying about the child. All those areas influenced the whole situation. The other four areas being important was; Having information, Participation in the child’s life, Strategies to cope with the new situation and Need for support- both support for the parent and being support for the child.

**Conclusion:** Following an adult child with a severe and maybe fatal disease can be an increased problem with the elderly population in Europe. So far there are limited research in this area and there is need for more research to increase knowledge.
Developing Capacity in End-of-Life and Bereavement Care: Hospices and Schools

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Background: The author was a hospice social worker responsible for coordinating a children’s bereavement service in Scotland. Often referrals to the service did not require specialised support and could have been managed within the child’s existing community networks. These practice experiences echoed movements within end-of-life care policy and practice that recognise the importance of communities in supporting and enabling positive end-of-life and bereavement care. This identifies the significance of a public health approach to palliative care that seeks to develop the capacity of communities to manage and support end-of-life and bereavement experiences.

Aims: To extend the work of a hospice to engage with local primary schools to advance education and support around death, dying and bereavement; and to explore the role of social work in working with communities around palliative care.

Methods: An action research approach was employed with two primary schools in Scotland. Participants included children aged 9–12 years, parents, teachers and hospice staff who participated in a series of interviews and focus groups to identify better practice and engage in change processes.

Results: Seven innovations were identified that were of relevance to the school curriculum and the relationship between hospices, school communities and wider society. The innovations involved refocusing the social work role on more proactive work with communities that prioritised both sharing and co-producing knowledge and expertise.

Conclusions: Developed practice suggestions require a reorientation of both hospice and school services. Transferring professional knowledge across hospice and school settings is essential for the development of successful and sustainable practice that engages and supports children on issues related to death, dying and bereavement. Social work has a significant role in the development of public health approaches to palliative care.
Defining Advance Care Planning

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Advance care planning (ACP) is increasingly being implemented yet its concepts and content vary considerably and are often not evidence-based. An ACP framework, consisting of a definition of and recommendations for ACP, that is supported by scientific evidence and expert opinion, and appropriate to a variety of cultural values, is currently lacking. Our EAPC-taskforce aimed to develop such an ACP framework, based on consensus by a panel of experts with varying professional and cultural backgrounds, achieved through a multiple round Delphi study and literature reviews.

In round 1, which was qualitative, 11 experts from 5 countries established a draft definition and core domains in a two-day invited expert meeting. Subsequently, 33 draft recommendations were formulated pertaining to recommended core elements of ACP, timing, policy, and evaluation. The recommendations were based on 41 identified literature reviews, additional literature searches, and expert opinion. Round 2 and 3 of the Delphi study concerned online surveys, asking panelists to indicate their agreement with our ACP definition and the 33 recommendations on a 7-point scale (1 indicating strongly agree; 7 indicating strongly disagree); qualitative comments could be added. In total, we invited 144 experts. 124 experts agreed to participate (86%) and were sent the online questionnaire. 109 responded (109/124=88%) of whom >100 also participated in Round 3. The results will be described in a white position paper and can provide guidance for clinical practice, policy and research in end-of-life care. We will present the full results at EAPC 2017. In our parallel session, we will present the ACP definition (Speaker 1), and our recommendations for its content and timing (Speaker 2), and policy and evaluation (Speaker 3). The session will be of high interest for a diverse population of healthcare professionals, policymakers, and scientist in the field of advance care planning and end-of-life care more general.
Recommendations for Advance Care Planning: Policy and Evaluation

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Advance care planning (ACP) is increasingly being implemented yet its concepts and content vary considerably and are often not evidence-based. An ACP framework, consisting of a definition of and recommendations for ACP, that is supported by scientific evidence and expert opinion, and appropriate to a variety of cultural values, is currently lacking. Our EAPC-taskforce aimed to develop such an ACP framework, based on consensus by a panel of experts with varying professional and cultural backgrounds, achieved through a multiple round Delphi study and literature reviews.

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Objectives: It is the aim of the EAPC to offer a consensus framework in the form of a White Paper. This presentations focuses on content and timing of ACP.

Methods: We chose the method of a Delphi study based on scientific evidence and expert consensus. Eleven experts established a draft definition and core domains in a two-day meeting. Based on systematic literature reviews, 33 draft recommendations were formulated pertaining to core elements of ACP, timing, policy, and evaluation. In two rounds of an online survey, experts indicated their agreement with our ACP definition and the recommendations on a 7-point Likert scale.

Results: Among 144 ACP experts worldwide invited, 124 agreed to participate (86%). Subsequently, 109 filled in the questionnaire (response: 109/124=88%; adjusted response: 109/144=76%). We formulated 18 recommendations regarding the content and 3 regarding the timing of ACP, most of them receiving very strong agreement, in particular the following: ACP should be adapted to the individual’s readiness to engage. ACP includes the exploration of the individual’s health-related experiences, knowledge, concerns and personal values across the physical, psychological, social and spiritual domains. ACP includes exploring goals for future care. ACP may include the appointment of a personal representative and documentation thereof. ACP includes information about the option and role of an advance care directive and may include the completion of it. Healthcare professionals should provide individuals and their family with clear and coherent information concerning ACP. A trained non-physician facilitator can support an individual in the ACP process. Individuals can engage in ACP in any stage of their life, but its content can be more targeted as their health condition worsens or as they age.

Conclusion: These highly consensual recommendations can serve as a robust basis for ACP implementation.
Implementing Advance Care Planning in German Care Homes for the Elderly and for People with Disabilities – Report from a National Consensus Process Based on Recent Legislation

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Background: Due to its forceful patient orientation, systematic implementation of Advance Care Planning (ACP) in regional health systems is often perceived to encounter significant barriers, and to bring about a cultural change. How to introduce ACP to a national legal framework may be a challenge, involving questions of definition, acceptance, standards, training, certification, coordination, and reimbursement.

Aims: To report how Germany became one of the first countries worldwide to include ACP for selected target groups in the general health care coverage, and to describe barriers and facilitators.

Results: A pilot trial with a German ACP program adapted from the US Respecting Choices, beizeiten begleiten, demonstrated feasibility, and positive effects of ACP on prevalence and quality of advance directives. On the basis of these and other empirical data, an option to introduce ACP to care homes for seniors and people with disabilities was included in recent palliative care legislation (12/2015). This top down process may have contributed to a lasting irritation on the side of some German stakeholders. Sickness funds and care home carriers have now been negotiating operational details for a year, supported by an expert task force; a regulation is expected by May. The challenge apparently is to make stakeholders appreciate that ACP facilitations constitute a communicative challenge requiring high qualification, and critical certification. Also, there is debate in how far ACP should focus on palliative care issues, and whether ACP facilitation requires palliative care expertise. Moreover, the role of ACP project coordinators is not anticipated in the legislation.

Conclusion: The German legislator has created an option for care homes to offer ACP to their residents, reimbursed by the sickness funds. However, the new law did not reflect a societal consensus at the time, not all stakeholders buy into the concept, and it is uncertain whether the opportunity will be used.
Clinical Relevance of MRSA in Palliative Care

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Meticillin-Resistant Staphylococcus aureus (MRSA) is a globally prevalent antibiotic-resistant bacterium. Even though invasive MRSA infections in healthcare settings are declining, MRSA remains a major threat to patients. While little is known about the impact of MRSA in palliative care settings, MRSA in palliative care has become an increasing focus of research in recent years. Studies have reported prevalence rates of MRSA colonisation of 4–10.7% in palliative care settings and while the current evidence suggests that MRSA can have a significant psychological impact on cancer and palliative care patients, the impact on morbidity and mortality remains unclear. However, one study found that MRSA colonisation did not significantly impact survival. As the management of MRSA in palliative care settings varies significantly both in- and between-countries, the available evidence can help to inform policy development for the management of MRSA in palliative care settings. In an era when antimicrobial resistance continues to increase, insights that the evidence offers will be reflected on and consideration given to the relevance of these findings to the management of other antimicrobial resistant pathogens in palliative care settings.
Emotional Reactions when Caring for Patients with MRSA

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Studies have shown that patients infected with multiresistant pathogens such as MRSA, found it to be a traumatic experience. Many patients compared it to having the plague or leprosy, expressing that they felt dirty and had become infected because they had not washed properly. Therefore, knowledge and empathy on the part of the health care personnel involved in their care is crucial to optimizing their experiences. For health care personnel, it is a challenge caring for patients with antibiotic resistant bacteria. There is a risk of spreading the bacteria among patients and of being infected themselves. We have interviewed health care personnel in Sweden, about caring for patients with MRSA. Although Sweden has a low prevalence of MRSA (about 1%), the germ still presents an increasing problem for society and health care in Sweden. In Sweden, all patient with MRSA are nursed in single rooms when admitted to hospital. The interviewed personnel had all been involved in the care of patients with MRSA, but not on a regular basis. The interviews showed various strong reactions among the personnel when they were asked to describe their experience of caring for patients with MRSA. The interviewed stated that they had ‘respect for the infection’ or that they had ‘some worries about it’, but there were also personnel who regarded the patients as a real ‘threat’ or ‘terror’. It was also reported that the patients were aware of the fact that the health care personnel sometimes were afraid of them and that they did not want to take care of them. When the personnel felt that they had inadequate knowledge in how to care professionally for the patients, it affected both the patients and the patient care situation. Education and easy access to guidelines felt particular importance for the interviewed when caring for patients with infectious diseases as MRSA. The knowledge gained from our study can provide guidance for future health care when new diseases and infections occur.
MRSA in End-of-Life Care: A Patient, Family and Team-centered Approach

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**Aims:** Little information is available about the impact of a positive methicillin-resistant Staphylococcus aureus (MRSA) or other multidrug resistant organism (MRDO) diagnosis for patients, their families and staff members in end-of-life care. Being MRDO carrier and the resulting protection measurements might not be in line with the need for holistic care, personal attention and maintaining rapport. The study’s aims were to integrate patients, families’ and staff members’ perspectives, and to deduce recommendations on handling MDROs in end-of-life care.

**Methods:** An interdisciplinary cooperative project used mixed methods in a geriatric and a palliative care study center. To gain patients’, families’ and staff members’ experiences and wishes qualitative semi-structured interviews and attached quantitative questions were applied followed by focus group discussions. Accompanying work packages were an analysis of MRSA risk factors and MDRO-prevalence at a palliative care unit, a document analysis and a cost analysis. Experts in the field of end-of-life care discussed the draft of the recommendation and affirmed the adapted final version.

**Results:** Patients’ and families’ experiences ranged from being little to strongly affected and burdened due to MDROs. Staff members felt ambivalent between patient rapport and protection of third parties, patients’ comfort and institutional rules. Participants contributed concrete wishes and suggestions to improve their situation in terms of communication and psychosocial support.

**Conclusion:** Our study is the first that integrates the perspectives of those affected. The deduced recommendations provide hand-on advice for the clinical routine on the topics: Strategy in dealing with MDRO at the end-of-life, MDRO diagnostics and therapy, frame conditions and resources, social participation and information, communication and knowledge.

The study “MRSA in end-of-life care” is funded by the German Federal Ministry of Education & Research (BMBF).
Mapping Palliative Care Development in Long Term Care Facilities in 29 EU Countries

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Background: Mapping of palliative care development by country has been undertaken by the EAPC and WHPCA. However, provision of palliative care in long-term care facilities (LTCF) is not adequately covered. As part of the EUFP7 PACE project, under the auspices of an EAPC Taskforce, mapping of LTCFs has been undertaken.

Aim: To map and classify different structures, organizational models, and policies related to palliative care provision in LTCFs in Europe.

Methods: Data was collected from 29 European countries using two methods:

i) country mapping survey using expert informants;

ii) documentary review of secondary data and international reports.

Data was sought on the following domains: organisation of care; place of death; types of LTCFs and terminology; resident populations in LTCFs; status of LTC provision; funding models; regulation; and key drivers for change in LTCFs. The data collected was collated by country and domain and then compared across countries by the domains of interest. A typology of development was then developed.

Results: Whilst an ageing population is common across Europe the structures of long-term care provision vary with different provider types, funding and regulatory models. The development of palliative care provision in LTCFs is shaped by macro (national and regional) and meso (implementation activity) level drivers. Macro level factors identified include legal, regulatory financial, and policy drivers. At the meso level implementation initiatives such as education, quality frameworks and service developments are used to develop palliative care. At the micro level is where the extent of palliative care practice in LTCFs is observed in a country and this varies from no activity to countrywide engagement.

Conclusion: The different levels of palliative care development activity in LTCFs is insufficient to meet the population needs of older residents across Europe. Further work to develop activity at all levels is required.
Quality of Care and Quality of Dying in Care Homes in 6 EU Countries: Main Results of the Epidemiological Study of the PACE Project

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Aim: Assurance of high-quality end-of-life care in care homes is hampered by a lack of cross-national epidemiological data on the quality of dying in this setting. We aimed to
(1) describe and compare the quality of dying of care home residents in six EU countries, i.e. Belgium (BE), Finland (FI), Italy (IT), the Netherlands (NL), Poland (PL), and the United Kingdom (UK); and
(2) to investigate to what extent resident and facility characteristics can explain country differences in quality of dying.

Methods: Cross-sectional retrospective study. We selected 50 care homes per country using proportional stratified sampling and included all deaths of residents that occurred over the three months prior to data collection. We studied care delivered in the last three months of life through questionnaires distributed to the nurse most involved in care, care home management, the resident’s GP and a relative. Quality of dying was assessed using Comfort Assessment in Dying with Dementia (CAD-EOLD) and Quality of Dying - Long-Term Care (QoD-LTC), both reported by nursing staff. All analyses controlled for data clustering.

Results: Response rates: 82% (nurse); 95% (management); 68% (GP); 58% (relative). We studied deaths for which we received valid nurse questionnaires (N=1384). Mean CAD-EOLD scores (theoretical range 14–42) were 31.6 (BE); 29.8 (FI); 32.6 (IT); 30.8 (NL); 30.9 (PL); 33.6 (UK) (p< 0.001). Mean QoD-LTC scores (theoretical range 11–55) were 38.7 (BE and FI); 35.2 (IT); 39.6 (NL); 39.6 (PL); 45.1 (UK) (p< 0.001). Country differences remained significant (p< 0.001) after controlling for resident and facility characteristics.

Residents not affected by dementia were more likely to have a higher quality of dying (QoD-LTC score; p< .001).

Conclusion: In all countries studied, there is room to improve the quality of dying of nursing home residents. The large cross-national differences suggest a need to tailor care improvement measures to country-specific needs.
Integrating Palliative Care in Long Term Care Facilities: Research Challenges in a Cluster RCT in Europe

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Aims: To study the effect of the PACE Steps to Success palliative care programme a cluster RCT is being conducted in 7 countries: Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland. Based on the experiences of designing and conducting this trial, in this presentation challenges of doing a cluster RCT of a complex intervention in different countries will be discussed.

Methods: In the trial, in each of the participating countries on average 12 LTCFs have been recruited; after randomization 6 were control homes and in 6 PACE was implemented (in total 40 intervention homes and 40 control homes). The intervention period was one year and effect measurements take place at baseline and after 13 and 17 months. Primary outcomes are (1) quality of dying of the residents, and (2) staff knowledge and attitudes about palliative care. Secondary outcome is quality of palliative care. Furthermore an extensive process evaluation following the RE-AIM framework takes place.

Results: Both in the phase of designing the trial, and in the phase of conducting the trial there were challenges related to performing a complex intervention trial in several countries. In the phase of designing the trial this concerned among others to make sure the intervention was similar and acceptable in all countries, and define the inclusion criteria in such a way that comparable LTCFs were recruited. In the phase of conducting the trial coordinating that the trial was carried out similarly in all countries was challenging. This could be related to differences in: pacing, health care organization, and culture.

Conclusion: Conducting a complex intervention trial in several countries is possible but challenging. An extensive process evaluation is essential to assessing and understanding differences in how well the intervention is implemented and how successful it can be.
Management of the ‘Fatal Trisomies’: Current Practice and Outcomes from 2 Centres

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Trisomy 18 and trisomy 13 have historically been referred to as ‘lethal trisomies’ and pro-active management has not always been offered due to the assumption of a universally devastating outcome. A recent survey of neonatologists found that 83% felt that trisomy 18 is a lethal condition, 60% thought that treatment is futile and 95% would recommend palliative management only in the neonatal period (1). Studies that include a large proportion of children who underwent medical interventions, however, have reported survival of up to 50% at 1 year (2,3,4). One study has found that a prenatal diagnosis is negatively associated with longevity (3). 36% of children diagnosed prenatally lived less than 24 hours with 47% survival to discharge, but only 1% of those diagnosed postnatally died in the first 24 hours and 87% survived to discharge.

We will present data from just over 100 patients with trisomy 18 and 13 referred to 2 specialist palliative care centres (in UK and USA). We will give an overview of our current practice, which includes interventions that may not previously have been considered a remit of ‘palliative management’. We will also present data for infants referred antenatally and challenge the finding that a prenatal diagnosis need be associated with a poorer prognosis for longevity.

The neonatal period carries the highest risk of dying along infancy and childhood. In developed countries, one third of children under 20 years old die their first month of life (due to extreme prematurity, congenital malformations, birth asphyxia and infections). Many children and adolescents die due to clinical situations originated around birth, causing severe sequelae that limit their life in length and quality.

In perinatal care, professionals have to work in different life scenarios (prenatal diagnosis, diagnosis at birth, life threatening situations in the NICU) that can become death scenarios.

Decision-making in childhood responds to the best interest of the patient. Family is well positioned in defining the best interest of their baby; always benevolent (wants good) but sometimes not fully beneficent (does good). It is important to develop decision-making procedures that preserve the best interest of the baby over the welfare of the family and suffering of professionals. We propose a three steps process.

Professionals and family have to reach an agreement on what is best for the baby. The term quality of life can produce disagreement because it can have different meanings for family and professionals.

Decisions about withholding or withdrawing specific measures can cause disagreement inside the team or with the family. Looking up at the best interest as the first step in decision-making can help us avoid several conflicts. The second step consists on defining the therapeutic goal. Only at the end of the process it is appropriate to discuss therapeutic measures.

A stepwise process can help the team decide according to the clinical and personal situation of the patient, adapting their therapeutic options to the real needs and possibilities of the baby. Some questions can be helpful:

1) What treatment is indicated? (Why?);
2) What is appropriate? (For what?);
3) What is possible? (How? When? Where?).
Palliative Care in the Neonatal Period

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In the United Kingdom (UK), approximately 90,000 infants are admitted to specialist neonatal intensive care units as a result of prematurity, a significant insult at the time of delivery or they are born with complex congenital conditions. This phenomena has been attributed to the rise in survival rate of extremely premature neonates, as well as the advancements in technology supporting infants with life-limiting conditions. In recent years, there has been increasing recognition of neonatal palliative care within the routine clinical neonatal environment and is emerging as a recognised specialty.

The most accurate definition of ‘neonate’ is the first 28 days of life regardless of gestation, however for the purpose of this presentation the term ‘palliative care within the neonatal period’ will reference the antenatal period and the time after 28 days of life for any infant who is being cared for on a neonatal intensive care unit and who has palliative care requirements.

Many national professional agencies and bodies have supported the growing need for good quality palliative care during the perinatal period via educational interventions and the development of frameworks and key documents. These publications provide a foundation on which healthcare professionals can develop local education and training initiatives, and emphasise the need for individualized care plans and family centered care, where family choice is given a high priority.

This presentation will address the appropriate identification of infants and the specific needs for their families; collaboration between healthcare professional teams in the provision of integrated care and the training and education for healthcare professionals and how to ensure that skilled healthcare professionals respond to providing consistent high-quality care for this emerging population of infants and providing appropriate practical and emotional support for their families.
Experiences of Older People Living and Dying with Frailty

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With enhanced longevity, many people in late old age find themselves living at home, with increasing frailty, often experienced as a dwindling pathway of decline. Whilst current policy drivers focus on managing the frailty syndrome through care at home, there is a marked lack of understanding of what this means for older people themselves.

To explore how people living at home experience frailty, the impact of changing circumstance on bio-psycho-social domains and how older people themselves understand “being frail”.

The complex dimensions of social, psychological and physical frailty require diverse methods of inquiry. This paper will draw on my doctoral and post-doctoral research using narrative, ethnographic and participatory action research methods to understand older people’s experience of living and dying with frailty.

The paper will suggest that the predominant models of frailty overlook the capabilities of older people. Not least their resilience as the survivors, outliving most of their birth cohort. It will argue for a new conceptualisation where frailty is understood in terms of potential capability – a state of imbalance in which people experience accumulated bio-psycho-social losses whilst working to sustain and create new ways of being in their worlds. Achieving a balance between loss and continuity is crucial for the well-being of older people and is supported, or undermined, by the quality of their interactions with health and social care, and the wider contexts of their lives. The findings suggest that living and dying with frailty does not fit well within current palliative care policy and practice. It argues for a flexible practice that works with uncertainty and transitions rather than a defined prognosis. The practice would seek to incorporate more fully the social worlds in which people live and perhaps to recapture McCue’s (1995) insight of life moving towards closure, and dying is perceived as a normal process rather than a problem to be fixed.
Frailty is a biologic syndrome of gradual decrease in reserve and resistance to stressors, resulting from cumulative declines across multiple physiologic systems. Frailty is causing vulnerability to adverse outcomes like morbidity, institutionalization and mortality.

The management of frailty in the hospitalized older patient will be discussed based on current literature review and expert based experience.

In hospitalized older patients a systematic assessment of medical, psychosocial and existential risk factors for frailty is important. Tailored interventions may reverse (partially) the frailty syndrome and prevent further decline or development of adverse events. A comprehensive geriatric assessment, by an interdisciplinary team, on well-organized medical units, is an evidence based intervention to improve outcome and functionality of frail older patients. To be successful, the intervention should be tailored to the needs of the older person and his caregiver.

In case of advanced frailty the functional status of the older patient will further decline despite an adequate management. At this moment caregivers should decide to stop stressful interventions like rehabilitation and medical treatments. Advance care planning should register the needs and wishes of the patients and a correspondingly adapted treatment plan should develop.

Balancing between undertreatment and futile treatments in an older hospitalized patient population, requires a systematic evidence and experience based approach to detect and manage the frailty syndrome. Moreover, taking into account the wishes and needs of patients will improve the end-of-life care of the frail older patient population.
Palliative Care and Frailty in Nursing Homes

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Aging in place is a relevant priority of government policy in many European countries. Older persons are encouraged to receive care in the community as long as possible. As a consequence, nursing home care is going through an impressive and challenging transition, with older persons being admitted to nursing homes in more advanced stages of disease and with a mean length of stay until death declining to less than one year in some countries / regions. However, parallel to this policy and demography driven transition, nursing homes are engaged in developing new forms of professionalization and in re-inventing the philosophy of long term care through focusing on a social care model instead of a so called medical model. “Continuation of the ordinary daily life” with an accent on normality and a home like environment are important elements of this model. These apparently contradictory developments with on the one hand more dependent nursing home residents with very complex care needs and on the other hand a care philosophy that accentuates normality and ordinary life create a challenge for the implementation of good geriatric palliative care. Indeed, at present palliative care in the nursing home setting is frequently suboptimal. The presentation will go into the various reasons underlying this situation with an emphasis on conceptual and ideological factors. Data from recent studies will be presented to illustrate how and what providers of nursing home care can learn from palliative care, but also vice versa: how a reflection on the reality of nursing home care can inform and invigorate the concept and practice of palliative care.
PS18 | Palliative Care for People with Heart Failure

Triggers for Starting Palliative Care and Palliative Care Needs Assessment in People with Heart Failure

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Millions of people worldwide are living with and dying from heart failure. Heart failure is associated with a poor prognosis. For those living with heart failure their symptom burden is high with majority of patients experiencing highly distressing symptoms of shortness of breath and tiredness. Psychological symptoms also predominate with high levels of depression. Palliative care services in heart failure are not widely available. Even in the United Kingdom, where there are well-developed heart failure and palliative care services, only around 4% of patients are referred for specialist palliative care. Many patients and their families would benefit from receiving specialist palliative care support.

Despite this poor outlook prognostication is difficult. Models to assess prognosis have been developed yet have their limitations, particularly in the elderly. This adds to the professional’s difficulty in knowing when to contact specialist palliative care services.

This paper will discuss the physical and psychosocial needs of patients with heart failure and outline the current guidance around referral to palliative care. It will also discuss the emerging literature on triggers for heart failure palliative care.
Unquiet Hearts – Avoiding Dilemmas Related to Implanted Cardiac Devices at the End of Life

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Over the past 20 years our understanding of the nature of acute and chronic heart failure has driven the development of robust evidence based guidelines, directed predominately for those with a reduced left ventricular ejection fraction (HFrEF). Such patients are prone to potentially lethal tachyarrhythmias. As evidence for benefit has accrued, there has been an exponential increase in the use of implantable cardioverter defibrillators (ICDs), either as standalone devices, or combined with cardiac resynchronisation therapy in those with moderate to severe HFrEF. Used either as a primary or secondary prevention strategy, many lives have been saved by this intervention. However, given the often inexorable progression of HFrEF, patient goals of care may change, and the continued utility of these devices needs to be reassessed along the disease trajectory. Heart rhythm guidelines suggest that the possibility of later ICD deactivation should be incorporated in the pre-implantation consent process but this discourse is unusual. ICD activity when clinically futile constitutes an avoidable harm and patient and family distress following painful device discharge close to the point of death is well documented. This presentation will describe dilemmas sometimes associated with this therapy and the practicalities of ICD management close to the end of life.
Spiritual Care for People with Heart Failure: An Area under Construction

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Aims: In this presentation we aim to give an overview of the results and challenges in the area of research on spiritual care for people with heart failure.

Methods: After a literature search on PubMed we analysed the results and discussed them in the light of current spiritual care research.

Results: The limited amount of studies that are available are of different quality and show a number of conceptual unclarities and methodological weaknesses.

Conclusion: There is a great disparity between the amount of patients dying every year of heart failure and the amount of research in this area. The research done until now, however, shows the importance of this research area under construction.
In this presentation I will be exploring the role palliative care plays in the delivery of bereavement support. A recent EAPC Bereavement Care Taskforce survey (2015) highlighted the variation in approach to, and delivery of, bereavement care which exists across the community, arguing that there is a role for the EAPC and palliative care services in Europe to formalise the planning of care. How do we do this within the context of significant diversity of culture and need?

Based upon the assumption that we will all experience bereavement and, that grief and loss, are everyone’s responsibility I will pose the question, what is the role of palliative care in providing bereavement support as part of the wider community? I will draw on a review of the literature to offer a brief historical perspective of the development of knowledge and how this has influenced the development of bereavement services. I will argue that one size does not fit all and I will suggest that the Bereavement Care Pathway (2013) and the Bereavement Care Standards (2014) offer useful frameworks which support the development of a comprehensive approach to service development, enabling the building of an evidence based service within the context of the community it operates in, this is particularly important if we are to address issues of diversity.

Using examples from practice I will show how services are being creative in developing a comprehensive approach to the delivery of bereavement support working as part of the wider bereavement support community.
In many developed countries, the most comprehensive strategy for bereavement support is advocated by palliative care services. Although policies and guidelines on standards of bereavement care propose that supports should be offered according to risk and need, studies demonstrate that palliative care services in general adopt a blanket approach to supporting bereaved families. The situation is intricate as there is a lack of clear evidence to guide the development and allocation of cost-effective bereavement support services. Offering professional bereavement support to all bereaved people irrespective of need is neither effective nor affordable. Therefore a public health approach to bereavement support in palliative care is suggested and requires partnerships between palliative care services and primary care practitioners, and also effective links with community based services. Drawing and building upon community resources using an asset based approach would ensure initiatives are cost effective and sustainable.

The presentation will report on the findings of an Australian population based bereavement survey delineating the spectrum of need for bereavement support and providing the research evidence to inform practice and policy. This study investigated the extent to which some of the clinical practice guidelines have been followed by palliative care services, the experiences of bereaved people with getting support and the informal networks they relied upon whether they used or did not use palliative care services for their deceased relatives with life limiting illnesses.
Living with a seriously ill parent and the threat of his or her death is a major trauma for a child. Parents who are seriously ill are likely to report high levels of psychological distress and so are their partners. Many express a need for support from health-professionals regarding how and when to talk with their children about their illness. Parents often try to protect their children by hiding facts about the illness and, in particular, about the risk of death. This hinders communication and can reduce the possibilities for the family to prepare emotionally for the impending death. Parentally bereaved children have an increased risk of psychological morbidity and even death. In our previous research we have found that family- and care related factors have a great impact on family members’ psychological health, both non-bereaved and bereaved. Few family- and child-centered interventions during ongoing palliative care as well as after bereavement have been evaluated. Yet, those few evaluated found that the intervention contributed to reduce conflicts, increase family communication, reduce psychological symptoms of the parents, increased the children’s knowledge about the illness, and decreased the children’s sad feelings and negative reactions. The goal of this project is to develop and evaluate two interventions aiming to increase family communication and to decrease psychological distress in families affected by cancer and loss. Both interventions will be delivered by health-professionals and consist of family meetings. One is a modified Beardslee family intervention and will be ongoing during palliative care and after the parent’s death. The second is a psycho educational family therapy intervention for bereaved family members.
WHO’s Initiative on Palliative Care

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Following the adoption by the World Health Assembly of a resolution on the strengthening of palliative care as a component of comprehensive care throughout the life course, in 2014, the World Health Organization has been working with its Member States on the implementation of this global commitment. The aim is to provide palliative care within the Universal Health Coverage framework, in an integrated manner, across disease and age groups. To do so, countries have to address a number of barriers that still exist regarding access to medicines, capacity strengthening, quality improvement and to develop national palliative care policies. Working at the three levels of the Organization and across programs, WHO has provided technical support and strengthened partnerships with non-state actors. Some progresses have been reported by 40% of countries with palliative care available at primary health care level and strong efforts are made to provide home based palliative care. New regulations have been adopted to facilitate the access to essential medicines. Interesting experiences from Low and Middle Income Countries establishing innovative palliative care programs will be presented, giving special attention to the people centeredness approach. The remaining challenges include the obstacles to equitable access to palliation, in poor settings and very critical situations such as humanitarian crises; the need to develop tools to evaluate the quality and efficiency of palliative care programs; the lack of commitment of some relevant stakeholders. To face these challenges new modalities of work have to be adopted at global level.
The Impact of a New Public Health Approach to End-of-Life Care: Results from a Systematic Review and Mixed Methods Study

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Social isolation is increasingly understood as a public health threat as the impact on mortality and morbidity is recognised. This can be particularly acute at the end of life, for both carers and those with life limiting illnesses. The new public health approach uses the principles of community development to support communities to find solutions for themselves, that augment but run in parallel to clinical end-of-life services. Examples of these initiatives exist around the world but they have not been well characterised.

This session will include an overview of a systematic review of evidence relating to community action in EOLC and articulate the questions the review poses. This will be followed by the presentation of the results of a large mixed methods study demonstrating the impacts such work can have and the facilitative processes underpinning it.
French Plan for Palliative Care 2015–2018 and its Connections with International Initiatives in Primary Palliative Care

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Background: The fourth Plan for Palliative Care 2015–2018 was launched by the French Minister of Health in December 2015. While the three previous plans contributed to develop the specialist palliative care provision (mostly in hospitals), this last one puts a strong focus on community palliative care (Axis 3).

Aims: To briefly introduce the main measures and the policy model for Axis 3, and to illustrate how international initiatives in primary palliative care have been helpful for designing clinical and collaborative tools in the French context.

Methods and approach taken: Top-down and bottom-up approaches are used so that implementation of the plan may occur at various levels in the health system and in social institutions. Collaboration between key actors in the community is the main challenge for Axis 3, and relies on a perspective shift, focussing on the patients’ trajectories. New tools and concepts for addressing end-of-life trajectories come from projects and initiatives in the European Association for Palliative Care, the International Primary Palliative Care Network, and the World Health Organisation.

Results: We displayed Axis 3 as a map where the four pillars of the public health strategy for palliative care (WHO, 2007) are represented: education, research, policy design/implementation, drug availability. International tools, initiatives and evidence base are closely related to the requirements and goals of implementation.

Conclusion/ lessons learned: International collaborations and cross-border comparisons may be very useful in guiding and inspiring the implementation of a national plan for the development of palliative care. Obviously, implementation must also take into account the policy context, public attitude, and the structural constraints within the national health system, in order to best meet the needs of people approaching the end of their life.
Meet the Expert

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ME02 Connected Health in Palliative Care
ME03 Exploring and Understanding Wish to Die Statements
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ME15 Children’s Palliative Care and Outcome Measurements
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Joining a Global Conversation: An Interactive Session on Social Media in Palliative Care

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Although the use of social media in professional contexts is increasing, many academics and clinicians still think Twitter is simply a source of celebrity news and cat photos. In this session we will present an overview of the benefits and opportunities of using social media, speaking from a clinical-academic perspective and a journal editor’s perspective. We will explain social media platforms including Twitter and blogging, and discuss the opportunities that these platforms present in academic palliative care. These opportunities include enhanced personal development through learning from and networking with others in the field, and increasing the impact of published research through international dissemination, and engaging with policy makers and the general public. We will explain the use of #hashtags, tweetchats, and the palliative care Twitter journal club (@hpmJC), and discuss the increasing role of altmetrics as a measure of impact. We hope to generate a lively discussion of the benefits (and potential hazards) of using social media in a professional context, and we will give practical tips and advice for those keen to get started. Bring your smart phone!
Connected Health in Palliative Care

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There is no single definition of “Connected Health”. It may however be considered as an umbrella term for the appropriation of information technology advances in the cause of improved health. As such it includes headline topics such as “Big Data”, “Sensor Technology”, “Internet of Things”, “Wearable devices” and “mHealth”.

Health areas involved in connected health include “Behaviour Change”, “Clinical Decision Support”, “Symptom Monitoring and Assessment” and “Assisted Living”.

Rapid technological advances offer ample opportunities in symptom management. The dynamic nature of advanced illness necessitates continuous monitoring in all locations, including the home. Contemporary medical devices interface sensors with the human body to continuously and non-invasively track physiological functions. Improved data collection should help symptom measurement, targeted treatment and improved quality of life. Objective measures can be combined with subjective patient reports to enable a more comprehensive patient assessment.

In this evolving area, to ensure optimal development of connected health in palliative care, strong interaction between technology professionals and palliative care professionals is vital. The presentation at this session is conducted by one expert from each discipline. The concepts outlined above are explored. Particular focus is placed on the feasibility and patient acceptability of wearable devices in the assessment of common symptoms. How these devices can be adapted for convenient use in a palliative environment is also discussed.

By the end of this session the attendees will have an appreciation of how new technologies, particularly mobile and sensor technologies, can improve patient outcome; knowledge of how to incorporate patient perspectives into changes in practice resulting from technology and increased familiarity with relevant technological concepts such as the “Internet of Things”.

Meet the Expert
Exploring and Understanding Wish to Die Statements

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The expert meeting is directed to all health professionals working with patients in palliative care. It aims at rising awareness to the diverse elements and communication skills to better understand a wish to die statement.

Wishes to die are often referred to as ‘desires to hasten death’. However, research shows that wishes to die are often not reducible only to wishes to hasten death. They are often multidimensional, situated in a broader web of thoughts and contain diverse wishes that might coexist at the same time. Exploring wishes to die at an early stage and not only in their form of a wish to hasten death, encourages a patient-centred dialogue on therapeutic scopes, may enhance palliative care efforts, and prevents patients’ self-perceived stigmatisation and isolation from help. All this might be important for prevention and early detection in palliative care.

In the expert meeting, an analytic model will be presented that can serve as a tool to explore patients’ wishes more systematically. This model points out various elements (intention, motivations, and social interactions around the wish to die) that are important to be investigated upon in communication with patients expressing such thoughts. We then explain the clinical approach and the most important communication skills in addressing these sensitive talks with patients. Participants in the expert meeting can learn that a wish to die can be explored systematically taking into account the diverse elements that contribute to it, distinguishing different forms of wishes to die, as well as recognizing diverse motivations, as objective clinical factors, subjective reasons, individual meanings, and functions in the patients’ narrative.
A Practical Workshop on How to Measure Individual-level Outcomes with Patients and Families in Palliative Care

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Aim: To share/learn best ways to measure and use patient-level outcomes data in palliative care.

Methods:
1. Brief presentation of i) published evidence, ii) emerging evidence from the Outcome Assessment and Complexity Collaborative project.
2. An interactive and participatory workshop to invite delegates to hear/learn from a team which has been engaged in implementing outcome measures into palliative care practice in the UK.

We conducted a project to implement a standard set of palliative care outcome measures into practice with nine local palliative care teams over three years, with a parallel qualitative research study (in-depth interviews with patients, family carriers, and staff) to assess this implementation.

Results: The implementation project itself revealed the importance of good leadership, champions of outcome measurement at several levels in the organisation, integration of patient-level outcomes into information technology/clinical databases, and senior understanding/use of aggregated outcomes data for service development and commissioning of services.

Interviews with 11 patients/family and 27 staff revealed the value of the outcomes interventions for patients (increasing empowerment and more active involvement in care), and for professionals (improving the focus and efficiency of care; especially prioritisation of symptoms/concerns and understanding changes over time).

The Consolidated Framework for Implementation Research helped understand facilitators (such as outcomes champions, ‘near patient’ data capture, and a systematic approach to use of the outcomes data) and barriers (time, training and poor integration into other clinical systems), as well as the inner and outer organisational factors Important for implementation.

Conclusion: Despite the initial extra work needed to implement outcome measures into palliative care, there are notable longer term benefits for patient care. Implementation needs to be well considered and conducted to achieve this.
The Meaning of Qualitative Research Methods and How to Use Them Appropriately

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Background: There has been a substantial amount of qualitative research addressing important aspects of palliative care but concerns remain about the requirements and differences in adopting these methods.

Aims: This session aims to highlight the contributions of qualitative research methods to the palliative care research agenda. It also aims to:

- Explain the epistemology underpinning different approaches to qualitative methods.
- Describe when these methods should be used to answer research questions.
- Explain the differences between qualitative data collection methods and qualitative analysis methods.
- Provide an illustrative example of using qualitative methods to elicit and understand patients’ experiences of living with advanced lung disease.
- Examine the ways to assess the methodological rigour of qualitative research.

Results: Qualitative research methods are based on a range of epistemologies (theories of knowledge) which has implications for how data are collected, how data are regarded during analysis, what claims are made for the findings and how the different methods are evaluated. We will argue that there are two major approaches for qualitative research – methods which focus on the manifest and explicit content and interpretative-reconstructive approaches which focus on the latent meaning. Qualitative data collection uses data including: talk, texts, observations, images and artefacts gathered during interviews, focus groups and observations. There are many methods of qualitative data analysis which are rigorous and usually do not transform data into numbers. There are a number of criteria for judging the quality of qualitative research that are congruent with the epistemology upon which they are based. An example of serial interviews conducted in Germany will be presented.

Conclusions: Qualitative research methods are among the most useful and frequently used methods in palliative care research. They can contribute to evidence-based health care.
How to Research Community Development in Palliative and End-of-Life Care

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The session will start with two introductory presentations from the chairs regarding the potential of community development for capacity building within end-of-life care and how this translates into research priorities and methodologies. The following interactive discussion will be framed around the key issues including; how change in communities can be stimulated, supported, understood, and captured, what are meaningful outcomes for participants and who decides these, how do we deal with the complexity of outcomes and how can questions of sustainability and transferability be addressed. The speakers have experience in using community participatory research approaches in end-of-life care and will share their expertise in grappling with the issues involved in translating research theory into practice.
ME07 | The Role of a National Palliative Care Programme and Moving Palliative Care Forward

The Role of a National Palliative Care Programme and Moving Palliative Care Forward

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Aims: Palliative care has come a long way the past decades. There have been strategic shifts in thinking about palliative care and its place in the national health system. Even within Europe, there are major differences in how palliative care is regulated, organized, and delivered. Despite good examples of palliative care integration in regional contexts, it is often a challenge to get palliative care to the foreground of national health policy. However, if we look at the growing figures of people living and dying with cancer and other chronic diseases, the societal need for a national palliative care strategy seems justified.

This meet the expert session is dedicated towards building of a national program for palliative care and aims to inspire participants to move on with a national program in their own countries. Target group: EAPC delegates who are interested to learn more about a national program in order to move palliative care development forward at a strategic level.

Methods: In this session we want to introduce two current examples of national palliative care programmes, namely those in the Netherlands and in Ireland. A brief introduction will be given into the genesis of these programmes in the country specific context. This will be followed by some practical thinking and working with participants about a palliative care program in their own context and the steps needed.

Results: The participants of the session will start working and thinking on a stepwise approach towards the building of a national program in their own countries, including mapping of stakeholders, barriers and opportunities.

Conclusion: the conclusion of the session will consists of participants briefly reflecting on the value of a national program in their own context and the formulation of steps to act upon.
End-of-Life Care for People with Alcohol and Drug Problems

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Aims: To present an innovative project exploring end-of-life care for people with substance problems; to highlight the challenges and opportunities of researching in an unexplored area of policy and practice; to discuss the process of identifying and exploring relevant health and social care datasets.

Methods: This is a mixed methods study comprising: a rapid evidence assessment, key informant interviews, secondary data analysis of qualitative and quantitative data, and the collection of new data from individuals, family members and professionals who have been living with, or working with, life limiting illness and problematic substance use. This session will consider the methodological processes for the key informant interviews and analysis of existing quantitative data and the implications for the future practice and recording of data.

Results: The key informant interviews highlight the frustration and anger for professionals working with this population in relation to the ‘revolving door’ of people in and out of services. There was also discussion of the appropriate place of death and the importance of planning for the end of life, even if someone wishes to continue using substances. They highlighted the lack of, and need for, care pathways to stop people falling between gaps in services. In exploring prevalence and incidence, key methodological barriers are the limited data collection and reporting by palliative care providers, and the reliance on medical diagnostics rather than patient/person centred information which reduces identification of cases.

Conclusion: Findings to date indicate that people with problematic substance use and end-of-life care needs may face inequitable service access due to their complex care needs and unpredictable disease progression, poor knowledge about the co-existing conditions, and few resources and care pathways available. The lack of data to evidence need is unhelpful in moving policy and practice forward.
How to Overcome Barriers to Early Palliative Care Provision for People with Heart Failure

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Improving quality of life and finally of dying of people with heart failure (HF) requires both optimisation of cardiological treatment and meticulous symptom control, psychosocial/spiritual care (elements of PC).

Both approaches are equally important along the whole disease trajectory. PC should be implemented always as needed, instead of transferring the patient from cardiology to PC only when “nothing more can be done”. Improving cardiovascular functions/prolonging life and improving the quality of life aren’t alternatives, but should be pursued equally. If cardiological treatment is sufficient, no additional interventions are needed. If problems persist despite optimal cardiological care, there is still a lot PC can do to support the ill person and relatives.

Caring together is challenging, as cardiology and PC have different perspectives on care and attitudes to professional mission.

PC teams need to learn how to:
- cope with patients who have unpredictable prognosis (compared to patients with cancer), sometimes improving from very wretched health conditions
- start PC along with the maximisation of therapy (LVAD implantation or heart transplantation)
- handle with ICD or pacemakers
- continuously navigate of cardiological treatment (diuretics).

Heart teams need to become accustomed to:
- addressing disease progression in advance in order to be prepared for crises and-ultimately-dying
- accepting patients’ values, which can include refusing therapies even promising from cardiology perspective
- recognising that “non-cardiological” problems are important and need to be addressed
- continuously navigating symptom-oriented medication,
**A New Syndrome of Chronic Breathlessness: Implications for Services, Research, and Health Policy**

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**Aims:** Breathlessness which is persistent despite treatment for the underlying disease is currently under-reported, under-recognised, and treatments for it under-provided and under-used. This session will discuss the implications of a new clinical syndrome of chronic breathlessness which seeks to address these problems.

**Methods:** The name and definition of the new syndrome was developed following consultation with 17 international experts, 3 Delphi survey rounds involving 35 international experts and an international workshop at the 2016 Dyspnea Paris conference.

**Results:** The agreed term, *chronic breathlessness syndrome*, was defined as breathlessness that persists despite optimal treatment of the underlying pathophysiology and results in disability.

**Conclusions:** Recognition of this syndrome could improve clinical care, focus research, empower patients and caregivers and encourage wider uptake of evidence-based interventions. At this session, the floor will be open for delegates to discuss their views on the name, definition and implications for:

1. Clinical practice, both their own practice and for service delivery more broadly.
2. Health policy and the future research agenda and funding priorities.
Vulnerability at the End of Life: The Experiences of Prisoners as Patients and Volunteers

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This session will present two different examples of vulnerability in relation to prisoners and palliative care. The first will draw on findings from a recently completed study in the UK, which explored the multiple and complex challenges faced by prisoners approaching the end of life. Data from interviews with prisoners and a survey of older prisoners highlighted high levels of vulnerability in this population, not just in terms of their physical frailty but also in relation to their psychological state and emotional concerns. The presentation will describe some of the ways in which the prison service has responded to the issues identified through the research and introduced measures to reduce vulnerability amongst older and dying prisoners. The second example will present innovative work from Poland whereby prisoners are trained and supported to work as compassionate carers of vulnerable people in hospices and nursing homes. The project which started in 2003 in Gdansk has spread to over 40 palliative care facilities in Poland. Initial research showed that the majority of prisoners-volunteers look realistically at their lives, which increases their chances of coping effectively with future problems. These elements are less noticeable in prisoners not involved in volunteering. Years of experience in hospice-palliative care volunteering programmes for prisoners make it possible to claim that the presence of illness and dying, experienced in everyday hospice reality, may influence changes in the values and life goals of the convicted. The phenomenon of voluntary work may prove to be important in understanding the meaning of life and the process of positive changes in the functioning of the prisoners after serving their sentence. New elements of this research and more detailed analysis will be presented. In this session the particular issue of vulnerability will be highlighted and delegates will have an opportunity to interact with the presenters and other participants.
How to Plan and to Perform Randomised Controlled Trials in Palliative Care

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Randomised controlled trials (RCT) are essential for the evaluation of interventions in medicine. Efficacy and effectiveness of interventions can only be determined by RCTs. Aiming to deliver high quality and best care for patients and carers in palliative care we need more well conducted RCTs. Which are the challenges in planning and performing RCTs in palliative care? What is needed to realize RCTs regarding qualification, experiences, resources and setting? The session will give some insights in planning and performing RCTs and will discuss and exchange experiences.
Resources for Research, Education and Implementation in Spiritual Care

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Spiritual care is a rapidly developing field in palliative care, and a key goal of this meet the expert session will be sharing experiences, tips and tricks for spiritual care research, education and implementation. The session will be an open dialogue for reflecting upon the latest developments in the field of spiritual care in palliative care in Europe and beyond, and considering possibilities for future activities which might contribute to taking this field forward. The session will be co-hosted by two members of the EAPC Spiritual Care Reference Group. The Reference Group includes colleagues not only from across Europe but also from multiple countries beyond Europe, and with a wide range of professional backgrounds. Prof Carlo Leget was trained as a theologian in the Netherlands, and dr Bella Vivat is a social scientist from the UK.
Palliative Care Needs of Refugees and Asylum Seekers

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We all are deeply affected by the humanitarian crises around the world and the pictures of the suffering of so many who have the misfortune to live in regions destroyed by war; forced to become refugees or asylum seekers, living in tents in neighbouring countries and are dependent on someone to provide for their basic needs and health care. Many of them must live with cancer, organ failure, and other life-limiting conditions or chronic disability.

From our work and research with patients with migration backgrounds, we know that they are treated differently compared to those without a migration background, are disadvantaged and discriminated against. Less often they are referred to palliative care, and health care professionals have problems in assessing their needs and are challenged by language and communication problems. There is a higher imbalance of power between patients and health care professionals.

The palliative care community with skills, knowledge, compassion and access to a global network of support, should support these people. The international palliative care community has articulated a simple but challenging proposition that palliative care is an international human right that applies equally to refugee populations.

The growing consensus between the disciplines of palliative care, public health, and human rights provides an opportunity to collaborate in advancing the access to palliative care for patients and family members facing the diagnosis of life-threatening illness. It strengthens our mandate to act as advocates for this group of people who, because of the place they have to live their illness or grief, have not had the capacity to demand the services they need.

The Meet the Expert session gives an opportunity to get in contact, present examples of palliative care for refugees and find new ideas to provide for these people adequate palliative care, whatever this may mean in such a demanding situations.
Palliative care for children and young people is an active and total approach to care, which begins at the point of diagnosis, and continues throughout the child’s life, death and beyond. The scope of paediatric palliative care (PPC) is broad and services care for children with a wide range of illnesses. Worldwide, more children are living longer with more complex life-limiting conditions due to advances in medical technology. One of the fundamental goals of PPC is to improve health related quality of life for both the child and their family, thus a multidimensional approach is needed which seeks to offer physical, psychosocial and spiritual support.

The use of outcome measures in PPC is essential to evaluate and monitor the impact of multi-professional clinical care, undertake audit and conduct research. There are currently no validated outcome measures for use within PPC and outcome measurement is rarely performed. There are many generic and disease specific measures for use within the paediatric population. Generic measures are designed to be used with healthy children and may lack sensitivity in those who are unwell or dying. The use of disease specific measures makes it impossible to compare outcomes across a group of children who have many different, often rare, conditions. In addition, it is important to consider the recall period and completion time of measures in this population. Many have recall periods of up to 4 weeks and can take up to 30 minutes to complete.

It may be desirable to combine patient centred outcome measures (PCOMs) with patient reported experience measures (PREMs) to gain a more rounded view of quality of care. PCOMs would allow the child and their family to decide which goals are most important to them. PREMs would allow the quality of services delivering care to be measured. What is certain is that more work is needed in this area in order to establish and develop validated and fit for purpose measures for use within PPC.
Bridging Primary Palliative Care in Europe

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Background: Exposure to death and dying had a strong influence on the present life of every citizen. While providing palliative care to patients, primary care workers often have to overcome barriers and myths.

Aim: The position paper seeks to facilitate the changes in service models, policy, education and research in primary care. It provides a backdrop for debate on the development of palliative care in primary care in Europe.

Methods: Collaboration with the representatives of International Primary Palliative Care Network was established from the very beginning. Barriers, opportunities, examples of good and bad practices were discussed at the workshops, which were focused on palliative care in primary care. EFPC organized workshops at the international conference of South-eastern European countries in Ljubljana (2015), at the regular conference in Amsterdam (2015), at the WONCA Europe conference in Istanbul (2015) and in Copenhagen (2016) and at the EFPC conference in Riga (2016). The position paper was further refined to contain relevant resource material.

Results: Effective palliative care services should be integrated into the existing health system, especially community and home-based care. The non-specialist palliative care needs should be considered by the staff delivering the on-going care, with initial guidance and support from specialists in hospitals and specialized palliative care teams. Caring for the caregivers is an essential area of palliative care in primary care.

Conclusion: Implementation of interdisciplinary care that focuses on effective communication, individualized care plans and care coordination should be established.
Free Communication Sessions

FC01  Dying in Old Age
FC02  Palliative Care for People with Dementia
FC03  Evaluating Palliative Care
FC04  Palliative Care in Patients with Organ Failure
FC05  Palliative Care across Various Contexts
FC06  Decision-Making for End-of-Life Care: The Patient’s Perspective
FC07  Palliative Care in Low and Middle Income Countries
FC08  Measurement and Assessment Tools 1
FC09  Audit and Quality Improvement
FC10  Population-based Datasets
FC11  End-of-Life Ethics
FC12  Pain and Other Symptoms
FC13  Family and Care Givers
FC14  Volunteers and Social Work
FC15  Primary Care
FC16  Models and Costs of Palliative Care
FC17  Death and Dying
FC18  Measurement and Assessment Tools 2
FC19  Research Methodology
FC20  Bereavement and Spirituality
FC21  Advance Care Planning: Research and Practice
FC22  Palliative Care in COPD
FC23  Special Patient Groups
FC24  Education
FC25  Social Aspects of Dying
**Aim:** With 20% people dying in care homes in the UK and increasing recognition of the important role of care homes in the context of the ageing population, enhanced standards of end-of-life care in care homes is a national priority. A well-known quality improvement programme the Gold Standards Framework (GSF) Care Homes programme was introduced to about 3000 homes, with positive outcomes but can it be sustained and embedded long-term amidst workforce pressures and staff turnover?

**Method:** The GSF Care Homes programme supports generalist frontline staff improve care for all people in their final years of life, and includes training, tools, evaluations and support to bring about deep-rooted transformational and cultural change.

Intrinsic evaluations for those undertaking GSF training then first and second time Accreditation include comparative online audits, portfolios, relatives’ feedback and an assessment visit. A key assessment for reaccredited homes is sustaining these standards plus further development.

**Results:** Evidence from 352 reaccredited homes demonstrates sustained improvements and further progress in quality end-of-life care. This includes early identification, advance care planning, anticipating residents’ needs, reduced hospitalisation, enabling more to die at home. Staff are more confident and competent in caring for all people in the last stage of life, showing a positive impact on proactive person-centred care.

**Conclusion:** The GSF reaccredited homes demonstrate embedding of improved systems and culture to ensure long-term sustainability. They show that it is possible to maintain improved standards of care over 8 years, with consistency and sustainability, leading to fewer hospital deaths and more living and dying well at home. The fact that some are able to attain such a sustained ‘gold standard’ of care demonstrates what is possible- the challenge now is ‘universalising’ the best so that this becomes standard practice in all care homes.
Dying Well in a Tapestry of Relations – factors that Influence End-of-Life Care for Older People in Long-stay Residential Care Units in Ireland

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Background: This study, ‘end-of-life’ is described as a continuum over time for residents in long stay care. Literature has revealed some of the factors that impact on end-of-life care, however, no study has examined end-of-life care for older people in long stay care homes in Ireland from the perspectives of residents, their relatives and nursing staff.

Aim: To identify the factors that hinder or facilitate end-of-life care in long stay care homes from the perspectives of key stakeholders, residents, their relatives and nursing staff and to construct a model to further inform nursing practice and make further recommendations for care practices in residential care homes.

Design: A qualitative approach using a grounded theory methodology was used (Strauss and Corbin 1998) to discover emergent themes from the data.

Methods: A purposive sample of 41 participants selected from 3 publicly managed long stay care homes in the West of Ireland.

Data collection: Semi-structured interviews, observation, were used over three time intervals to collect data between 2010–2012.

Data analysis: Analysis was guided by the approach used by Strauss and Corbin (1990) by using a process of line-by-line open-coding, axial coding, memo writing and selective coding was completed. Data management was facilitated by using NVivo 10 software to organise data and assist with further coding.

Findings: Dying well within a tapestry of relations emerged as the core category from the findings. Four categories emerged: Ethos of caring, Organising care, Living environment and Resident Centred relationships.

Results: Dying well occurs when relationships are centred on residents’ needs, where there is an ethos of caring, organised care, and a good living environment.

Conclusions: Nurses are key in shaping the way end-of-life care is delivered in residential care and need to access to adequate resources to deliver this.
Medication Use in the Last 3 Days of Life in Nursing Homes. Results from the FP7 EU-funded PACE Project in 6 European Countries

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Background: Nursing home (NH) residents increasingly present multiple, incurable pathologies, which makes palliative care (PC) a key-component of NH care. Little is known about medication use at the end of life in NHs. This study focused on the use of opioids (OP), antipsychotics (AP) and hypnotics (HP) in the last 3 days of life of residents dying in the NH.

Methods: In a retrospective cross-sectional study, end-of-life (EOL) and PC delivery in NHs in 6 EU countries (BE, FI, IT, NL, PL, UK) was studied. NHs were selected by proportional stratified random sampling. Facilities reported all resident deaths over the previous three months.

This study included residents who died in the NH, of whom the researchers received the structured after-death questionnaire of the nurse, directly involved in the care of the deceased.

Logistic regression was performed to adjust for patient characteristics.

Results: The response-rate for the nursing questionnaires was 81 %. Medication use was evaluated in 1047 NH deaths, occurring in 270 NHs. The prevalence of opioid use ranged from 20 to 76 % of dying NH residents, antipsychotic use from 5 to 22%, hypnotic use from 8 to 47 % in the 6 European countries. The differences in medication use between countries were significant for OP use (P < 0,001) and HP use (P = 0,001). These differences remained significant when controlling for patient characteristics (e.g. age, gender, length of stay, cause of death, having dementia) in multivariate analyses.

Conclusion: Opioid and hypnotic use in the dying phase differs significantly between European countries. Detailed study of EOL medication use is needed to develop good practice guidelines.
Where and Why Do Patients with Dementia Die?

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Background: Dementia is increasingly regarded as a terminal disease due to the chronic progressive nature, with special needs in palliative care. To better tailor palliative care and advance care planning (ACP), the aim of the study was to describe the place of death for people with dementia and cofactors, which might influence this place of death.

Methods: Descriptive analysis of place of death from deceased patients with dementia aged 65 and older of two cities (Bochum/Muenster) and two rural districts (Borken/Coesfeld) in Germany, using death certificates from 2011. Factors influencing the place of death were investigated, using multivariate regression analysis.

Results: A total of n=10,364 death certificates were analyzed. Dementia was present in 15.9% (n=1,646) of all deceased aged 65 and older. The place of death for people dying with dementia was as follows: at home 19.9%, hospital 28.7%, palliative care unit 0.4%, nursing home 49.9% and hospice 0.9%. Acute medical deterioration, was associated with a decreased probability of dying in a nursing home or at home and conversely associated with a higher probability of dying in a hospital, when aspiration (OR 1.51; 95%-CI 1.03–2.22, p=0.036), pneumonia (OR 2.43; 95%-CI 1.83–3.23, p=0.001), acute myocardial infarction (OR 2.25; 95%-CI 1.38–2.22, p=0.036) or sepsis (OR 7.97; 95%-CI 4.81–13.21, p=0,001) occurred.

Conclusion: People with dementia aged 65 years and older die most often (50%) in nursing homes, and only one of five at home. Disease specific deterioration like aspiration, pneumonia and sepsis or disease independent causes like acute myocardial infarction lead to a higher probability of dying in the hospital. Better ACP is mandatory to enable dying in the familiar surroundings (nursing home, at home) and to avoid stressful and preventable hospital admissions at the end of life.
Palliative Care Knowledge of Care Home Staff and their Confidence in Communicating End-of-Life Issues with Residents and their Families in Six EU Countries: Results of the FP7 EU-funded PACE Project


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Background: Care homes in Europe struggle to meet the needs of those who are approaching the end of life.

Aims: To study the knowledge of PC of care home staff in Belgium (BE), Netherlands (NL), UK, Finland (FI), Poland (PL) and Italy (IT), their confidence to communicate end-of-life issues with residents and families, and to study differences between countries.

Methods: Retrospective cross-sectional study of staff in care homes in 6 EU countries (2015). Care homes were selected using proportional stratified random sampling. A questionnaire was given to all nurses and care assistants present at the time the researcher visited the home.

Measurement instruments: Palliative Care Survey, measuring basic knowledge about PC (scores between 0 and 1, higher scores=better knowledge); and Self-efficacy in End-of-Life Care Survey, measuring confidence in communicating end-of-life issues with residents and their families (scores between 0 and 7, higher scores=greater confidence).

Results: 2292 staff members (1045 care assistants, 1247 nurses) from 322 care homes participated (response rate 67.6%). Knowledge about EOL factors was highest in BE (estimated means (EM) 0.61) and lowest in PL (EM 0.21) and IT (EM 0.29) (p< 0.001), about physical aspects that contribute to pain was high in all countries (from EM 0.81 in PL to EM 0.91 in NL, p< 0.001), and about psychological aspects was highest in FI (EM 0.87) and lowest in UK (EM 0.56). Confidence in communication was highest in NL (EM 5.68) and comparable in the other countries (between EM 4.06 IT and EM 5.19 FI, p< 0.001).

Conclusion: The education and training of staff in PC is one of the most important means of improving care. Based on this study effective education and training strategies can be developed and tailored to the specific needs in each country.
Compared to the Conventional Palliative Care Population, How Do Older People Die?

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Background: Older people are the disadvantaged dying.

Aim: To compare data from St Christopher’s Bromley Care Coordination Service (BCC) and Home Care Team (HCT) to provide evidence of dying older people’s needs. BCC enables older people with progressive illness in their last year to live and die “in place”. HCT cares for patients receiving conventional hospice care.

Design: Observations from comparable accumulative data sets over 6 months from Service and OACC measurements (Outcomes Assessment and Complexity Collaboration, including the IPOS).

Results:
BCC 203 patients, 85% principal diagnosis non-malignant: 78% died “in place”.

HCT 180 patients, 7% principal diagnosis non-malignant: 72% died “in place”.

OACC at referral profiled BCC patients as older with lower performance daily living status (AKPS BCC-20/HCT-50). Prevalence of symptoms and problems concentrated into five areas: weakness, poor mobility, drowsiness, appetite and family worry. HCT patients had a diffuse distribution across IPOS. Length of phase of illness showed a marked difference in the deteriorating phase (BCC 41 days/HCT 27 days).

Discussion: These data suggest BCC patients are more unwell, moving through the phases of illness differently with a longer deterioration phase. Limitations may include small sample size and rating reliability. However, data suggest a period of gradual decline for older people which, if normalised, may obscure palliative care needs. This long period of “stable deterioration” poses fresh questions:

- What evidence enables us to meet these needs effectively?
- Do older people with prolonged decline require a different ACP focus?
- How does prolonged decline challenge recognition of active dying?
- How do models of Palliative Care develop flexibly?

These data suggest older people enter palliative care services later with a higher level of dependency and focused need. How services and commissioners respond to ensure inclusivity equality and equity is a pressing concern.
Emergency Department Attendance by People with Dementia in their Last Year of Life: A Retrospective Cohort Study

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Introduction: While hospital deaths in dementia in England have fallen over recent years, less is known about other markers of potentially aggressive care towards the end of life.

Aim: To describe the frequency of Emergency Department (ED) attendance by people with dementia in the last year of life, and understand the demographic, illness-related and environmental factors associated with ED use.

Methods: Retrospective observational study using data from a large mental health database in South London, with individual-level linkage to Office for National Statistics mortality data and Hospital Episode Statistics. People with a clinical diagnosis of dementia, aged over 60, who died between 2008 and 2013 were included. The main outcome was ED attendance in the last year of life, modelled using negative binomial regression analysis.

Results: 4,867 patients were included. 78.6% (3,824) had at least one ED attendance during their last year of life. The mean number of ED attendances per patient was 2.13 (SD 2.34, range 0–54). ED attendance was more likely for men (IRR 1.16, 95% CI 1.09 to 1.25), for people with vascular dementia compared to Alzheimer’s (IRR 1.16, 95% CI 1.07 to 1.26), for people with depression (IRR 1.12, 95% CI 1.01 to 1.24), and for people with less severe cognitive impairment (IRR per unit increment in MMSE 1.01, 95% CI 1.00 to 1.01). Living in a care home (IRR 0.81, 95% CI 0.75 to 0.86) and in less deprived areas (IRR 0.79, 95% CI 0.69 to 0.91), and having a longer interval between last clinical contact and death (IRR per month increment 0.99, 95% CI 0.98 to 0.99) were associated with reduced likelihood of ED attendance. ED attendance became more common over time (IRR 1.62, 95% CI 1.45 to 1.80 for 2012–2013 compared to 2008–2009).

Discussion: ED attendance in the last year of life for people with dementia is common and is increasing. Policy makers must turn their attention to indicators of poor end-of-life care other than the place of death.
Disenrollment from Hospice Care for Patients with Dementia in the U.S.: A Longitudinal Cohort Study

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**Background:** Patients with dementia form an increasing proportion of those entering hospice care. However, they have higher disenrollment rates from hospice than those with other terminal diseases. Little is known about the types of hospices serving dementia patients and the patterns of hospice care, including timing of hospice disenrollment between dementia and non-dementia patients.

**Aims:** To characterize the hospices that serve dementia patients, to compare patterns of hospice disenrollment for dementia and non-dementia patients, and to evaluate patient-level and hospice-level characteristics associated with hospice disenrollment.

**Methods:** We used data from a longitudinal cohort study (2008–2011) of Medicare beneficiaries (N=149814) newly enrolled in a national random sample of hospices (N=577) from the National Hospice Survey and followed until death (84% response rate).

**Results:** 7328 patients (4.9%) had a primary diagnosis of dementia. Hospices caring for patients with dementia were more likely to be for-profit, larger sized, provide care for more than 5 years, and serve a large (>30%) percentage of nursing home patients. Patients with dementia were less likely to disenroll from hospice in conjunction with an acute hospitalization or ED visit and more likely to disenroll from hospice after 165 days as compared to non-dementia patients. No significant difference was found between dementia and non-dementia patients for disenrollment before 165 days. In the multivariable analyses, patients were more likely to be disenrolled after 165 days if they were served by smaller hospices and hospices who served a small percentage of nursing home patients.

**Conclusion:** Dementia patients are more likely to be disenrolled from hospice following a long length of stay compared to non-dementia patients. “Failure to die in a timely fashion” may limit hospice availability for late stage dementia patients near the end-of-life, which may be a marker for poor quality care.
Advance Care Planning in Dementia: Recommendations for Healthcare Professionals Working with People Living with Dementia

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Background: Despite universal recognition of the importance of advance care planning (ACP) for people with dementia who gradually lose their ability to make informed decisions themselves, it is still performed infrequently and evidence-based recommendations on when and how to perform this complex process are lacking. In an attempt to improve its prevalence, quality and consistency we aim to develop recommendations for the practical application of ACP in people with dementia across settings.

Methods: Following the Belgian Centre for Evidence-Based Medicine’s procedures, we
1) performed an extensive literature search to identify international guidelines, articles reporting heterogeneous study designs and grey literature;
2) developed recommendations based on the available evidence;
3) performed a validation process via written feedback from experts, a survey for end-users (healthcare professionals across settings), and two peer-review groups (with geriatricians and general practitioners);
4) added additional recommendations perceived necessary by the core author group.

Results: Based on 67 publications and validation from 10 experts, 51 end-users and 2 peer-review groups (n= 24) we developed 32 recommendations covering 8 themes: initiation of ACP, evaluation of mental capacity, ACP conversations, the role and importance of family, ACP when it is difficult or no longer possible to communicate verbally, documentation and information transfer of wishes and preferences, end-of-life decision-making and preconditions for optimal implementation of ACP. Almost all recommendations received a grading representing low to very low-quality evidence.

Conclusion: Little high-quality evidence is available for ACP in dementia care. By combining evidence with expert and user opinion we defined a unique set of recommendations for ACP in people living with dementia. These recommendations form an important tool to educate healthcare professionals on how to perform ACP across settings.
Advance Care Planning in Dementia: Do Family Carers Know the Treatment Preferences of People with Early Dementia?

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When a person with dementia (PWD) has lost the ability to make treatment decisions, clinicians often have to rely on family carers to ascertain their preferences. We used three hypothetical scenarios to explore whether carers’ choices show agreement with the end-of-life (EoL) care preferences of the person with dementia and what factors influence this.

Methods: Cross-sectional interviews of 60 dyads (PWD and carer) to assess how closely carers’ choices resembled the PWD’s preferences for treatment in three health states: the here and now; severe stroke with coma; terminal cancer. Agreement was assessed using Kappa and Prevalence-Adjusted Bias-Adjusted Kappa (PABAK) statistics. We examined whether carer burden and distress, and relationship quality, influenced agreement.

Results: PWD were able to indicate their treatment preferences across scenarios. In the here-and-now most (98%) wanted antibiotics, fewer cardio-pulmonary resuscitation (CPR) (50%) and tube feeding (47%). In severe stroke and coma antibiotics remained the more preferred treatment, less so CPR and tube feeding. In advanced cancer PWD expressed lower preferences for all treatments. Carers’ choices were similar to the PWDs’ preferences in the here-and-now (κ = 0.03; PABAK = 0.4) with much less agreement for future hypothetical health states. In severe stroke and coma carers tended wrongly to suggest that the PWD preferred more intervention. In advanced cancer agreement between PWD and carers was low. However, both PWD and carers showed marked uncertainty about preferences for EoL treatments. Relationship quality, carer distress and burden did not influence agreement.

Conclusion: Carers showed low to moderate agreement with PWD on treatment preferences. Planning for EoL care is beset with uncertainty, even when the carer and PWD perceive their relationship is good. Families affected by dementia may benefit from early and ongoing support to discuss future decision-making.
Supporting People with Dementia to Die at Home in Ireland

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Background: The Irish National Dementia Strategy (2014) highlights the need for early diagnosis and establishing a dementia friendly Ireland to enable people with dementia to live well in their communities. However the needs of people with advanced dementia are not often discussed and little is known about what supports people with dementia need to enable them to live well and die well in their own homes.

Aim: To explore the components of care which support a person with dementia who accessed a national night nursing service to die at home.

Method: A mixed methods approach was used. Quantitative data from a national night nursing service (which supports people with dementia to die at home) was accessed. Supplementary information from specialist palliative care teams (SPCT) was gathered for 52 dementia referrals to the night nursing service between June and December 2015. Data retrieved was analysed. Findings were compared against the literature available on people with dementia who are enabled to die at home.

Result:
Of the 4,200 people with dementia who die in Ireland every year, just 5% (210) die at home.

The availability of family/ friends to provide care to a person with dementia appears to be a key determinant to people with dementia dying at home.

Having a supportive GP available to do weekly home visits was important for 63% of the sample.

The decision to stay at home was made by the person with dementia or their families in over 50% of the sample.

The majority of the sample were referred to SPCT in their last week(s) of life.

28% of the sample had no other comorbidities.

Conclusion: The biggest enabler to address improvements in this area will be commitments from service.
**FCO2 | Palliative Care for People with Dementia**

**Informal End-of-Life Care for Community-dwelling Older Persons with or without Dementia: Caregiver Burden and Positive Experiences**

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**Background:** Previous reports have shown that the majority of older people with chronic disease wish to be cared for at home until death, which results in increasing demands for informal end-of-life (EOL) care at home. Sharing EOL care at home with other informal and professional caregivers may alleviate informal caregiver burden and enhance positive experiences, but also have downsides.

**Aims:** To assess which care and support factors are associated with burden of care and positive experiences for informal caregivers providing EOL and non-EOL care to older people with and without dementia.

**Methods:** A sample of 1,267 informal caregivers of community-dwelling older persons was drawn from a Dutch cross-sectional, nationally representative study on informal caregiving. The Self-Perceived Pressure from Informal Care Scale and the Positive Experiences Scale were used to assess caregiver burden and positive experiences with care. Structured telephone interviews were administered and the data was analysed using ANOVA and multivariable regression analyses.

**Results:** Informal caregivers reported the most positive caregiver experiences when providing informal EOL care to older persons without dementia, regardless of the care intensity and care needs. Informal EOL care for older persons with dementia was associated with the least positive experiences and the greatest caregiver burden, which in turn was associated with more involvement of professional and other informal caregivers resulting in more disagreements, less support-seeking and more unmet needs on the part of informal caregivers.

**Conclusions:** Our results highlight informal EOL caregivers’ needs, particularly in dementia, such as better communication about dementia and its impact and caregiver support services tailored to the specific needs of informal caregivers. They may guide future research and policy aimed at improving palliative home care experiences for chronically ill older persons and their informal caregivers.
How to Evaluate Mobile Specialized Palliative Care: Lesson Learned from Czech Republic

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Background: In the Czech Republic, mobile specialized palliative care (MSPC), which would provide support to families caring for their loved ones at home, is currently not financed through national health insurance scheme unlike the other services in Czech public health care system.

Aim: The aim of the study was to evaluate the effectiveness, safety, and cost of MSPC provided at patients’ home.

Methods: This was a prospective study of 327 (mean age 77 years, 49% of men) patients being supported by MSPC for at home. Primary outcomes were place of death and symptom management (measured by regular ESAS assessment). Health care cost measurement was based on national health insurance company data. Control group was constructed from patients’ database of national insurance company, including 70 000 cases of patients who died without MSPC, linking the characteristics (gender, primary diagnosis) to the intervention group by propensity scoring method.

Results: Almost all patient in the intervention group (95 %) died at home with good symptom control (mean ESAS score pain – 1.3, depression – 2.3, nausea – 2.4, anxiety – 2.9). MSPC group was also less expensive, with cost reduced by 10€ per patient and day.

Conclusion: MSPC was proved to be an effective way of providing support to patients at the end of life who prefer to die at home. Specific value of this study was the involvement of both government and national health insurance provider, which were both involved in every stage of the study. Design and outcome measures used in the study proved to be useful for collaboration with policy makers and non-academic stakeholders.
Background: For palliative care to be accessible to all, it must be available in the community early in the disease trajectory. In Europe, primary palliative care services have been developed in response to this need. In addition, some hospice providers offer day services. Both services enable people diagnosed with a life-limiting illness to be cared for in the community.

Aim: Ambiguity concerning the organisation and content of day services persists. We aimed to address this by mapping services in England, Scotland and Northern Ireland.

Methods: A systematic review of the literature guided a descriptive analysis of three day services, one in each country. Data were collected from:
- policy and operational documents, to provide evidence on the organisation of care, and;
- the records of a 25% random sample of new patients attending in 2015, to provide evidence on the content of care.

Results: The three day services were based on a mixed medical and social model of care. In addition:
- a wide range of care and support is offered, from intravenous therapies to arts & crafts;
- care is provided to both patients and their informal carers;
- care is extremely proactive, based on regular assessment and follow-up;
- many of the identified needs are responded to ‘in-house’;
- where such response in unavailable, onward referral and follow-up occurs;
- there is extensive liaison with other health and social care providers, operating in both the community and acute sectors;
- such liaison occurs throughout, and often after, patient attendance.

The breadth and depth of service provision means that day services act as a community-based ‘locus’ of well coordinated, multi-disciplinary and cross-sectoral care.

Conclusion: Findings contribute to the limited evidence base on the organisation and content of day services. They highlight how these services are firmly rooted in, but extend beyond, their immediate community context to promote holistic, patient-centered care.
Patient-perceived Needs, Gaps in Service Delivery, and Quality Indicators in Seven Dimensions of Palliative Interventions (PCIs) in Cancer Care

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Background: Integration of PCIs in routine oncology care remains challenging, specifically in resource-restricted settings with variable training of health care professionals (HCPs). Patients (pts) who get adequate PCIs may have more favorable quality indicators for Palliative Care (PC).

Aims: To explore if high level of unmet needs for PCIs are associated with symptom burden and/or aggressive end-of-life care.

Methods: Prospective 6 month study in Romania and Switzerland of adult incurable cancer pts with defined PC needs (IPOS, ECOG 1–3). Needs for 7 “Key PCIs” perceived by pts and their recalled delivery by hcp (if lacking: gap) were collected monthly by a nurse-led assessment. Quality indicators: toxicity resulting from inappropriate anticancer treatment, pt-reported burden (IPOS), repeated ER admissions, aggressive end-of-life care (CPR, ICU admission, new chemotherapy started < = 1 month or given < =14 days before death, ICU as place of death), and the Quality of Death and Dying score. Pearson’s chi-squared tests for relationship between gap level and burden and aggressive end-of-life care, respectively, at Follow-Up 1. Longitudinal analyses on the dataset are ongoing.

Results: Of 308 pts 24% had a high level of gaps (≥ 3 gaps) in delivery of PCIs. A significant relationship (Χ²= 7.452, p=.006) between high depression burden and high level of gaps in service delivery was seen; all other symptom categories showed non-significant relationships. The occurrence of aggressive end-of-life care was low (e.g. last month ICU=5, CPR=19; death ICU=3). 35% of the 102 respondents to the QODD questionnaire had a score of ≤60, indicating a poor quality of death, longitudinal analysis of related unmet needs for PCI are ongoing.

Conclusion: This prospective longitudinal study assessing patients’ unmet needs for predefined PCIs suggests that they are related with patients depression consistent with RCTs of early PC. Further analysis may identify most vulnerable pts groups.
What Defines a Model of Palliative Care? 
A Multi-method Study across the UK to Determine a Set of Criteria to Describe Models of Palliative Care

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Background: Specialist palliative care services have various configurations of staff, interventions, and other characteristics which determine how care is delivered. Currently, there is no consistent way to define models of palliative care.

Aim: To establish criteria to describe and define models of care across palliative care services.

Methods:
1) Semi-structured interviews with services to identify preliminary criteria.
2) Delphi study of UK stakeholders; round 1 to agree/refute criteria (consensus predetermined at 75%) and round 2 to rank criteria (consensus IQR ≤ 1 and median > 4).
3) Structured interviews to verify refined criteria.

Results:
1) Interviews: with leads in 8 organisations (5 hospice, 5 community, 2 hospital consult) (median 72 mins, range 48–101 mins) resulted in 37 preliminary criteria.

2) Delphi study: Round 1 (54 participants): 37 criteria were refined to 34, based on experts’ evaluations and comments. Round 2 (30 participants): 34 criteria were ranked and rated resulting in 16 criteria. These criteria included: setting, type of care, size of service, number of disciplines, mode of care, training, use of experience measures and range of interventions. It also included the ‘out of hours’ characteristics of referrals, care, availability, mode, type, as well as bereavement follow-up and risk assessment.

3) Structured interviews: 21 interviews tested if the full list of criteria showed variability of service models. Following these interviews, 7 criteria (ability for patients to self-refer, medical responsibility, components of care, discharge criteria, outcome measures, age, and public or voluntary) were added to further increase ability of the set of criteria to discriminate between services.

Conclusion: We identify a set of key criteria to define models of palliative care; a major advance to enable accurate description and comparison of different models of palliative care.

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An Innovative Model of Proactive, Consistent Best Supportive Care. A Service Development for Patients with Advanced Lung Cancer in NHS Fife, Scotland

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Background: In NHS Fife, 40% of patients with newly-diagnosed lung cancer are unfit for anti-cancer treatment and are for ‘best supportive care’ (BSC). Many more become for BSC following palliative anti-cancer treatment or disease relapse. But there is no consensus about what constitutes BSC and who should deliver it. Patients and families are left unclear about realistic goals of care, and about what support and follow-up they can expect. The lack of consistency in BSC can be a serious barrier to high-quality end-of-life care. Fife Specialist Palliative Care have developed and piloted a model of ‘proactive best supportive care’ for patients with incurable lung cancer.

Methods: The new model of best supportive care was based around the following framework:

- Robust identification of all patients for BSC
- Comprehensive palliative care assessment and care planning
- Care coordination and follow-up

Every assessment began with sensitive discussion about the lung cancer diagnosis and BSC. Detailed assessments of multidimensional needs followed and immediate care plans were agreed. Where appropriate, anticipatory care planning was started. Structured letters were available online to all health professionals within two days. Patients were supported for as long as they lived.

Results: Over 350 patients have been supported by the new model of care. The detailed evaluation, including health economic analysis, provides substantial evidence of the benefits of the new model of care, both in terms of improved quality of care and more appropriate use of healthcare resources. Under the new model of care, patients spent significantly less time in the acute hospital and were less likely to die there.

Conclusion: A new model of proactive BSC in lung cancer has been successfully developed and piloted in NHS Fife. Patients and those close to them are now consistently supported from the point of diagnosis, with the impact of improved quality of care and more appropriate use of healthcare resources.
Evaluation of the Effectiveness of Music Therapy in Improving the Quality of Life of Palliative Care Patients: A Randomised Controlled Pilot and Feasibility Study

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Background: Music therapy is increasingly being used as a palliative therapy, with the aim of improving people’s quality of life. To date, primarily because of a paucity of robust research, the evidence for music therapy’s effectiveness on patient reported outcomes is positive but weak, and no guidelines have been developed.

Aims: The primary aim of this pilot study is to test the feasibility of administering the McGill Quality of Life Questionnaire (MQOL) in terms of acceptability to hospice inpatients, and whether attrition affects the viability of a three week music therapy intervention in order to calculate the sample size required for a phase III randomised trial. The secondary aim is to evaluate the potential effectiveness of music therapy for improving the quality of life of hospice inpatients.

Methods: A pilot randomized controlled trial (RCT) supplemented with qualitative methods with n= 52 hospice inpatients. Baseline data collection included the MQOL and socio-demographic data. Participants in the intervention arm were offered two 30–45 minute sessions of music therapy per week for 3 consecutive weeks, in addition to care as usual. Participants in the control arm received care as usual. Follow-up measures administered at 1, 3 and 5-weeks. Qualitative data collection involved focus group/interviews with HCPs and carers.

Results: Twenty patients recruited to date. Data recruitment will continue until May 2017. Data will be analysed at that time and the results presented at this conference. Challenges in relation to eligibility and high attrition will also be discussed.

Conclusion: Findings from this study will inform the design of a phase III multi-site RCT. Findings in relation to the potential effectiveness of music therapy will provide support for NHS and third sector Specialist Palliative Care commissioners and service providers to make an evidence-based decision on whether to incorporate music therapy in palliative care services.
Unmet Palliative Care Needs among Patients with End-stage Kidney Disease: Results of a National Registry Study about the Last Week of Life

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Background: End-stage kidney disease (ESKD) is a condition with significant illness burden and high mortality. However, palliative care is seldom integrated into renal care. This underlines a need to explore care at end of life according to key components of palliative care.

Aims: To describe end-of-life care in terms of symptom prevalence, symptom management and communication during the last week of life for patients with ESKD.

Methods: This cross-sectional registry study is based on data from the Swedish Register of Palliative Care – a national quality register for end-of-life care irrespective of diagnosis and setting. Data is reported after the patient’s death by the responsible physician or registered nurse. Registry data over two years resulted in 472 included patients with ESKD who died an expected death. Descriptive statistics were used.

Results: Pain was the most prevalent (69%) of six predefined symptoms, followed by rattles (46%) anxiety (41%), confusion (30%), shortness of breath (22%) and nausea (17%). Of patients with pain and/or anxiety, 32% and 44% respectively, were partly relieved or not relieved at all. A majority of patients (55%-84%) with the other symptoms were partly relieved or not relieved at all. The use of assessment scales was 14% for pain and 9% for other symptoms. End-of-life conversations were reported for 41% of patients and for family members of 71% of patients. The patient’s desire about place of death was met in 41%. Of all patients 19% died alone. A minority died in specialized palliative care; 8% in hospice care and 5% in palliative home care. Bereavement follow-up was offered to 38% of families.

Conclusions: Patients with ESKD, although dying an expected death, have unmet palliative care needs. Results show remaining challenges for the provision of adequate palliative care for these patients. This stresses the need for improved competence in palliative care, as well as collaboration between renal and palliative care specialists.
Specialized Palliative Care for Patients with End-stage Renal Failure in Denmark. A National Survey

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Background: Since 1992, Danish specialized palliative care (SPC) has developed continuously. Services have, however, mainly been provided for cancer patients. End stage renal failure (ESRF) patients have symptoms and mortality rates similar to cancer patients. Rather more than 500 Danish dialysis patients die each year. No data on conservatively managed patients exist. The extent of SPC for Danish patients with a primary renal diagnosis is so far unknown.

Aim: This survey aimed to assess the current provision of SPC to Danish patients with ESRF.

Methods: An electronic questionnaire was sent to leaders of all Danish SPC units (hospices, palliative hospital departments, and regional palliative care teams). Respondents accepted participation by self-registration. Data were handled anonymously. Descriptive statistics were used.

Results: Fifty-eight SPC units were invited. The overall response rate was 76%. Patients with ESRF were accepted in all of the 18 responding hospices, in two of 5 SPC hospital departments, and in 15 of 21 SPC teams. Most SPC teams and one department accept ESRF patients regardless of treatment modality, i.e. ongoing haemodialysis (HD), peritoneal dialysis (PD) or conservative care, or patients withdrawing from dialysis. Hospices accept all patients withdrawing from dialysis, but other modalities were accepted less frequently (HD, 38%; PD, 31%; conservative care, 56% of units.) Three hospitals and six teams accept only cancer patients. During the last year, a majority of units saw no or only 1–5 ESRF patients, mainly due to few referrals (92% of units) or patient referral criteria (77% of units). No unit had clinical guidelines for patients with ESRF. Respondents mentioned the need for guidelines, mutual collaboration, and extension of SPC services for improvement.

Conclusion: SPC is under-utilized among Danish patients with ESRF. SPC service extension, education and better collaboration between specialties are important in further development.
**The Effect of Planned Care on End-of-Life Outcomes and Costs in Liver Disease Patients with Diuretic Resistant Ascites. A Retrospective Cohort Study of Deaths in England**

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**Introduction:** Ascites is the most common complication of liver cirrhosis, with a median survival of 6 months when refractory to diuretics (DRA). Patients require repeated large volume paracentesis (LVP), either as elective or emergency care.

**Aim:** To assess the impact of planned care on resource use and end-of-life outcomes in patients with DRA.

**Method:** Data for patients who died of liver disease and had ≥2 LVP in the last year of life was extracted from the NHS Digital linked database of Hospital Episode Statistics and The Office for National Statistics mortality data. Patients who had > 75% of LVP on an elective basis (planned care group – PC) were compared to patients who had all LVP following unplanned admission (emergency care group – EC). Number of admissions, inpatient bed days in Last Year of Life (LYOL) place of death, and use of invasive/ITU procedures on terminal hospital admission were recorded as outcome measures.

**Results:** 1,651 patients with DRA were identified. EC group = 1024 (62%), PC group = 266 (16.1%). Median age at death was higher in the PC group (65.2 vs 62.0), there was a higher proportion of patients with alcohol related disease in the EC group (42.7% vs 27.1%). Whilst mean number of admissions in LYOL was higher in the PC group, mean number of emergency admissions was significantly higher in the EC group (2.71 vs 0.37, p< 0.05). Mean number of bed days in LYOL was significantly higher in the EC group (44.5 vs 24.6, p< 0.05). Patients in the PC group were less likely to die in hospital following unplanned admission (53.3% vs 40.2% p< 0.05), and significantly less likely to have invasive procedures (mechanical or non-invasive ventilation, haemofiltration, CPR) on their terminal admission.

**Conclusion:** This national study of hospital use in LYOL for all patients who died with cirrhosis and DRA demonstrate a strong association between planned care and improved economic and clinical outcomes.
Exploring Carers’ Experiences of Supporting a Person with Palliative Heart Failure: A Mixed Methods Study

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**Background:** Heart failure (HF) is a complex condition prevalent in older people and is associated with debilitating symptoms and psychosocial issues. As the prevalence of HF increases so are the numbers of family carers who face the challenges of coping with unpredictable symptoms, medications and frequent hospital admissions.

**Aims:**
Examine the impact of caring on carer quality of life (QoL).
Explore factors influential to carers’ perception of caring.
Explore the acceptability of a Carer Support Plan (CSP).

**Methods:** A mixed methods study recruited carers from HF nurses’ caseloads.

Phase 1: Quantitative component, cross-sectional survey using FAMQOL, developed for carers of HF patients. Data were analysed using descriptive statistics, correlations and ANOVA.

Phase 2: Qualitative component used a phenomenological methodology; 14 carers were interviewed.

**Findings:** Living arrangements and how long the person had been caring was statistically significant on overall QoL, physical wellbeing and psychological wellbeing. Working status showed statistical significance; carers who had previously worked reported better QoL, physical health and social wellbeing. Carers were mainly spouses who had significant lower social wellbeing scores than non-spousal carers. 40% of carers reported caring adds purpose to their lives.

Social isolation, emotional issues and fragmented support were recurrent themes. However carers valued the role in bringing them closer to the person and viewed the CSP as a positive initiative.

**Conclusion:** The study demonstrates the effectiveness of FAMQOL in measuring carer QoL. Carer experience is positively influenced by close social networks, proactive support and strong partnerships between patient and carer. Carers welcome the idea of a CSP reporting they desire more information and streamlining in support services available. Findings highlight the importance of social capital and biographical disruption leading to the development of a new theoretical model.
A Feasibility Study of Improving Care for People with Advanced Liver Disease and their Families

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Background: Liver disease is the third biggest cause of early death in the UK, but care planning and palliative care in this area is poorly developed.

Aims: To test the feasibility of an innovative complex intervention delivered by a supportive care liver nurse specialist to improve care coordination, anticipatory care planning and quality of life for people with advanced liver disease and their carers.

Methods: Mixed-methods feasibility study. Patients with one or more unplanned hospital admissions due to cirrhosis were recruited, and their carers. Patients/carers received a 6-month intervention during which the study nurse: acted as case manager and coordinator; supported patients/carers to live as well as possible with the condition; and supported the care delivered by community-based professionals. We assessed resource use, care planning processes and 5 patient and 2 carer outcome measures over 6 months. Qualitative interviews explored acceptability, effectiveness, and feasibility.

Results: We recruited 47 patients, 27 family carers and 13 professionals. Our findings indicate that the intervention and methods for evaluation were acceptable and feasible. Patients, their families and professionals all welcomed the specialist nurse role and the advice, support and continuity of care it provided. Their help with symptom management and a more timely and patient-friendly hospital admissions process was particularly appreciated. While patients’ generally poor understanding of their condition made conversations about future planning difficult, the intervention successfully prompted the creation of a care plan from 29% to 85% of participating patients. We identified and shortlisted candidate outcome measures related to service use, processes of care and quality of life.

Conclusion: This feasibility study conducted an acceptable and potentially effective intervention, and identified recruitment processes and outcome measures for a future randomised controlled trial.
Integrating Heart Failure Care and Advanced Palliative Home Care – Family Members’ Experiences of an Intervention

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Background: Chronic heart failure is a disease with high morbidity and symptom burden that places great demands on the family members.

Aim: The aim was to describe family members’ experiences of an intervention that integrated heart failure care with advanced palliative home care.

Design: The study is a part of a wider evaluation of an intervention and uses a qualitative descriptive design.

Setting and participants: Patients were invited to take part in an intervention to support care at home involving collaboration between specialists in palliative and heart failure care. The intervention consisted of nine key components, one of which was support to family members. Altogether, 14 family members participated in semi-structured interviews for evaluation after intervention completion. Data were analysed with content analysis.

Results: Family members expressed thankfulness and happiness from witnessing the patient feeling better due to symptom-relief and empowerment. They also felt relieved and less worried as they were reassured that the patient was being cared for properly and their own responsibility for care was shared with the healthcare professionals. Family members, however, felt as though they were living in the shadow of severe illness, without receiving any support of their own.

Conclusion: Family members expressed gaining several benefits from an intervention that integrated heart failure care with advanced palliative home care although they still felt a lack of support for their own individual needs. Future interventions may need to focus more on the individual needs of family members.
**Betwixt and Between: A Conceptual Utility of Transition Theory in the Experience of Living with Mucopolysaccharidosis (MPS)**

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**Introduction:** Mucopolysaccharidoses (MPS) comprise a group of rare life-limiting conditions characterised by a variable trajectory with prognostic uncertainty. This presentation will focus on the conceptual utility of transition and specifically Van Gennep’s (1960) theory of rites of passage and Turner’s (1975) theory of liminality, to better comprehend the complex transition experiences of parents of children, adolescents or young adults with MPS.

**Aim:** This study intended to broaden and strengthen our understanding of MPS diseases’ progression and the parents’ transitional experience of being in their world of caring for their children over a given period.

**Methods:** A qualitative approach, utilising hermeneutic phenomenology was used as a guide for data collection through serial interviewing and data analysis. A purposively selected sample of parents’ (n=8) attending the Irish National Centre for Inherited Metabolic Disorders was invited to participate. The data was collected over a 17 month period.

**Results:** This study examined data related to the parents’ experience of uncertainty due to illness and their transitional process to becoming a parent of a child with a rare life-limiting condition. Parents spoke about their experience of being the parent of a healthy child to being the parent of a child with a life-limiting condition, and they described as living in a state of liminality within this transition. Parents experienced a range of uncertainties concerning ‘no man’s land’, and ‘future is unknown’ to describe their life world.

**Conclusion:** This study offers a record of transitionally processed experiences in the context of space, time, body and human relations as they live day to day. In this study, the parent of a child mostly normal at birth becomes the parent of a child with a life-limiting illness, who will ultimately die, despite all of their hopes and aspirations. This may be an ultimate expression of living a liminal experience.
Percutaneous Venting Gastrostomy in the Management of Malignant Bowel Obstruction: A Qualitative Study Exploring Patients’ Experiences

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Malignant bowel obstruction (MBO) affects around 3% of patients with advanced cancer. The incidence is high in certain cancers: up to 50% in ovarian and 28% in colorectal cancer. Life expectancy is short with a median survival of 10 weeks. There is a lack of evidence guiding clinical practice on the use of percutaneous venting gastrostomy/gastrojejunostomy (PVG) in MBO. Alternative management options for MBO such as surgery or stenting are only appropriate for a small subset of patients, and medical management (e.g. nasogastric tube decompression) is only justified as a short term measure due to complications of prolonged use.

Our study aimed to explore patients’ experiences of undergoing a PVG at a tertiary centre, its impact on quality of life and views as to how the service could be improved. This is the first study eliciting patient views on PVG for MBO.

We interviewed all 11 patients who had recently undergone PVG insertion and consented to participate. The interviews were semi-structured and were audio-recorded, transcribed verbatim and analysed using Framework. We also collected information on patients’ clinical journeys.

Analysis of the data revealed several recurring themes including issues regarding information provision, care of the PVG post-procedure and complications experienced by the patients. These findings will be highly influential in guiding local service development e.g. more timely and detailed information giving, training for staff and patients in caring for a PVG and heightened awareness of the complications of a PVG and consideration of ways to minimise these.

The detailed analysis results will be presented along with recommended improvements to enhance patient experience and outcomes. The study outcomes will feed into a larger project on the role of PVG in MBO in the UK, aiming to develop a national registry of PVG.

This project did not receive external funding and was undertaken as the academic project of trainee doctors (RS and EE).
How to Identify Patients with Progressive Neurological Conditions that Require Palliative Care: Development of an Evidence Base for the Use of Triggers

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Many patients with progressive neurological conditions (PNCs) require palliative care, but access to services remains restricted. Several groups have recommended the use of ‘triggers’ for palliative care involvement in national policy guidance. The triggers suggested are based on expert opinion and evaluation of the proposed triggers is limited.

**Aims:** Determine
(i) the frequency of triggers in the last 2 years and 6 months of life,
(ii) whether the triggers could be reduced to fewer components,
(iii) the association between triggers and survival from diagnosis and referral to palliative care services.

**Methods:** Twelve palliative care units conducted a case-note review of consecutive patients with a PNC who died between 2009–2014, using a standardised data collection form. Principal component analysis (PCA) assessed the correlation between the triggers and multi-variable Cox-regression analyses assessed the association with survival.

**Results:** 300 participants were included. The mean number of triggers was 16 in last 2 years of life and 10 in last 6 months of life. Four factors explained 64% of the variance in the data: Factor 1 – deterioration in physical function, dysphagia, significant complex symptoms, pain; Factor 2 – weight loss, respiratory symptoms; Factor 3 – recurrent infections, cognitive decline; and Factor 4 – aspiration. There was a significant association between the number of triggers at 3 months prior to death and survival from diagnosis (hazard ratio (HR) 1.08, (95%CI 1.02, 1.14)) and survival from referral (HR 1.10 (95%CI 1.03, 1.17)). Different triggers were significantly associated with survival for different PNC diagnoses.

**Conclusion:** There is evidence of a high burden of triggers for patients with PNC. PCA indicated that the triggers could be reduced to four components, which will aid routine data collection. The association between each trigger and survival varied, indicating that certain triggers may be more important for different PNCs.
Palliative Care across Various Contexts

**Parkinson Support: Palliative Care for Patients with Parkinson’s Disease and their Family Caregivers**

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**Background:** Parkinson’s disease (PD) is a progressive and neurologic disorder and (still) incurable. Little is known about the palliative care and the problems that patients, family caregivers and health care professionals experience at the end of life. Palliative care (PC) in PD is beneficial and recommended in guidelines. However, when to start palliative care and the fact that little evidence is known about which palliative care interventions are effective makes it difficult to provide PC.

**Aim:** The objective of the study is to examine the experiences of patients, (former) family caregivers and professionals in order to get more insight in PC needs in Parkinson’s Disease.

**Methods:** We perform a mixed method study to evaluate the experiences of patients, (former) family caregivers and professionals in PC. We have sent a questionnaire among 3000 professionals to explore issues in PC for PD. Subsequently, we retrospectively explore the views of former family caregivers and professionals by conducting individual-and focus group interviews. Finally, 5 patients with PD and their family caregiver will be followed in a prospective case study for 8–12 months. Data collection involve semi-structured interviews and questionnaires at three consecutive contact moments.

**Results:** Results from the questionnaires show that there is little consensus among health care professionals (n=268) about the definition of a ‘palliative patient with PD’. Several starting points were mentioned; “after a diagnosis of PD” till “a day before dying”. Furthermore, health care professionals describe a lack of knowledge in providing palliative care. Specific areas that were mentioned are: pain, dystonia, swallowing, feeding and posture.

**Conclusion:** This study provide information on palliative care from a broad perspective and can be used to develop palliative Parkinson care in the Netherlands. This study also establish an important foundation for future intervention research.
Describing the Patterns and Care Outcomes of Emergency Department Presentation for Patients with Cancer in Victoria, Australia

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**Background:** While emergency department (ED) attendance is reported to be frequent for people with cancer, the scope and the nature of service delivery for this cohort is poorly understood.

**Aim:** This study sought to determine the ED presentation and hospital utilization characteristics for patients with cancer and to compare these with those without cancer.

**Methods:** This retrospective, multicentre cohort study used routinely collected service data. ED presentation characteristics amongst cancer and non-cancer groups were explored using descriptive and inferential statistics. Outcomes of interest were level of acuity, ED and inpatient length of stay, re-presentation rates and admission rates amongst cancer patients and non-cancer patients.

**Results:** In 3 years, 529,377 ED presentations occurred including 2.4% (n = 12,489) cancer-related. Cancer-related attendances had higher acuity classifications, requiring greater management time and length of stay in ED. Cancer patients had nearly double re-presentation rates (64 vs 33%, p < 0.001), and rates of hospital admission (90 vs 46%, p < 0.001), with longer inpatient length of stay (5.6 vs 2.8 days, p < 0.001) and higher inpatient mortality (7.9 vs 1.0%, p < 0.001).

Arrival by ambulance and acuity were significant predictors of hospital admission, with cancer-related attendances having ten times the odds of admission compared to other attendances (OR = 10.4, 95% CI 9.8–11.1).

**Conclusions:** Patients with cancer presenting to ED are more urgent, more complex, and more frequently require hospital admission compared to other cohorts. Close collaboration and integration of oncology, palliative care and ED providers is required to improve patient-centred care.
**FC05 | Palliative Care across Various Contexts**

**The Need for Information Regarding the Risk of Secondary Lymphedema in Cancer Patients**

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**Background:** Secondary lymphedema is a consequence of cancer, of surgery (radical mastectomy, hysterectomy) or radiotherapy. Lymphedema management should be initiated before surgery and continued even when the active cancer treatment ends.

**Aim:** To understand who and what information is delivered to patients at risk or with lymphoedema and identify areas of improvement for the work of clinicians.

**Method:** A prospective cross-sectional study, using a 25 items self administered questionnaire specifically designed for the study, piloted in the day center and refined, Alfa Chronbach=0.684. Cancer patients with lymphedema in the study were recruited in the cancer department and palliative care unit after signing an informed consent.

**Results:** 55 patients in the study; women 98.2%, men 1.8%; main age group was 61–70 years. 85.5% breast cancer, 14.5% genital cancer. 69% of participants received not enough information about lymph edema; 29.1% of patients were informed about the risk of lymph edema, 43.6% about prophylactic measures (out of them 12.5% exercises and massage, 12.5%-not to allow blood taking from the affected member, 41.69% to avoid activity and stress !?; 20.83% about skin care) and 47% about the exercise recommended to reduce swelling. In 38.2% the person that provided the information was the surgeon, 14.5 the oncologist no single patient remembered nurses alone as being the source of information. Self referral to the specialized lymphedema clinic in 82% of cases (51% went to a specialist in the first year after surgery) with a perceived benefit in 95.6% of cases.

**Conclusion:** The level of information regarding the risk of lymph edema, preventive measures and referral to specialized services is low and content sometimes incorrect. Training of clinicians and especially nurses in delivering competent information is required and collaboration with lymphedema clinics to become routine as it shows benefit at patient level.
Patients’ Perspective on Autonomy at the End of Life

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Background: The predominating definition of autonomy as a capacity to make an independent rational choice may not be suitable to inform nursing and care for seriously ill and older patients. Therefrom arises actual need for more contextualized perspectives on autonomy that would help to promote the quality of life and satisfaction with care of terminally ill patients.

Aim and methods: This review aims to develop a theoretical structural model of autonomy for patients at the end of life by synthesizing and analyzing findings on patients’ preferences related to autonomy from both qualitative and quantitative studies.

Results: Of the 5540 articles surveyed, 19 qualitative and 8 quantitative studies met the inclusion criteria, resulting in a dataset of 2924 patients. We identified two core structural elements of autonomy as defined by the patients: (1) being normal and (2) taking charge. By further analysis we arrived at 8 items from the perceptual perspective (perception of the body; energy and strength; physical contact; to deal with emotions; to be treated as a whole person; not to be burden to the family; to understand the meaning of the disease; to maintain dignity) and 13 items from the activity perspective (normal everyday activities; striving in roles; making plans; managing time; helping others; giving gifts; expressing preferences; fulfilling needs; preparation; making choices and decisions; completion; awareness of the disease; maintaining integrity), which map the conceptual structure of autonomy within this patient population.

Conclusion: This review shows that maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care but that emphasis should be also put on supporting the patients’ engagement in daily activities, in contributing to others and in active preparation for dying.
Use of the Short Form of the Schedule of Attitudes toward Hastened Death (SAHD-5) in Clinical Practice

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Background: The Spanish short form of the Schedule of Attitudes toward Hastened Death (SAHD) has recently been developed. The 5-item form (SAHD-5) has demonstrated a good correlation with the original SAHD. Nonetheless, until now the SAHD-5 consistency and accuracy on real clinical grounds has not been assessed, nor has the SAHD-5 inter-rate agreement with Desire for Death Rating Scale (DDRS) as the most commonly clinically use scale been evaluated.

Aims: 1) To evaluate feasibility of using SAHD-5 in daily clinical practice, 2) to assess the inter-rate agreement between the SAHD-5 and DDRS, and 3) to determine test-retest reliability of the SAHD-5.

Methods: This study included 107 advanced cancer patients (pts), 48 (45%) from the outpatients palliative care clinic, 56 (52%) from the oncology ward and 3 (3%) from palliative care unit. All pts were evaluated using the SAHD-5 and the DDHS in usual clinical conditions. To check test-retest reliability, stable pts (n=57) were re-assessed after a median of 7 days using the SADH-5. The kappa coefficient and interclass correlation coefficient (ICC) were calculated.

Results: 100% of the pts answered all 5 items of SAHD-5. The SAHD-5 mean was 0.5 (SD 1.02). The correlation between SAHD-5 and DDRS was ρ=0.69. For a DDSR cutoff score of 2, the recommended SAHD-5 cutoff was 2, with a sensitivity of 95.7% and specificity 64.3%. The kappa coefficient was k=0.62. As for test-retest reliability, the IIC was 0.71.

Conclusion: SAHD-5 shows good inter-rate agreement with the DDHS and test-retest reliability in real clinical practice conditions. Therefore, it appears to be a feasible and reliable instrument to assess and detect the WTHD in clinical practice due to its simplicity and reduced number of items.

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Dignity, Control and Wish to Hasten Death in Advanced Cancer Patients: A Cross-sectional Study

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Background: The wish to hasten death (WTHD) has been defined as a reactive phenomenon to multidimensional suffering. Some studies have identified depression as the major predictor of the WTHD. However, a perceived loss of dignity or control have been signalled as the principal causes of wishing to die, especially in countries where euthanasia or assisted suicide are legalised. Until now, no study has evaluated the relation between these variables using standardised instruments.

Aims: To assess the potential relationship between WTHD and the perception of both dignity and control.

Methods: Cross-sectional study of 107 advanced cancer patients enrolled in a Palliative Care Unit. Patients were assessed using the Schedule of Attitudes toward Hastened Death short form (SAHD-5), Patient Dignity Inventory (PDI) and General Self-efficacy Scale (GSE). Correlations and regression multivariate analysis were conducted.

Results: Mean (SD) scores of the questionnaires were 0.5 (1.02) for SAHD-5, 36.08 (12) for PDI and 31.82 (6.35) for GSE. There were a positive correlation between SAHD-5 and PDI (\(\rho=0.43\)) and a negative correlation between SAHD-5 and GSE (\(\rho=-0.35\)). Moreover, a negative correlation was found between PDI and GSE (\(\rho=-0.38\)).

Discussion/conclusion: There is a relationship between the WTHD and the perception of dignity and control. The results support the idea that the greater the perception of dignity and control, the lesser the WTHD and vice versa. What’s more, there is also a direct relationship between the perception of dignity and that of control. That is, the greater the perception of dignity, the greater that of control.
What Influences Changes in Patients’ End-of-Life Treatment Preferences over Time?

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Background: End-of-life (EOL) treatment preferences related to life extending vs. palliative care may change over time, yet there are limited studies in this area, and findings related to the direction of change have been equivocal.

Aims: To identify the clinical, demographic and psychosocial predictors of the stability of the EOL treatment preferences of older Latinos with advanced cancer.

Methods: One-hundred and three older Latinos with metastatic, recurrent or locally advanced cancer enrolled in a longitudinal study were interviewed once a month up until 12 months or death to assess preference stability over time. Measures included: patient EOL preferences, demographics, ESAS, EQ-5D, ECOG, FACT-G, Powe Fatalism Index, Lubben Social Network Scale-6 and Medical Mistrust Index. Data were analyzed using a generalized linear model with repeated measures over time.

Results: Fifty percent preferred palliative care (PC) and 50% preferred life extension (LE) at baseline. The percentage of patient preferences shifting from LE to PC was 5X greater than that shifting from PC to LE (P=0.005). Thirty-eight percent changed their treatment preferences (32% changed from LE to PC and 6% from PC to LE) and 62% remained stable. Those with no problems in mobility or usual activities (EQ-5D) showed a greater preference for LE (P< 0.04). Male gender, older age, low overall well-being (ESAS) and low fatalism predicted greater increases for PC preferences over time (P< 0.04).

Conclusion: This is the first longitudinal study to investigate how clinical, psychosocial and demographic/cultural factors influence the stability of EOL treatment preferences in older Latinos with advanced cancer. Findings suggest a combination of these factors influence the stability of preferences over time. Findings will inform culturally appropriate PC strategies, including fluid, culturally responsive advance care planning and the types and frequency of discussions physicians should have with patients.
The role of Patient Preferences in the Decision-making Process of Continuous Deep Sedation Until Death in Cancer Patients: Findings from the UNBIASED Study

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Context and aims: Guidelines encourage physicians to discuss the decision to use continuous deep sedation until death with the patient and obtain consent. This study describes how patient preferences were taken into account when making a decision to use continuous deep sedation.

Methods: Qualitative interviews with 26 physicians, 30 nurses and 24 relatives (involved in the care for 24 cancer patients who received continuous sedation prior to death in Belgium, UK, and the Netherlands) explored decision-making process in the use of sedation. Constant comparative analyses were used to compare the findings with Charles’ decision-making model distinguishing initiation, deliberation, and final decision phase.

Results: Especially in the initiation and decision phase, there was large variety in the role of patient preferences. In some cases, the decision to use sedation was predominantly driven by the patient’s clear preference for sedation, while in other cases, the decision was fully driven by physicians. The variety of responses to preferences was shaped by medical, cultural-legal factors, although overall the goal of providing comfort was similar in all cases. In Belgium and the Netherlands, patients could sometimes “choose” sedation (sometimes presented by physicians as an alternative to euthanasia) and physicians predominantly evaluated whether and when the patient fulfilled the medical criteria. Respondents from the UK pointed to the gradual process of decision-making, where the decision is primarily clinical and physician-driven. Furthermore, the patient’s role in the decision-making was limited in case of acute medical reasons that necessitated sedation, and in case of compromised capacity.

Conclusion: The large differences in the role of patients’ preferences in the decision-making of continuous sedation suggests variety in the extent to which patients and healthcare providers considered the use of sedation as being part of regular medical practice.
Does Ethnicity Make a Difference in Understanding of Palliative Care and Involvement in Decision-Making for People Affected by Severe Multiple Sclerosis?

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**Background:** Multiple Sclerosis (MS) is increasingly common among Black and Minority Ethnic (BME) groups. Recognition and understanding of the term palliative care may influence uptake of services. MS sufferers have consistently valued receiving information to enable decision-making and have concerns about coordination of their care. However, an ethnic comparison of these concerns has not been undertaken.

**Design:** A secondary analysis of a cross sectional study of 43 Black Caribbean (BC) and 43 White British (WB) People with MS (PwMS). Face to Face interviews were conducted to identify understanding of palliative care and importance of involvement in decision-making. Statistical analysis was conducted including multivariate logistic regression. A framework approach was used to analyse the qualitative data.

**Results:** Recognition of the term palliative care was 63% WB vs 44% BC (P=0.084). However, on sensitivity analysis correct understanding was found in 23% WB and 28% BC. Incorrect understanding included the provision of personal care and respite care. 81% of BC PwMS felt that they didn’t have enough information about palliative care services to be able to access them if needed. Also more BC PwMS admitted they were less knowledgeable about their illness and its progression (47% BC vs 16% WB, P=0.003). Both groups wanted to know all about their illness with family included even if that was bad news. Reasons for this included autonomy, preparation for the future and the importance of family.

**Conclusion:** In this study, ethnicity did not affect understanding of palliative care. However BC PwMS more often felt they lacked information to access palliative care services and information about their condition. PwMS want clear accurate information, family involvement in their care and thorough and timely communication between healthcare professionals involved. A palliative care approach may meet this unmet need and be beneficial and complementary to existing services.
End-of-Life Care Experience at the Paediatric Oncology Unit at the Uganda Cancer Institute: What Role Can Oncology Nurses Play?

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**Background:** Although the majority of childhood cancers are curable, this is not yet true for low resource countries. In Uganda, cancer care is only at the Uganda Cancer Institute. Between Jan 1st and Dec 31st, there were 4,321 new cancer cases registered and about 8% were among children. The mortality rate is 70% annually, that is every 3 in 5 children diagnosed with cancer will not survive past one year after cancer diagnosis. Here, we review the factors contributing to poor outcomes and potential solutions.

**Objectives:** To determine the role of an oncology Nurse at the end-of-life care of cancer children.

**Findings:** Majority of the children present with advanced disease at cancer diagnosis. The chemotherapy is prescribed for palliative intent more frequently and high rates of complications are observed. Family involvement in decisions regarding the role of palliative chemotherapy at end of life is low. The concept of quality of life for cancer patients with advanced cancer is not well perceived among caretakers and some clinicians at UCI. Nurses play an integral role, identifying symptoms, providing care coordination, and assuring clear communication.

**Conclusions:** Educational initiatives for patients, families and health-care providers, are essential. The oncology nurses play a key role in the multidisciplinary team approach to paediatric patients at end-of-life care.
**FC07 | Palliative Care in Low and Middle Income Countries**

**What Are the Components Contributing to a Successful Children’s Palliative Care Programme in Sub-Saharan Africa: Results of a Multi-method Evaluation**

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**Background:** Children’s Palliative Care (CPC) is in its infancy in many parts of sub-Saharan Africa (SSA), with a lack of evidence identified as a key limitation in ongoing service development. More understanding is needed on models of service provision, what makes them work and how challenges can be overcome.

**Aim:** To identify the different components contributing to the success of CPC service provision through an evaluation of different models of care in SSA.

**Methods:** A multi-method evaluation was undertaken consisting of: an online survey of 28 CPC programmes from across SSA, in order to generate information on different CPC programmes;

A focus-group discussion with 12 participants from eight CPC providers; and qualitative interviews with representatives from 7 organisations in Uganda (2), South Africa (4) and Malawi (1).

**Results:** A variety of themes emerged from the data including: the unique elements, and components of service provision; elements and reasons for success; challenges; communication; models; and development and sustainability. Similarities were seen in terms of the uniqueness of a programme, what makes it successful and the lessons learnt. Models need to be developed according to local need, culture, the environment and available resources. Challenges include lack of financial resources, the high burden of disease, a lack of resources, staffing and palliative care not being seen as a priority within the health system.

**Conclusion:** Whilst sharing common core elements, each programme had unique aspects which ensured they were appropriate for and embedded in the local community and context, which is key to the success of CPC service provision.
A Scoping Review of the Literature of Country-level Palliative Care Development in Africa

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**Background:** A large proportion of the recent global advances in palliative care (PC) are from countries in Africa, but the last comprehensive review was published ten years ago.

**Aims:** To conduct a scoping review of the literature to study the state of development of PC in countries in Africa.

**Methods:** A scoping review of peer-reviewed, published articles on the development of PC in each country in Africa was conducted using PubMed, CINAHL, and Embase. A combination of the following search terms was used: palliative care/medicine/nursing, hospice, hospice care/patient, cancer palliative therapy, and [country name]. 2 investigators independently rated each article by title, abstract, and full text according to the following inclusion criteria: country-level data; mention of at least one dimension of the WHO PC Public Health Strategy and vitality; published 2005–2016; language in English, Spanish, French, or Portuguese.

**Results:** The search resulted in 654 total articles; 510 after removing duplicates. 146 abstracts were screened for inclusion, of which 72 full texts were screened and included in the final analysis. 85% (435/510) of unique articles found in the scoping review and 82% (59/72) of full text articles were from Anglophone (Angl.) countries. 29 countries resulted in zero searches on PC development, of which 72% (21/29) were non-Angl. countries. Kenya had the largest number of full-text (12) articles. According to the analysis, Uganda has the most advanced integration of PC into its healthcare system. Uganda, Kenya, South Africa, and Tanzania have integrated PC into healthcare policies. South Africa has the highest morphine consumption, though Uganda stands out for initiatives in making morphine available. Postgraduate diplomas are available in Uganda, Kenya, South Africa, and Tanzania.

**Conclusion:** There is growing published research on PC development in Africa with a greater proportion from Angl. African countries.
Defining Country-level Indicators of Palliative Care Development through an Expert Process for the African Atlas of Palliative Care

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Background: Existing studies that measure indicators of palliative care (PC) development are not specific to the African context.

Aims: To develop an African-specific set of indicators as a component of a broader future project to develop an African Atlas of PC.

Methods: In-depth and open-ended in-person and Skype interviews, structured based on the WHO PC Public Health Strategy were conducted with 16 PC experts, identified by the African Palliative Care Association, of 7 African countries (Ghana, Namibia, Kenya, South Africa, Cote D'Ivoire, Mozambique, & Sudan). After the first 5 interviews, 2 researchers independently analyzed the transcripts and derived indicators on PC development. All 16 experts were asked to rate the derived indicators on a scale from 0–4 and to circle their top choices of indicators in each category based on feasibility and content validity.

Results: 178 indicators were derived from the initial 5 interviews, and after applying exclusion criteria (duplicates, individual-level data, data unavailable), 103 indicators were submitted to the 16 experts, of which 88% (14) completed the ratings. 31 indicators had average scores ≥ 3 for both content validity and feasibility. 7 indicators had average scores greater than 3.2:

1) existence of a periodic national conference, 2) number of hospitals with palliative care services and 3) university hospitals providing PC, 4) nurses with basic training and 5) nurses with specialized training, 6) existence of a national cancer program with a PC section 7) availability of oral liquid morphine.

From the remaining 11 interviews, an additional 21 unique indicators were derived. The final 52 (31+21) indicators will be reviewed by an “International Committee on Experts” and sent to two “Country Informants” per African country to assess the state of PC development in each country.

Conclusion: A set of specific indicators to study the development of PC in Africa was identified and is available for further research.
An Emergent Framework for Integrating Palliative Care into National Health Systems in Africa

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Background: Few models exist on how to achieve sustained integration of palliative care (PC) in low-income countries health systems. A DFID/THET funded programme set out to provide a blueprint for integration. The programme was delivered through a partnership between the University of Edinburgh, Makerere Palliative Care Unit and the African Palliative Care Association, working with the National Associations of Zambia, Uganda and Kenya and the Government of Rwanda.

Aims: To describe an integration trial, identifying the change indicators and tipping points.

Methods: We conducted a baseline assessment, and ongoing review to establish the local vision for integrated palliative care in 12 representative hospitals in Kenya, Uganda, Rwanda and Zambia. Building on a four pillar approach of advocacy, staff training, service delivery and partnership support we collected data on the components that each hospital identified as essential for vision, delivery and sustainability.

Results: The process of defining and developing an integrated model of palliative care was unique for each setting. However, a set of common overarching themes emerged captured in an ‘11 P’ framework. These were: Policies at national and local level, a Hospital Management agreed Programme of palliative care (whether through link nursing on wards channelling to a central service, or a separate unit, or a combination), Preceptorship, Pathways, Protocols, purposeful Prescribing, Procurement and Performance systems, Partnerships, Pastoral care and a visible Presence.

Conclusions: Though each hospital delivered their palliative care differently the 11 core components emerged in all settings and helped to create a shared agenda for palliative care. The common themes of the framework provide a systematic way of identifying activities, and organising systems to achieve integration within an existing service. This framework is also relevant to more economically developed countries.
‘I Find them so Secretive’ Information Needs of Patients Living and Dying of Advanced Heart Failure in Kenya: A Qualitative Serial Interview Study

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Background: Meeting patients’ information needs is essential for quality palliative care. The information available to patients with advanced heart failure in Sub Saharan Africa remains unknown.

Aim: Describe the information needs of Kenyan patients with heart failure in the context of their lived experiences.

Methods: We purposively recruited 20 patients admitted with advanced heart failure at a district hospital. We conducted in depth interviews with patients at 0, 3 and 6 months after recruitment, initially in hospital and then at home. Bereavement interviews were conducted with carers. Interviews were conducted and recorded in local language of Kiswahili, transcribed into English and analysed thematically, assisted by Nvivo software package.

Results: At diagnosis, patients wanted to know the cause of their illness so they could prevent a similar episode in the future. Some, especially once acute symptoms had subsided, expressed little need for information as they felt they had been cured of their illness. As the illness progressed, most patients wanted to know the likely course of their illness and what changes to make to their diet and levels of physical activity. At the end of life, patients felt frustrated by their deteriorating health and expressed greater need for information about their treatment and possibility of cure. Many patients found it difficult to ask doctors and to a lesser extent nurses for information. Patients often turned to social networks, the media and the internet to learn about their illness.

Conclusion: Patients with heart failure in Kenya experience significant information needs. However, their experience, with and perceptions of, health professionals limits their requests for information. There is an urgent need to improve the availability of information, and communication between patients and health professionals. This is vital to provide more patient centred care to improve quality of life for patients with heart failure in Kenya.
The Myeloma Patient Outcome Scale (MyPOS) is a Psychometrically Valid and Brief Measure for Monitoring Quality of Life in Patients with Follicular Lymphoma

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Background: The development of novel agents and an ageing population has led to an increasing number of patients with follicular lymphoma (FL) living longer with their disease. The disease remains incurable and patients experience long-term effects of treatment including physical symptoms, persistent fatigue, depression and anxiety. Health-related quality of life (HRQOL) is a priority for patients and is now guiding clinical decision-making.

Aim: This study is the first to test the psychometric properties a HRQOL questionnaire for use in the clinical care of FL patients.

Methods: The Myeloma Patient Outcome Scale (MyPOS), originally developed for myeloma, was validated in a cross-sectional survey recruiting 124 FL patients. Content and construct validity, structural validity in the form of confirmatory factor analyses, reliability and acceptability were evaluated.

Results: Factor analyses confirmed three subscales: Symptoms & Function, Emotional response and Healthcare support. Results from the model fit indices indicate a promising fit; \( \chi^2/df = 2.385 \), CFI=0.774 and RMSEA=0.109 (90% confidence interval: .097 – .121). MyPOS Symptom and Function scores were higher (worse) in participants with poorer ECOG performance status (F=26.2, p< .000) and discriminated between patients on and off treatment. Good convergent and discriminant validity against EORTC-QLQ-C30 and FACT-Lym were demonstrated. Analysis of content validity suggested potential additional FL-specific symptoms including problems sleeping, sweating and lower limb swelling.

Conclusions: MyPOS was shown to be reliable and valid for use in FL. This is the first HRQOL tool developed specifically for clinical use that has been validated in FL. Inclusion of items about healthcare is novel and supports optimal patient care. Potential for use of MyPOS in other similarly chronic and fatal haematological malignancies is indicated.

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Validation of the Integrated Palliative Care Outcome Scale (IPOS) to the Portuguese Population – Completion Assessment and Thematic Analysis of the Open Question Items

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Context: IPOS is a patient-centered outcome measure that includes 2 open questions. Each allows 3 responses.

Aim: To assess completion and main themes of the open questions for patients and healthcare professionals.

Methods: Multi-centred observational study. Data was collected in 9 centres using convenience sampling. All patients attending the participant services were screened for eligibility. Inclusion criteria: ≥18 years, mentally fit to give consent, diagnosed with an incurable, potentially life-threatening illness, read, write and understand Portuguese. Exclusion criteria: patient in distress, cognitively impaired. The measure had been previously culturally adapted using translation, back translation and cognitive interviews. Proportion of completion are presented for each open question. Content analysis was performed.

Results: 1703 individuals were screened between July 1st 2015 and February 2016. 135 (7.9%) were included. Mean age is 66.8 years (SD 12.7), 58 (43%) are female, 74 (54.8%) have up to 4 years of formal education, 74 (54.8%) are from the Northern region. Most patients had a cancer diagnosis 109 (80.7%). Completion by patients for item 1: 96 (71.1%) for item 1a, 49 (36.3%) for 1b and 22 (17%) for 1c. Main 3 themes emerging were “worrying about the disease”, “pain” and “other physical symptoms”. For clinicians, rate of completion was 124 (91.9%) for item 1a, 87 (64.4%) for 1b and 41 (30.4%) for 1c. Main 3 themes emerging were “other physical symptoms”, “pain” and “worrying about the disease”. In relation to item 2, patients’ completion was between 37 (27.4%) for 1a and 4 (3%) for 2c. Clinicians: 53 (39.3%) for 2a to 2 (1.5%) for 2c.

Conclusion: By providing free text items, IPOS allows respondents to add problems, arising in the week prior to completion, whether or not listed in IPOS. This allows to emphasise the main problematic issues which might need to be prioritised.

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Health Professional’s Clinical Intuition vs. Response to the Surprise Question: Secondary Outcomes of an International Prospective Study Investigating the Last Days of Life

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Background: There is increasing evidence highlighting the usefulness of the ‘surprise question’ as a screening tool to identify patients who may die at different time points (12, 6 or 3 months; 30 or 7 days), in different settings and from various illnesses.

Aims: As part of an international, prospective study which aimed to identify which signs and symptoms present in the last days of life could be employed to accurately diagnose dying, we compared responses to the surprise question against the intuition of the health professional (HP) to identify differences or similarities in their diagnostic value.

Methodology: Between October 2012 and July 2013, nurses and physicians prospectively observed for 7 days, 239 patients in acute hospital palliative care units, nursing homes, and hospice. The HPs responded the surprise question and stated their intuition of whether the patient would die within 7 days. Statistical analyses, and content analysis of open responses to the HPs’ intuition were performed.

Results: Of the observed patients, 80% died within 7 days. The surprise question was not significantly associated with death at 7 days ($X^2=0.566, p=0.452$), its sensitivity was 78.4% and specificity 16.7% with an AUC of 0.460. In contrast, intuition was significantly associated with death at 7 days ($X^2=104.393, p<0.001$), and showed a better diagnostic accuracy: sensitivity 97.3%, specificity 61.3% with an AUC of 0.794. Content analysis revealed the main aspects involved in expressing intuition.

Discussion: The differences identified between the surprise question and the HPs intuition have not been recognised elsewhere and are important in furthering current understandings as well as to aid in the development of tools and processes to diagnose dying. The HPs clinical intuition, based on the identified underlying aspects, would seem a more effective ‘tool’ to aid in the diagnosis of dying, and potentially at other stages of prognostic prediction, than the surprise question.
Enhancing Clinical Decisions about the Antimicrobial Use at the End of Life – Should the Palliative Prognostic Score Be Considered?

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Easy-to-understand formats of accurate tools, such as the Palliative Prognostic Score (PaP) may facilitate decision-making. The median survival of patients with PaP>11 in literature was no better than 2 weeks (95%CI < 1–3w). To our knowledge, no study explored the ability of the PaP to identify candidates to a potentially appropriate anti-infective treatment at the end of life.

Aims: To compare the survival of patients with PaP>11 according to treatment decision; to describe the accuracy of the PaP in predicting 14-day survival.

Methods: Prospective cohort study, in advanced cancer patients, with a non-mucosal infection (suspected or documented), at the first visit of a hospital-based Palliative program. Demographics, clinical condition, PaP, infectious episode (sepsis or organ-related), place of care, and anti-infective use were recorded. Survival analysis used Kaplan-Meier curves and log-rank tests. Discrimination ability and calibration for 14-day survival were assessed [area under the receiver-operating characteristics curve (AUC) and Hosmer Lemeshow test].

Results: 128 of 412 (31%) enrolled patients had PaP>11 at admission. Their median overall survival (median age 70y, 46% gastrointestinal tumours, 18% under active treatment, 54% with sepsis, 77% hospitalised) was significantly shorter [7d (95% CI 5–9d) vs 52d (95% CI 42–62d)]. Prescribing rates of antimicrobials (72%) were slight but no significantly higher in the group. In contrast, this patients (and families) were less frequently involved in decisions concerning anti-infective use. No differences were found in the survival curves of those who get antimicrobials [median 9d (95% CI 6–12d) vs 5d (95%CI 2–8d), p=0.33]. PaP was calibrated and good in discrimination (AUC 0.84, 95%CI 0.8–0.88). A PaP>11 had a high (85%) specificity and negative predictive value.

Conclusion: The use of anti-infective drugs in our PaP>11 sample didn’t improve survival. This potential utility of the PaP should be further explored.
What Aspects of Quality of Life Are Most Important from Palliative Care Patients’ Perspectives? A Systematic Review and Framework Analysis of Qualitative Interviews

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Background: Economic evaluations in the palliative setting are rare. One major challenge when conducting such evaluations is capturing and valuing benefits.

Aims: To identify quality of life (QOL) domains important to people receiving specialised palliative care services for validating preference-based instruments used to measure benefit in economic evaluations.

Methods: First, a framework synthesis was conducted of key themes identified from a systematic review of published, peer-reviewed, English-language articles reporting primary qualitative data investigating QOL domains in adults with a progressive, life-limiting illness. Second, framework analysis of 18 digitally recorded, in-depth, face-to-face interviews explored the key determinants of QOL to augment the initial conceptual model of QOL. Purposively sampled participants were recruited from patients under the care of a Southern Adelaide Palliative Services (SAPS) and Daw House hospice, South Australia.

Results: Eight important aspects of QOL matched key determinants from the framework synthesis: cognitive; emotional; healthcare; personal autonomy; physical; preparatory; social; and existential. Overall, 28% of participants ranked either social or physical aspects as the most important QOL domains, while 44% reported financial aspects as the least important QOL domain.

Conclusion: Preparation for death and other less tangible aspects of health care provision are seldom included in currently available preference-based measures used to inform value for money decisions in palliative care. Consequently, services for palliative care patients may be inappropriate or inadequate, leading to suboptimal and inefficient care.
Assessment of Cognitive Function in Patients with Metastatic Cancer: A Validation Study


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**Background:** Cognitive deficits are frequent complaints in patients with cancer, but there is a lack of validated neuropsychological assessment tools.

**Aim:** This study aimed at analyzing the validity and reliability of the Continuous Reaction Time (CRT), Finger Tapping Test (FTT), Digit Span Test (DST), Trail Making Test-part B (TMTB) and Mini-Mental State Examination (MMSE) in patients with metastatic cancer.

**Methods:** A convenience sample, composed by 80 adult patients and 81 healthy controls (≥8 years, ≥6 years of schooling, fluent Danish language, stable medications ≥4 days), was assessed between July 2010 and November 2015. Those on stable medications were scheduled for a second assessment in an interval of 2–7 days (test and retest). The five neuropsychological tests were analyzed regarding construct/discriminant/criterion validity, reliability and statistical power.

**Results:** Patients and controls had similar sociodemographic characteristics, but differed regarding income (P=0.00019) and sensation of rest after night sleep (P=0.0054). These differences were expected and not adjusted. Construct validity: it was not possible to estimate a model for MMSE because of skewed response distribution. Discriminant validity: patients were slower on CRT 50th (P=0.00483) and 90th (P=0.00030) percentiles and FTT dominant hand (P=0.00306). Regarding sensitivity and specificity, only DST and TMTB seemed to predict cognitive deficit; however, ROC curve areas were ≤0.73. Criterion validity: few significant correlations and almost all very weak between the tests, sociodemographic and clinical variables. Reliability was adequate for TMTB, DST, and FTT.

**Conclusion:** The findings of the validation analyses of these neuropsychological assessment tools in patients with metastatic cancer were not clear-cut. However, CRT, DST, FTT and TMTB demonstrated partial positive results, indicating that these tests have good potential for use in clinical settings and require further study.
Palliative Sedation Practice in a Hospital and a Hospice in London, UK: A Clinical Notes Audit for I-CAN-CARE

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Background: The I-CAN-CARE research programme seeks to improve the care and assessment of dying patients. One of its two components is the investigation of sedation at the end of life.

Aims: To audit notes of patients in London, UK receiving end-of-life care in a hospice and from a hospital palliative care team, and explore the prescribing and monitoring of palliative sedation.

Methods: We reviewed notes and drug charts of deceased patients, working backwards from 31/12/2015, collecting basic sociodemographic and clinical data. We continued until we had identified 25 patients at each site who received continuous subcutaneous infusion (CSCI) of midazolam at the end of life. For these patients we recorded details of sedation and analgesia, plus indications for, and monitoring of sedation.

Results: We retrieved 92 sets of notes; 44 at the hospice, 48 at the hospital. Thus, 25/44 (57%) hospice and 25/48 (52%) hospital patients received CSCI midazolam. Levels of CSCI midazolam 24 hours prior to death were similar at the two sites: median at the hospice 10mg (range 0.35–58mg); median at the hospital 11.4mg (range 0.83–69.5mg). Overall, the median ‘as required’ dose given was 5mg; median total dose 15.7mg. Only 12/50 (24%) received ≥30mg midazolam. The primary indication for midazolam was noted as distress, anxiety, agitation, or dyspnoea for 40/50 patients (80%), and for 5/50 (10%) as seizure prevention (doses of 15–30mg). Other sedative drugs (levomepromazine, phenobarbitone, haloperidol) were rarely used in combination with midazolam. All hospital patients receiving CSCI midazolam also received analgesia but three hospice patients did not. Higher doses of analgesia were used at the hospice: median 170mg vs. 72mg in hospital.

Conclusion: Just over half the patient notes audited in both settings showed CSCI midazolam use in the 24 hours before death, mostly at low doses for symptom management, rather than sedative doses.

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Improving the Delivery of End-of-Life Care in Residential Homes through Audit

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Background: The use of audit can support the implementation and sustainability of end-of-life care programmes into care homes. An example is presented of where a baseline audit revealed a lack of confidence and knowledge to provide high-quality end-of-life care in four residential care homes.

Aim: To evaluate the impact of audit and end-of-life training in the daily practice of staff working in residential care homes.

Method: In 2015, four care homes agreed to undertake an audit. Audit standards on advance care planning, pain and depression assessment were co-developed. The audit proforma was completed using residents’ care plans and medicine administration records [MAR charts]. An end-of-life staff questionnaire was also issued.

The audit had three phases. Initially a baseline audit was undertaken; three group training sessions per care home and ongoing weekly individual role modelling on advance care planning, pain and depression recognition/assessment/management then commenced. Eight months after the training a re-audit was undertaken.

Results: In the baseline audit the care plans and MAR charts of all residents in the care homes were reviewed (n=180) and 44% [94/212] end-of-life staff questionnaires returned. The re-audit included 162 residents with 50% [80/160] staff questionnaires returned.

Comparing the results the number of advance care plan discussions increased from 38% to 54%; pain assessment using a validated tool increased from 7% to 75% and depression assessment with a validated tool increased from 1% to 48%. The overall self-reported staff confidence regarding end-of-life increased from 8.0 to 8.8. Its achievement required the support of external professionals.

Conclusion: Combining audit alongside implementation of an end-of-life care programme enabled learning and change in practice to occur. This process achieved demonstrable improvement of care home staffs ability to assess pain and depression and undertake advance care plan conversations.
Effects of Audit and Feedback on the Quality of Care and Comfort in Dying with Dementia (FOLlow-up)

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Background: Despite increased attention for palliative care in patients with dementia dying in nursing homes, recent studies found burdensome symptoms and unmet family caregivers’ needs in the last phase of life. Audit- and feedback were expected to improve quality of palliative care.

Aim: To assess the effect of two audit- and feedback strategies on care quality in Dutch nursing homes using the EOLD-Satisfaction With Care scale (EOLD-SWC) and on outcome using the EOLD-Comfort Assessment in Dying scale (EOLD-CAD).

Methods: In a cluster randomized controlled trial, two audit-and feedback strategies, either generic feedback based on mean EOLD-scores or feedback with patient-specific EOLD-scores (six nursing homes each) were compared to a control group (six nursing homes) without feedback. The intervention groups discussed EOLD-ratings representing family views after death in team meetings and formulated actions for care improvement. Multi-level analyses were performed to assess effects and a process evaluation catalogued barriers and facilitators of the intervention using semi-structured interviews.

Results: A total of 668 families rated the EOLD-instruments. Compared to no feedback, the generic strategy resulted in lower satisfaction in both adjusted and unadjusted analyses, while the patient-specific strategy increased comfort in unadjusted analyses only. The interviews showed that staff felt that regular team discussions about EOLD-scores were not always feasible. Improvement actions were not formulated sufficiently clear enough and were not followed-up, and favorable EOLD-scores did not seem to motivate teams to do better.

Conclusion: The disappointing effectiveness of audit and feedback may be explained by suboptimal conditions and insufficient skills to translate the feedback into care improvements. Feedback with favorable family ratings might even have triggered opposite effects in the context of Dutch long-term care.

Trial number: NTR 3942.
Effect of Duration and Intensity of Palliative Care on End-of-Life Quality Markers for Cancer Patients: A Retrospective Cohort Study

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Background: Integration of palliative care alongside oncology management should be considered early in the course of illness for any patient with metastatic cancer or high symptom burden.

This recommendation is based on randomised controlled trials largely from North America which have demonstrated improved symptoms and quality of life, and a reduction in acute hospital admissions and in aggressive cancer treatments at the end of life. In order to more directly inform models of service delivery, better quality data is needed on how much and for how long patients with cancer need to receive palliative care before important improvements in end-of-life care can be observed.

Methods: Retrospective cohort study linking cancer registry, primary care and secondary care data to explore associations between palliative care provision and a series of quality markers for end-of-life care. The linked dataset consisted of 2474 deceased cancer patients who died of cancer between 2010 and 2012 within a large metropolitan UK city.

Results: Palliative care was significantly associated with patients dying outside hospital. Number of palliative care events was more important than duration of palliative care in predicting place of death. More patients that received palliative care had access to strong opioids before death compared to patients who did not receive palliative care, 53.9% versus 25.2% (p< 0.001). Emergency hospital admission was associated with significantly fewer palliative care events and a significantly shorter duration of care (4 versus 7 weeks, p< 0.001). Patients who received palliative care for longer than 4 weeks before death were significantly less likely to require emergency hospital admission within the last four weeks of life.

Conclusions: This study has demonstrated for the first time a dose response relationship in relation to palliative care and a series of quality indicators for end-of-life care.
How Many People Will Need Palliative Care in 2040? Projections in England and Wales

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Background: Current population estimates show that about 75% of people who die may benefit from palliative care. A growing number of older people and increasing prevalence of chronic illness mean that palliative care need will rise, but this has not been quantified.

Aim: To estimate future population palliative care need in a high income region.

Methods: We used mortality statistics for England and Wales from 2006–14. Building on previous diagnosis-based approaches, we calculated age- and gender-specific proportions of deaths from defined chronic progressive illnesses to estimate the prevalence of palliative care need in the population. We calculated annual changes over the nine-year period. Using explicit assumptions about change in disease prevalence over time, we projected this estimate forward using national population projections, up to 2040. We undertook separate projections for dementia, cancer, and organ failure.

Results: By 2040, annual deaths in England and Wales are projected to rise 25.4% (from 501,424 to 628,659). If the proportion with palliative care need remains the same as in 2014 (74.9%), the number of people requiring palliative care will grow 25.0% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006–14 continues, the increase will be 43.1% (161,842 more people/year, total 537,240). Disease-specific projections show that dementia (increase from 59,199 to 214,078 deaths by 2040); and cancer (increase from 143,638 to 206,733 deaths by 2040) will be the main drivers of increased need.

Conclusions: If recent trends continue, 43% more people will need palliative care by 2040. This is far larger than currently anticipated. Countries with similar demographic patterns and disease changes will experience comparable rises in need. Healthcare systems must start to adapt now to the age-related growth of dementia and cancer, and increase integration of palliative care for these illnesses.

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Expanding the Footprint, Enhancing the Dialogue: Implementation of a Hospital-based Physician Led Hospice Consultation Service

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Background: Hospice enrollment teams in U.S. community hospitals are routinely comprised of hospice staff nurses, plus social workers. To better assist patients and families in navigating discharge options, to expedite hospice enrollment and discharge, and to educate medical staff in the breadth of hospice services, we expanded our hospital team to include a physician and registered nurse practitioners.

Objectives: To qualitatively and quantitatively examine the early results of this intervention.

Design:
1. A 3 page confidential questionnaire was submitted to 40 hospital case managers.
2. A retrospective study of in-hospital hospice referrals from a three month time period 6 months prior to team enhancement, compared to those from a similar time period 6 months after.

Results: The case manager survey ranked the expanded hospice team performance 30% higher in facilitating patient decisions and expediting discharge plans. 1557 hospice referrals were studied in the two 3 month time periods of 01 through 03/2014 and 01 through 03/2015. A 10% increase in hospice referrals was noted. Of the patients enrolled, we observed a 30% reduction in delays (>72 hours) to enrollment (O.R. 0.69, 95% C.I. 0.66–0.71, p< 0.001). Of those patients not enrolled, we found that 46% fewer chose a Medicare funded skilled nursing bed as an alternative to hospice (O.R. 0.54, 95% C.I. 0.49–0.59, p< 0.001), and that our capacity to finalize within 24 hours of referral the plan of care rose by 39% (O.R. 0.75, 95% C.I. 0.71–0.80, p< 0.001).

Conclusion: Expanding the in-hospital hospice enrollment team to a physician led hospice consultation service has expedited discharge plans, reduced delays in patient and family decision-making, and begun to educate some referring clinicians in the scope of hospice services.
Free Communication Sessions

FC10 | Population-based Datasets

Do Different Subgroups of Patients Starting Specialized Palliative Care Have the Same Levels of Symptoms and Problems? A Nationwide Study of 21,234 Danish Cancer Patients

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Background: Large, nationally representative studies of health-related quality of life (HRQOL) in cancer patients in specialized palliative care (SPC) are missing.

Aims: The aim of this study was to describe HRQOL (symptoms/problems) in cancer patients at the start of SPC and to investigate how age, gender and cancer site were associated with these outcomes.

Methods: Data from the Danish Palliative Care Database was used in this study. We included cancer patients who died 2010–2015 and who completed EORTC QLQ-C15-PAL at admission to SPC. For these patients we calculated mean scores for the 10 QLQ-C15-PAL subscales according to age, gender and cancer site and performed ordinal logistic regression to test if age and gender (controlled for the effect of cancer site) were associated with each outcome.

Results: 21,234 patients were included in the analyses. The average age was 68.6 years, about half were women and the most common diagnosis was lung cancer. The patients had the highest scores for symptoms/problems for fatigue (mean 75, range 0–100 where 100 is maximal fatigue), appetite loss (58) and pain (56) and had poor physical functioning (29, range 0–100 where 100 is best functioning) and poor overall quality of life (QOL) (40, 100=best QOL). Results from the ordinal logistic regression showed that increasing age was associated with lower levels of pain and insomnia but increased risk of poor physical functioning. Compared to men, women had higher risk of nausea but lower risk of insomnia. Overall, patients with brain and central nervous system cancer had the lowest levels of symptoms/problems, whereas patients with ovarian cancer had the highest levels.

Conclusion: The patients starting SPC were troubled by severe levels of symptoms, poor physical functioning and reduced QOL. Our study showed marked differences in symptomatology according to diagnosis, age and gender.

Main source of funding: University of Copenhagen and Danish Cancer Society.
**Where Will People Die in Future Years? A Population-Based Analysis of Future Projections (2015–2040) and Implications for Health and Social Care Services**

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**Background:** Worldwide, deaths are set to rise from 57 million to 70 million in the next 15 years. Understanding where these deaths will occur is essential for service planning to ensure health and social care systems can support the needs of people at the end of life. Trends in place of death in England and Wales have shifted in the last 12 years, necessitating a re-evaluation of where people will die in the future.

**Aim:** To project where people in England and Wales will die across all settings until 2040.

**Methods:** We analysed death registration data on place of death for all deaths in England and Wales from 2004–2014 (N=5519486) and projected deaths for 2015–2040. We first examined past trends. Using simple linear modelling and explicit assumptions, we then projected these trends forward, by applying age and gender specific proportions of deaths in each setting to the number of people expected to die in the future.

**Results:** There are projected to be 134390 more deaths in 2040 than in 2014. Between 2004 and 2014, proportions of deaths in care home and at home rose (16.7 to 21.2%; 18.3 to 22.9%) while deaths in hospital – the least preferred setting – fell (57.9 to 48.1%). If the decline in hospital deaths to 2040 is sustained, then care home, home and hospice deaths will need to increase by 114749, 101521 and 19032 respectively, together accounting for over three-quarters of deaths. However, if care home capacity does not increase and it is assumed that surplus deaths occur in hospital, the decline in hospital deaths will reverse by 2022.

**Conclusion:** If the decline of deaths in hospital is to be sustained, there is an urgent need to invest in community services and social care, and expand the number of care home places. These projections point to future global pressures on health and social care services. To support increasing numbers of deaths, more training in palliative and end-of-life care for health and social care professionals is essential.

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Uptake of Policy Measures to Support Palliative Home Care: A Population-level Study Using Linked Administrative Databases

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Background: Most developed countries have implemented supportive policy measures to facilitate home-based palliative care, for instance in the form of financial compensations to families. Evaluating the uptake of these measures and the equity in this uptake is an important public health concern in palliative care.

Aim: To examine the uptake of policy measures to support palliative care in the home setting and the sociodemographic and disease-specific characteristics associated with this uptake.

Methods: This study uses linked full-population databases containing information on sociodemographic and disease characteristics and healthcare use for all home-dwelling decedents in Belgium in 2012 (n=87,465). Identified policy measures concern “all health care forfeits that can support the patient to remain at home in the last phase of life”, distinguishing 3 measures specifically for palliative home patients and 8 generic measures. Logistic regression analyses were used to examine factors associated with uptake.

Results: 17.8% (n=15,565) of all home-dwelling decedents received a policy measure specifically for palliative home patients; 55.9% (n=48,891) received at least one generic supportive measure; 39.4% (n=34,473) did not use any measure. Being female, older, Belgian, lower educated, not living in a single person household, and not living in a highly urbanised area were factors associated with a greater chance of using any supportive measure. Those dying from cancer had substantially better chances of receiving specific palliative home care supportive measures compared to those dying from heart failure, respiratory disease, or neurodegenerative disease.

Conclusion: While a relatively large proportion uses some measure to support palliative care in the home setting, a rather small proportion uses the available specific palliative home care measures. Further research should focus on this low uptake and the inequalities between certain population groups.
Background: Palliative care for non-cancer conditions has not been widely implemented and internationally a systematic change in healthcare policy has been recommended. In 2008, the UK End-of-Life Care Strategy represented a major policy shift to extend palliative care to all potentially in the year of life regardless of diagnosis.

Aims: To investigate if the change in policy improved entry onto the palliative care register as a proxy marker of recognition of a palliative care approach, for patients who died of non-cancer compared with cancer conditions.

Methods (design, data collection, analysis): Secondary analysis of contemporaneously collected data from Clinical Practice Research Datalink, CPRD the world’s largest primary care database. Adult decedents with a diagnosis of cancer, heart failure (HF), dementia and COPD that died during the periods Apr 09 to Mar 10, Apr 11 to Mar 12 or Apr 13 to Mar 14; were identified. To explore if the proportion of patients on the palliative care register had changed over time a chi square test for trend was used. Data were analysed using Stata version 14.1.

Results: For those with dementia (N= 7,339) the proportion on the palliative care register has increased over time, from 13.0% in 2009–10 to 30.5% in 2011–12 and 41.4% in 2013–14. There was a more modest rise for COPD (N=5,426) (13.4%, 17.3%, 22.6%), HF (N=2,154) (13.0%, 16.8%, 24.2%) and cancer (N= 18 668) (57.6%, 60.2%, 61.7%). (χ² test for trend, p< 0.001). For those on the palliative care register the non-cancer decedents were also recognised late: proportions just a week prior to death for dementia 515/2,174 (23.9%); COPD 160/949 (15.2%); HF 205/1119 (18.3%) compared with 979/11,139 (8.8%) for cancer decedents.

Conclusion: Although the number of patients recognised as needing a palliative care approach has increased over time, the change in policy to recognition of “last year of life” has not improved the inequity in recognition of non-cancer conditions.
Palliative Care Service Use by Older People: Time Trends in Belgium between 2005 and 2014

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Background: It is increasingly recognized that older people approaching the end of life could benefit from palliative care regardless of their illness. This study investigates
1) whether there has been a time trend in the use of palliative care services,
2) the timing of their initiation for older people, and
3) if the proportions of different patient groups using palliative care services have changed.

Methods: A nationally representative General Practitioner (GP) Sentinel Network participated in a mortality follow-back survey in 2005–2010, 2013 and 2014 in Belgium. GPs reported all patients in their practice who died non-suddenly at age 65 or over. A standardised registration form surveyed sociodemographic and clinical data, use of any of the palliative care services available in Belgium and when the first of these was initiated.

Results: GPs identified 5344 deaths. Overall, palliative care service use increased from 39% in 2005 to 63% in 2014 (p<0.001). The use of a reference person for palliative care in a care home increased from 12% to 26% (p<0.001) and the use of a palliative homecare team from 14% to 17.5% (p<0.01). There was no increase in the use of hospital-based palliative care services. In multivariable analyses controlling for age, gender and cause of death, all types of palliative care services showed a significant increase in the proportion of people aged 85+ though the median age of the sample remained the same. No differences over time were found in the proportion of cancer/non-cancer patients. The timing of initiation of palliative care services remained unchanged at a median of 15 days before death.

Conclusions: Palliative care service use has increased mostly in care homes, while progress in hospital-based palliative care services lags behind. Contrary to recommendations, access for non-cancer patients may remain difficult. The continued late initiation points to palliative care still being terminal care in too many cases.
Access to Palliative Care for Patients with Advanced Cancer: A Longitudinal Population Analysis

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Background: The UK National Health Service is striving to improve access to palliative care for cancer patients by moving towards a unified supportive care service. Limited information exists, however, on the extent and duration of palliative support currently provided to cancer patients in the UK by community and hospital palliative care teams and the patient characteristics associated with receiving such care.

Aim: To establish, by provider, the duration and intensity of palliative care received by patients with advanced cancer, and assess associations between level of palliative care provision and patient characteristics.

Methods: Retrospective cohort study linking cancer registry, primary care and secondary care data to explore associations between demographic characteristics and palliative care provision. The linked dataset consisted of 2474 deceased cancer patients who died of cancer between 2010 and 2012 within a large metropolitan UK city.

Results: Overall 64.6% of patients received palliative care. The average palliative care input for these patients was 2 contacts over a six week period. Patients less likely to receive palliative care were: male, over 80 years of age and those with a diagnosis of lung cancer. Women, patients with gynaecological or head and neck cancers and patients diagnosed < 3 months before death were more likely to receive hospital than community palliative care. Patients receiving community palliative had more palliative care events, for a longer duration compared to those receiving hospital palliative care.

Conclusion: We have determined the characteristics of cancer patients currently underrepresented in terms of access to palliative. For patients who receive palliative care, the average duration and intensity of involvement is short in relation to the level of engagement the research evidence suggests is optimal.
Euthanasia and Unbearable Suffering in Hospice Patients: A Retrospective Analysis

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**Background:** In the Netherlands euthanasia is defined as the termination of life by a doctor at the request of a patient. This is legal when the 6 requirements of due care are met. One of these requirements is ‘unbearable suffering’. Aim of our study is to analyse the symptoms and considerations on unbearable suffering in patients requesting for euthanasia in a professional driven hospice.

**Methods:** A retrospective study of all patients who died by means of euthanasia during hospice admission between July 2007 and July 2016. Notes of physicians about the symptoms and considerations on unbearable suffering were analysed and studied in the context of the somatic, psychological, social and existential dimension.

**Results:** All 28 patients who died as a result of euthanasia were included (5,1% of all admissions). Patients mentioned 3 to 5 different symptoms as a cause of the unbearable suffering. The combination of somatic and existential symptoms caused unbearable suffering for 21 patients (75%).

The prevalence of somatic symptoms was 92%; mostly fatigue (54%), pain (36%) and physical decline (32%). Existential symptoms was mentioned by 82%; mostly hopelessness (46%), loss of autonomy (39%), physical dependency (36%) and futility (32%). Psychological symptoms were present in 33% of patients; predominantly the fear for dying without dignity (25%). In the social dimension only one patient (4%) mentioned a symptom.

**Discussion:** Unbearable suffering in the context of euthanasia in a hospice consists of a combination of symptoms, mostly a combination of at least a somatic and an existential symptom. Psychological and social symptoms are less prominent. Despite intensive support and continuous attention available for all patients and provided by complementary therapist, music therapist, creative therapist, physical therapist and a chaplain, existential symptoms are hard to control. The percentage of patients who died due to euthanasia is in accordance to the Dutch national number of euthanasia-cases.
Measuring Fidelity of Implementation of Advance Care Planning Model in ACTION Project

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Introduction: Although fidelity of implementation of an intervention is crucial in interpreting the results, there are only few studies suggesting methods of fidelity assessment to a core model in complex interventions. Part of ACTION project, a randomized controlled trial to explore the impact of advance care planning (ACP) in cancer patients, was to establish fidelity process and tools according to the literature and to specific characteristics of the intervention.

Aim: To present the first results of the fidelity assessment of ACP conversations at the midpoint of the patients’ inclusion period.

Methods: Audio-taped ACP conversations between 29 facilitators, patients and their personal representatives in ACTION project in six countries: Belgium, Denmark, Italy, Nederland, Slovenia and UK were assessed against the fidelity checklists in an agreed process. Firstly, the adherence to the ACP interview guides was assessed in quantitative terms of % of questions ‘asked as written, or all elements of question were covered’. Secondly, assessment of appropriate use of six core general interview skills was obtained, and thirdly, specific qualitative determinants of the ACP conversation were evaluated. Fidelity assessment of implementation of ACP model was obtained at the midpoint and it is also planned at the end of the intervention.

First results of the midpoint fidelity assessment are showing an average of 85% fidelity to interview guides and the overall quality of the conversations is assessed as ‘good’ (from 5 point Likart scale, from ‘very good’ to ‘very poor’).

Conclusion: The process of fidelity assessment at different points in the intervention period has a potential to reflect actual implementation of the ACP model.

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Rise and Decline of Medication Use in the Last Months of Life of Advanced Cancer Patients. The International Multi Centre EPCCS Study

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**Background:** Little is known how medication evolves in the last months of life of advanced cancer patients.

**Aim:** To describe the medication use in advanced cancer patients being admitted to a palliative care (PC) program at different time points before death.

**Method:** In this prospective study, advanced cancer patients were recruited in 30 oncology / PC units in 16 countries. From recruitment on, medical data and symptoms were registered every 3 to 5 weeks, using case report forms completed by patients and health care providers at each encounter. Medication was dichotomous; use: yes/no for 19 therapeutic groups. Data were analysed retrospectively using death as the index date. Only patients with a verified date of death with at least 1 case report were included here. We compared medication use at 0, 1, 2, 3 and 4 months before death by constructing 5 cross-sectional subsamples with medication use during that month.

**Results:** On average age was 67 (SD 12.735), 54% were males (n=653). The most prominent diagnoses were bowel (37%), lung (22%) and breast (8%) cancer. Treatment with chemotherapy decreased from 43.8 at 4 to 15.5% at 0–1 month before death. While the use of non-opioids declined from 54.8 at 4 to 46.4% at 0–1 month before death, significantly more opioids (61.8 to 80.5%) were prescribed. Comparing drug use between 4 (n=249) and 0–1 month (n=400) before death, a significant increase in the use of corticosteroids (43.9 to 70.6%), neuroleptics (9.6 to 19.6%), sedatives (35.1 to 46.0%), laxatives (56.5 to 65.5%), antibiotics (9.7 to 18.6%), diuretics (18.9 to 28.0%) and antithrombotics (27.1 to 38.3%) and a decrease in cardiovascular drugs (36.6 to 26.9%) were found.

**Conclusion:** When death approached, medication for symptom control increased, as well as most other medication groups. To appraise the decrease in cardiovascular drugs, more detailed medication data are needed.
A Delphi Process to Develop a Documentation Template for Palliative Sedation in Germany Based on the EAPC Framework

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Background: Palliative Sedation (PS) has become an accepted treatment option in case of intolerable and otherwise untreatable symptom burden. In 2009, the EAPC published a framework (FW) for PS, but still clinical practice differs.

Aim: To develop a German template for the documentation of PS according to the FW.

Methods: Based on the FW and on 52 existing single unit documentation tools collected during a previous study, a first draft of a template was generated by the project team. Domains with sub items were: demographics, indication, capability to consent, process of consent, PS strategy and monitoring. Professionals (n=137) from inpatient and outpatient specialist palliative and hospice care were invited to assess all items of the draft regarding “relevance”, “wording” and “feasibility” using a 4-point Likert scale in a Delphi survey (Unipark®). Approval was granted when acceptance (agree, rather agree vs. rather disagree, disagree) exceeded 75%. The professional background of the participants was analysed.

Results: Two rounds of the Delphi process were completed by 47 experts. All but one item reached consensus. In the domain monitoring, the item “vital signs (RR, SpO2, HR)” remained controversial in regard to relevance (accepted by 69%) and feasibility (67%). While 80% of experts from palliative care units and community teams agreed to the relevance and 74% to the feasibility, 47% of the leaders of hospices confirmed the relevance and 53% the feasibility of the documentation of vital signs.

Conclusions: The necessity to document vital signs remains in dispute in spite of a clear statement in the FW. This finding is associated with the context patients are treated within. Next step will be an expert panel to finalize the template and to publish a recommended documentation tool for PS in Germany. The developed template is a first comprehensive approach to document PS according to the FW. This documentation tool may foster a more standardized clinical practice of PS.
Medical Assistance in Dying: Initial Experience of the Edmonton Zone Palliative Care Program

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Introduction: As of February 6, 2016 medical assistance in dying (MAiD) was legally possible in Canada (through a complex court process), and on June 6, 2016 it became more readily accessible. The Edmonton Zone Palliative Care Program (EZPCP) identified the early days of this new legislation as a unique opportunity to identify patient demographics and clinical correlates with requests for MAiD. While this has been available in other jurisdictions for decades, this is the first time that the Canadian medical system has encountered such requests with any legal ability for patient follow through.

Methods: We collected data on patients who were referred to the EZPCP for palliative medicine consultation who made a request to their attending physician for MAiD, and who expressed desire for MAiD during the consultation with the EZPCP. We collected the following data: demographic information, symptom severity scores, cognitive status, information regarding the specific “intolerable suffering” triggering the MAiD request, and the outcome if known.

Results: At 6-months the sample size remained very small (N=14). There was a trend towards patients being male, with higher education (college-level), and mean age of 62 years. Symptoms rated with the highest severity were tiredness, drowsiness, lack of appetite, and sense of wellbeing. Pain, nausea, dyspnea, and lack of mobility were common physical triggers for requests for MAiD; increased dependence on others, existential distress, and poor quality of life were notable psychological triggers.

Conclusion: Consistent with previous research, drivers for requests for MAiD include high burden of physical symptoms as well as concerns over caregiving needs. However, the number of MAiD interactions represents a very small fraction of the over 3000 consults done by the EZPCP annually. This emphasizes the need to maintain the EZPCP’s focus on the needs of the majority of palliative care patients and families.
Disturbing and Distressing – The Tasks and Dilemmas Associated with End of Life

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Background: In 2016 a Medical Council Ireland report identified educational gaps in communication skills, legal and ethical aspects and dilemmas around end-of-life care, in new entrant doctors to the healthcare system. Learning the specific knowledge, skills and attitudes to deal with end-of-life issues is challenging and currently achieved by observation in an apprenticeship model.

Aims: To determine the frequency with which Senior House Officers (SHOs) deal with tasks and dilemmas associated with end-of-life care and evaluate the impact of patient death on their psychological wellbeing.

Methods: A questionnaire was distributed to SHOs to record the number of times they had been involved in end-of-life tasks, e.g. pronouncing death. A modified Post Traumatic Stress Disorder (PTSD) checklist was used to evaluate psychological distress following a patient death.

Results: 53 SHOs responded, with a mean of 28 months in clinical practice (range=60).

Almost all (96.2%) had pronounced a death. The majority (88.7%) had discussed a patient at the end of life with their family members, with 30.2% doing so >10 times. Most, (79.2%) had discussed resuscitation status and 45.3% had discussed withdrawal of care.

Nearly all (90.6%) had experienced patient death with 15.1% doing so >10 times. Over half of the respondents (52.8%) had been disturbed by the death of a patient and had repeated disturbing memories of the incident while 56.6% had experienced moderate to extreme distress.

Two thirds (64.2%) did not know of any resources available when experiencing low mood and/or distress. A further 50% showed gaps in their knowledge and over 88% reported that they would like more training.

Conclusions: This small study demonstrates that SHOs performing end-of-life tasks regularly, would like more training and report a significant impact on their psychological wellbeing. Both new entrant doctors and experienced SHOs require education and training in this area.
Procedural Pain in Palliative Care: Is it a Breakthrough Pain? Results from an Italian Multicenter Prospective Study

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Many patients with advanced disease undergo daily minimally invasive care-related procedures that can cause pain. A controversial point is whether procedural pain should be included in the definition of breakthrough pain (BTP). There is a particular lack of literature on procedure-induced pain in palliative care, as well as how often patients undergo treatment and daily care nursing procedures.

The main aim was to assess the prevalence of BTP provoked by 6 common procedures in palliative care patients. The secondary aims were to assess frequency and characteristics of pharmacological treatment for procedure-induced pain.

This was a prospective, cross-sectional, multicenter, national study. The subjects included in the study underwent one of the six selected procedures: turning, personal hygiene care, transfer from the bed to an armchair or wheelchair, bladder catheterization, pressure ulcer care, and subcutaneous drug administration. The Numerical Rating Scale was used to measure pain intensity before, during, and after the procedure.

One thousand seventy-nine eligible patients were enrolled; 49.7% were male and their mean age was 78.0 ± 11.2 years. The overall prevalence of procedure-induced BTP was 11.8%, and the mean intensity score (Numeric Rating Scale) was 4.72 ± 1.81. Notably, patients experienced a significant increase in pain intensity during all procedures (P < 0.0001). A small proportion of patients (12.7%) received analgesics before undergoing any of the procedures, and almost none (1.7%) received analgesics during the procedures to alleviate acute pain.

Our findings highlight that simple daily care procedures can lead to BTP among patients with advanced disease. Because such procedures are performed so often during palliative care, more individualized attention to procedural pain control is necessary. Further research should be encouraged to provide evidence-based guidance on the use of the available medication for predictable pain flares.
Aim: To assess the characteristics of BTP and factors influencing its presentation. To assess BTP medication and their efficacy in a large sample of patients diagnosed with BTP according to an algorithm.

Methods: Characteristics of patients, stage of disease and BTP, BTP medications, time to meaningful pain relief, satisfaction, adverse effects, presence of oral lesions.

Results: 4016 patients, mean age 64.6, 54.2% females, with a mean intensity of background pain of 2.98; 88.4 mg/day of oral morphine equivalents. The mean number of 2.4 BTP episodes/day. Higher with higher Karnofsky, head & neck cancer. BTP onset ≤10 minutes and >10 minutes in 68.9% and 31.1% patients, respectively. The mean duration of untreated BTP episodes 43.3 minutes. Longer with lower Karnofsky, pancreatic cancer, lower background pain intensity, nociceptive pain; shorter with targeted therapy, fast onset BTP, higher BTP intensity BTP was unpredictable and unpredictable in 69.5% and 30.5%, respectively. Associated with older age, type of cancer, anticancer therapy, lower background pain severity, lower BTP intensity, and oral mucositis, nociceptive pain. Mean intensity of BTP was 7.5. High levels were associated with younger age, lower Karnofsky, pancreatic cancer, neuropathic-mixed pain mechanism, oral mucositis, fast-onset BTP, longer duration of BTP, higher background pain intensity. 86.8% patients were receiving opioid drugs for BTP. The choice of BTP medication was influenced by age, Karnofsky, and setting. Adverse reactions attributed to BTP medications were reported in 2.5% of patients.

The mean time for achieving meaningful pain relief after BTP medication was 16.5 minutes. Shorter in aged, with opioids, fast onset BTP, background pain intensity, and cancers. 14.2% had oral mucositis.

Conclusion: The study provided huge amount of information regarding the characteristics of BTP and related factors. This data may better inform to target BTP treatment.
Decreasing Variability in Opioid Prescribing by Palliative Medicine Physicians

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Background: Variability in medical practice is common. Reducing variation is an approach to improve quality while reducing cost.

Aims: Reduce the variability in prescribing ‘as needed’ opioids by physicians serving a 12 hospital integrated hospital system.

Methods (design, data collection, analysis): Using the electronic medical record, all orders for ‘as needed’ opioids prescribed by palliative medicine physicians in calendar year 2015 and administered orally, subcutaneously, or intravenously were collected as part of this quality improvement approach. The results were shown to the physicians in January, 2016. There was high variability. Each physician was shown the performance of the group, as well as the physician’s individual performance as compared with the group. ‘Standard textbook’ prescribing was identified as an interval corresponding with the time to the maximum serum concentration of opioid: 1 hour for oral, 30 minutes for subcutaneous, and 15 minutes for intravenous routes. Data collection was repeated for the months of February, April and June and the data shown to the physicians in the same manner. Uniformity of practice was defined as 80% of medical orders consistent with the standard.

Results: For all 3 routes of administration, prescribing moved to ‘the standard’ more than 80% of the time during the April time period, and sustained during the June time period for the oral, subcutaneous, and intravenous routes of opioid administration.

Conclusion / Discussion: A simple Quality Improvement approach of making prescribing practices visible to individual physicians as compared with peer physicians and the standard made for rapid change to a uniform practice. These data have implications for ensuring a single standard of palliative medicine practice across an integrated health system.
**The Efficacy of Naldemedine with Patient Reported Outcome Assessments in Cancer Patients with Opioid-induced Constipation**


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**Background:** Opioid-induced constipation (OIC) is one of the most common side effects in cancer patients receiving opioid analgesics. Naldemedine (NAL), a peripherally-acting μ-opioid receptor antagonist, is being developed for the treatment of patients with OIC. The primary efficacy and safety data in phase 3 studies of NAL in cancer patients with OIC in Japan were reported previously. The objective of this report is to evaluate the efficacy of NAL using the validated patient reported outcome (PRO) questionnaires.

**Methods:** A 2-week, randomized, double-blind, placebo-controlled study (DBT; oral NAL 0.2 mg QD vs placebo (PBO)) and subsequent 12-week, open-label extension study (EXT) for cancer patients with OIC were conducted. The validated Patient Assessment of Constipation Symptoms (PAC-SYM) and Patient Assessment of Quality of Life (PAC-QOL) were used to assess the impact of NAL on these PROs.

**Results:** A total of 193 patients were randomized in DBT and 131 patients were enrolled in EXT. Change in the stool symptoms domain of PAC-SYM from baseline (NAL: -0.45 vs PBO: -0.23) as well as the dissatisfaction domain of PAC-QOL (NAL: -0.50 vs PBO: -0.16) showed significant improvement with NAL in DBT (P=0.0451 and P=0.0151, respectively), but the differences of overall scores and other domains were not statistically significant. The responder rates (%) of patients with ≥1 decrease in the score from baseline) for overall PAC-SYM and the dissatisfaction domain of PAC-QOL in NAL were significantly higher with NAL compared with PBO at Week 2 in DBT. The improvement of PAC-SYM and PAC-QOL scores was retained during EXT.

**Conclusion:** The stool symptoms domain of PAC-SYM (incomplete bowel movement, hard stool, straining etc.) is a clinically meaningful proxy of the main complaints in OIC patients. NAL can bring symptom improvement and satisfaction in the quality of life in cancer patients with OIC.
Health-related Quality of Life in Patients with Inoperable Malignant Bowel Obstruction: Secondary Endpoint from the Double-blind, Placebo-controlled Randomised Trial of Octreotide

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Background: The effect of adding octreotide or placebo to standardised therapies on health-related quality of life (HrQOL) for patients with inoperable malignant bowel obstruction (IMBO) is yet to be determined.

Aims: To evaluate whether there are clinically meaningful differences in mean change in global health-related quality of life (HrQOL, primary) and nausea and pain scores (secondary) when octreotide is compared with placebo.

Methods: Adults with IMBO and vomiting were randomised to subcutaneous octreotide infusion (600 mg/24 hours) or normal saline (placebo). The primary outcome was number of days free of vomiting at 72 hours. Secondary outcomes included HrQOL measured using the EORTC-QLQ-C15-PAL questionnaire administered at baseline and treatment cessation. Changes within and between groups were estimated using a linear mixed model, adjusted for baseline score, sex, age, time, study arm and study arm x time interaction. Mean changes of ≥10 (HrQOL) and ≥13 (pain; nausea) points out of 100 were considered clinically meaningful.

Results: Overall, 112 participants were randomised to treatment with days free of vomiting similar (octreotide 1.87, placebo 1.69; p=0.47). Mean baseline HrQOL scores were low (octreotide 24.19 (15.43, 32.96); placebo 31.06 (19.82, 42.30). No statistically significant or clinically important changes in HrQOL, pain or nausea scores between groups were observed. Mean unadjusted changes from baseline were small and favoured octreotide: HrQOL octreotide 5.38 (-4.78, 15.53), placebo 0.76 (-11.41, 12.93); nausea, octreotide -31.18 (-47.25, -15.11) and placebo -18.93 (-34.45, -3.42); pain octreotide -18.28 (-30.44, -6.12), placebo -13.64 (-26.05, -1.22).

Conclusion: The findings suggest the HrQOL of patients with IMBO and vomiting is poor. Octreotide did not result in clinically meaningful differences in mean changes in HrQOL, pain or nausea compared with placebo in patients with IMBO in this setting.
Which Symptoms Predict Unwellbeing of Cancer Patients in Hospice Care? A Multi-method Cross-sectional and Longitudinal Analysis

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Hospice patients suffer from 6 to 7 symptoms concurrently. Symptom management is key in hospice care to optimize quality of life.

Aim: The identification of symptoms predicting unwell-being of cancer patients admitted to hospice, to support clinical and shared decision-making to optimize quality of life.

Design: A multi method cross sectional and longitudinal study of patients reported outcomes. Cancer patients admitted to a seven bed hospice facility from June 2007 to June 2015 were enrolled. Symptom intensity of 11 symptoms and wellbeing was measured using the Utrecht Symptom Diary, a Dutch adapted translation of the Edmonton Symptom Assessment System.

Cross sectional: the 1st USD’s within the first week of admission were included. A multivariate regression analysis using a step wise approach was performed.

Longitudinal: all USD measurements were included, a Generalized Estimated Equation (GEE) analysis was performed using a backwards procedure.

Both models were corrected for gender, age, marital status, cancer diagnosis, and survival.

Results: In total 230/371 patients were enrolled in this study. In total 213 USDs were included for the cross sectional analysis and 1236 USDs were included for the longitudinal analysis.

Fatigue (B .364; CI .196–.531), depressed mood (B .273; CI .135–.411) and anorexia (B .217; CI .090–.345) predicted 48.7% of the variance of unwellbeing at admission. In addition, fatigue (B .373; CI .297–.449), depressed mood (B .189; CI .108–.269), pain (B .171; CI .108–.234), lack of appetite (B .130; CI .08–.180), anxiety (B .097; CI -.188–.005) and dyspnea (B .085; CI .003–.167) predicted unwellbeing over time.

Conclusions: A model of fatigue, lack of appetite and depressed mood, predicts almost half of the variance of unwellbeing. Longitudinally, pain, anxiety and dyspnea are added to the model. Fatigue is largest predictor, a change of 1 point on fatigue, indicated a change of .373 on unwellbeing.
Co-constructing Innovative and Culturally Appropriate Resources with Family Caregivers

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**Background:** Strategies to improve support for family carers are typically professionally designed with limited input from carers themselves.

**Aims:** To conduct a participatory action-research project in collaboration with family caregivers to develop practical resources to address the challenges caregivers face when providing end-of-life care.

**Methods:** The project has been conducted in 2 phases in New Zealand. In Phase 1, 3 focus groups were held with Māori, Pacific and NZ European family carers to identify key issues where carers would benefit from additional support. In phase 2, volunteers from the focus groups formed 3 work groups to evaluate current resources available to carers and work with the project team to develop new resources.

**Findings:** The Māori group focused on Māori underutilisation of hospice; participants wanted to share their experience to inform other carers about how some hospices can support Māori cultural values and practices. The Pacific work group developed a resource relevant to cultural concerns such as Pacific people’s reticence to ask for caregiving help from family and friends and the value of traditional music and dance for enhancing wellbeing. The NZ European group highlighted the invisibility and isolation of caregivers, the need for practical support and greater knowledge about help available from statutory services. Both the Pacific and Māori group chose video as the medium for their resources, while the NZ European group chose to develop a book for caregivers. The presentation will include a viewing of extracts from the Pacific and Māori video resources and an overview of the caregiver book.

**Conclusion:** This presentation showcases highly innovative, and culturally appropriate, new resources co-constructed with family carers. This approach is congruent with a public health approach to palliative care which positions family carers as experts.
What Are the Barriers and Facilitators to Introducing the Practice of Family Caregivers Administering Subcutaneous Medications for Symptom Control to Palliative Care Patients Dying at Home? A Mixed Methods Study

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Background: The administration of subcutaneous medications for symptom control by family caregivers of patients dying at home may allow improved symptom control, increased satisfaction for caregivers and more home deaths.

Aims: To explore the feasibility of family caregivers administering subcutaneous medications for symptom control to palliative care patients dying at home.

Methods: Mixed methods study comprising a survey of healthcare professionals and qualitative interviews with bereaved caregivers of palliative care patients who died at home.

Results: There were 60 completed surveys and 14 interviews with caregivers. In Part I, a number of potential barriers were highlighted, including concerns regarding caregivers’ ability to manage symptom control medications and the safety of the practice. However, potential benefits, such as timely symptom relief, were also suggested and overall respondents were positive regarding the feasibility of the practice: 46/60 said yes, 1/60 said no and 13/60 said not sure. Of note, no district nurses responded to the survey and their views are unknown. Most bereaved caregivers reported being supportive of administering medications and were willing to take on this role themselves. They also reported potential benefits of improved symptom control and highlighted how this task could empower their role. However, they emphasised the importance of adequate training and professional support.

Discussion: This is the first UK-based study to explore the feasibility of introducing administration of subcutaneous medications by family caregivers of relatives dying at home. We identify correspondence between the two data sets highlighting the potential for this adjunct to professional care. However, the study identifies challenges, particularly training and professional support for family caregivers. Further research into how professionals can enable caregivers to adopt this practice is now required.
Family Caregivers within Integrated Palliative Care: A Multinational, Mixed Methods Study in Five European Countries

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Background: Family caregivers (FCs) are an important pillar in palliative home care. The effects of caregiving on FCs’ quality of life are well known and discussed, but it is still unknown how interventions from health care professionals from integrated palliative care initiatives (ICPI) alleviate FCs’ burden.

Aim: The aim of this research is to analyse factors which reduce FCs burdens by focussing on institutional support settings of ICPI.

Methods: FCs were recruited at 22 ICPI in Belgium, Germany, Hungary, the Netherlands and the United Kingdom in the course of the project. The results are based on 156 semi-structured qualitative interviews and 90 quantitative questionnaires (CRA, POS, CANHELP Lite). Qualitative interviews were analysed with transnationally agreed thematic codes (MAXQDA). Quantitative analysis was descriptive (SPSS).

Results: FCs had multiple roles in the palliative care network of the patient. They described the palliative home care situation as a fulltime homebound job. Quantitative data showed on average moderate burden, but the qualitative findings indicated that this was underrated. There is some evidence that ICPI with well-developed professional care networks and communication systems relieved FCs’ burden by direct and indirect interventions; e.g. having a case manager as main contact person. However, in all countries the offers for FCs were singular events, lacking systematic or institutionalised support structures. Most of the provided services were patient-centred and not FC-centred.

Conclusion: Needs of FCs were similar in all participating countries. Most ICPI did not pay enough attention to FCs, and did not offer pro-active care for FCs (e.g. trainings, respite care, access to resources). The study recommends to recognise FCs as partners in caregiving, to improve their access to support and their knowledge about available support options.

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Effectiveness of a Therapeutic Conversation Intervention for Family Members who Are Experiencing Cancer at the End Stage of the Illness

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Background: Family caregivers (FCGs) caring for a family member with advanced cancer are at risk for psychological distress and other long-term health problems. However, less evidence is available regarding effective interventions to improve caregivers’ outcomes and few family nursing interventions have been conducted and tested in advanced cancer population.

Aim: To evaluate the effectiveness of a family therapeutic conversation intervention (FAM-TCI) to improve caregivers’ outcomes for home-based FCGs of a family member with advanced cancer.

Methods: The theoretical frameworks that guide the study are the Calgary Models and the Illness Beliefs Model from the Family Systems Nursing. Caregiver outcomes; a quasi-experimental; one-group pretest-posttest design. A sample of 48 home-based FCGs answered questionnaires at three time points. Data were collected over 2 years in 2014–2016. Three study hypotheses regarding positive outcomes of perceived emotional and cognitive support, psychological distress and caregiving burden were tested using repeated measures ANOVA.

Results: In total 48 FCGs were included in the final analysis of caregivers’ outcomes. FCGs receiving the intervention reported significant improvements in perceived support (P< .001) and stress symptoms (P< .05). However, the results of appraisal of caregiving were not statistically significant. Large effect sizes favouring the intervention were found for perceived support. 

Conclusion: The results support that the FAM-TCI is an effective intervention for families caring for a family member with advanced cancer and two out of three study hypotheses were confirmed.
Embedding Evidence Based Assessment and Support for Family Carers into Practice: Strategies for Success

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Background: The Carer Support Needs Assessment Tool (CSNAT) intervention comprises an evidence based comprehensive support needs assessment tool incorporated into a five stage person centred process. Together they enable a systematic process of assessment and support that is carer led. This ‘CSNAT Approach’ represents a change from existing informal practitioner led practice.

Aim: To identify aspects of organisational preparedness needed to accommodate implementation of the CSNAT as a carer-led process of assessment and support.

Method:
Design: mixed methods case study of one large hospice organisation using a planned process to implement The CSNAT Approach. Data collection (ongoing): field notes at site visits, document review, interviews, focus groups and survey of practitioners using the CSNAT Approach. Participants to date in interviews/focus groups: 28 staff (1 clinical services director, 3 implementation project leads, 24 practitioners including departmental CSNAT champions).

Results: Three key strategies contributed to successful implementation of the CSNAT Approach in practice:
(1) a dedicated planning process: involving a core team to lead on implementation, senior management support/overview, and an intense pre-implementation planning period providing the ‘groundwork’ to support and sustain the process;
(2) project leads’ investment in CSNAT departmental champions: including use of stakeholder analysis to identify key staff with relevant skills, and involving them in the planning process;
(3) development of an ‘issues log’ as a crucial means to ensure implementation concerns of CSNAT users were heard and acted upon effectively.

Conclusion: Adoption of these key strategies has enhanced engagement of practitioners with the implementation process: they will be reviewed for potential to sustain embedding of The CSNAT Approach in practice in the longer term. These findings are currently being used in development of a CSNAT implementation toolkit.
He Took Exception to the Word Zombie: A Qualitative Study on Conflict in Specialist Palliative Care

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Background: Despite how much of a significant and recurring problem conflict is in health care, little research has explored conflict between staff and families in palliative care. This study examined staff and relatives’ perspectives the causes, consequences and outcomes of conflict and serious disagreement in adult palliative care.

Methods: Qualitative interview study involving 25 staff and seven bereaved relatives. Participants were interviewed individually and were recruited from a single site in Australia. Data were analysed thematically.

Results: Communication breakdown caused conflict, including insensitive use of terms such as ‘zombie’, relating to drug side-effects. Dissimilar understandings regarding disease process, syringe drivers and providing nutrition/hydration also caused conflict. Warning signs of conflict were identified, such as a history of disagreements with clinicians and relatives taking extensive details (notes and photographs) to document care provided. Unique to palliative care, families explained and justified conflict scenarios identifying systemic rather than personal causes. Conflict was rarely directly resolved, but ceased to be a concern when the patient died.

Conclusion: The characteristics of conflict in palliative care have overlap but also important differences to other healthcare specialities. Understanding the warning signs of conflict can help staff de-escalate conflict, thereby improving team morale and family/patient experience. Proactive resolution has the potential to reduce risk of complicated grief responses from families who feel that they were exposed to suboptimal care.
Experience of Sources of Meaning in Life in Family Caregivers of Terminally Ill Cancer Patients

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Introduction: Meaning of life is crucial to human well-being, but evidence on sources of meaning in family caregivers (FC) of terminally ill patients is rare. This pilot study evaluates meaningful sources in FC of cancer patients receiving specialized inpatient palliative care, including the relationship with the FC’s well-being and needs.

Methods: Fifty-one consecutive FC’s rated the degree of meaningfulness they experienced from certain domains (Sources of Meaning in Life Profile-Revised, SOMP-R). The SOMP-R consists of 17 items (total score: 17–119) and four meaning orientations: individualism, collectivism, pre-occupation (scales: 4–28) and self-transcendence (scale: 5–35). Well-being and caregiver-specific needs were assessed by validated self-rating measures: Distress Thermometer (DT), GAD-7 (anxiety), PHQ-9 (depression), SF-8 (quality of life) and FIN (needs).

Results: FC’s (56% male, age 56±15.5) experienced a mean number of 6.8 (±15.5) out of 17 areas to be highly meaningful in present life. The overall score was 66.7 (±18.5) reflecting a moderate density of meaningful sources. FC ascribed higher relative importance to sources comprising personal relationships and ultimate meaning (self-transcendence: 23.0±5.5) or satisfying immediate needs (pre-occupation: 16.8±5.8). Less meaning was derived from sources referring to the betterment of groups/societal causes (collectivism: 14.2±6.2) and self-development/-realisation (individualism: 12.8±5.5). Higher total score, collectivism and pre-occupation correlated with larger numbers of needs, higher collectivism with lower distress and higher individualism with better physical quality of life (r=-.299–.424, all p < .05).

Discussion: Overall density and diversity of sources that provide FC with meaning and purpose were rather moderate. Meaningful sources may mediate FC’s well-being and needs during caregiving for terminally ill patients. Underlying mechanisms are currently evaluated in a larger longitudinal study.
Failure of the French Health System?
Impact of Financial Distress on Quality of Life in Patients with Advanced Cancer

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Purpose: We examined the frequency and severity of financial distress (FD) and its association with quality of life (QOL) and symptoms among patients with advanced cancer in France.

Design: In this cross-sectional study, 143 patients with advanced cancer were enrolled. QOL was assessed using the Functional Assessment of Cancer General (FACT-G) and symptoms assessed using Edmonton Assessment System (ESAS) and Hospital Anxiety and Depression Scale (HADS). FD was assessed using a self-rated numeric scale from 0 to 10.

Results: Seventy-three (51%) patients reported having FD. Patients reported having FD are younger (53.8 (16.7SD)) (p<0.001), single (p<0.001) and had a breast cancer (p=0.024). Patients with FD had a lower FACT-G score (59, p=0.005). FD decreased physical, emotional (p=0.008), social wellbeing (p=0.04). Patients with FD had higher HADS-D (8, p=0.007) and HADS-A (9, p=0.009) scores. FD is linked to increased ESAS score and spiritual suffering.

Conclusion: The high rate of patient-reported FD was unexpected in our studied population, as the specific cancer treatment is cover by the National Health Insurance. The FD is associated with a poorer quality of life. Having a systematic assessment, with a simple tool, should lead to future research on interventions that will increase patients’ QOL.
Surveying the Roles and Tasks of Palliative Care Social Workers in Europe

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Social work is an integral part of palliative care. Yet little is known about how social work is integrated within the different palliative care settings across Europe.

The aim of the study is to collect data about palliative care social work (PCSW) across Europe and thus gain insights into the working conditions and into the main tasks of PCSW.

Questionnaires were sent to all collective members of the EAPC (55 institutions from 31 countries) asking for some basis data on PCSW in their country and the name of a contact person for the distribution of another questionnaire addressed to palliative care social workers. The link to this second questionnaire was sent to the contact persons who passed it on to the social workers in their country. This questionnaire asks for sociodemographic data, working conditions, tasks and roles. Data were analyzed with SPSS 23.

We received 52 questionnaires (25 countries) from collective members back. The presence of social workers in different palliative care settings varies a lot from country to country. There are national guidelines in 7 countries and some have specialized training for PCSW. The working conditions were rated insufficient in 5 countries.

360 social workers (19 countries) completed the second questionnaire. The average age of the participants is 46 (22–70), 89% were female. They work across all palliative care settings. Their main tasks are emotional support for family members (82%), advocacy and information giving (80%) and counselling for family members (80%) and for patients (74%). In addition, they promote the social perspective in the team (88%) and deal with administrative activities (63%). Their main roles are counselor (46%), advocator (41%) and case manager (34%). They experience role overlap with nurses (80%), psychologists (79%) and chaplains (74%). 69% rate their working conditions as very good or good.

Data collection is still ongoing and more detailed results will be presented at the congress.
There’s No Place Like Home. Improving End-of-Life Home Care Provided by Domiciliary Teams Using the Gold Standards Framework (GSF) Domiciliary Care Programme

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Aim: Domiciliary care workers play an important but often unrecognised role in supporting people to remain at home as they near the end of life, especially those with dementia and frailty. Despite this, few receive specific training in end-of-life care. Focused training enables home care workers to improve the quality of care for such people working with primary care, and contribute to better co-ordinated cross boundary care.

Method: The GSF Domiciliary Care training programme in End of Life Care focuses on enabling generalist frontline staff in end-of-life competencies. The Train-the-Trainer cascade programme works with Agency trainers using action based, interactive learning and reflective practice in 6 modules, with virtual learning Zone/DVD, and resources. Comparative before and after qualitative and quantitative evaluation is intrinsic including. We present an evaluation of progress of several teams using GSF training to Domiciliary Home Care Teams in end-of-life care.

Results: Homecare workers in various areas of the country show improvements in:

- Confidence and competence of home care staff
- Communication, working relationships and collaboration with Primary care
- More Advance Care Planning discussions, with service users keen to be involved in these discussions.
- Encouragement and empowerment of staff to advocate for their service users leading to improved communications with other professionals
- Increased awareness of the knowledge they already possessed and future training needs.

Conclusion: This highlights the important role that Domiciliary Care workers play, and the importance of empowering care staff who interact with the service users on a daily basis. The GSF Domiciliary Care Training Programme boosts the confidence and competence of care workers, improves collaboration and coordination with others and helps to improve care for more people nearing the end of life at home, which is for most the best place to be.
Volunteer Befriending Services: What Are the Benefits for Patients, Family Carers, Volunteers and Paid Staff? A Multiple Qualitative Case Study

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Background: Volunteer befriending services are increasingly common in palliative care. Most studies focus on staff and volunteers rather than patients, and show that such services are valued. Few studies have explored patient perspectives on services and their outcomes, and what influences these outcomes.

Aim: To explore experiences of volunteer befriending services from multiple perspectives and identify and explore the factors that influence experience.

Methods:
Design: Multiple qualitative case studies conducted alongside a trial of a volunteer intervention.

Participants: Patients estimated to be in their last year of life, their family carers, volunteer befrienders and paid staff.

Setting: 8 end-of-life care providers in England, with variability in geographical location, organisational type and service characteristics.

Data collection: In-depth interviews, observation of staff meetings, documentary analysis.

Analysis: A framework approach to analysis, with in-case analysis preceding cross case pattern matching.

Results: Eighty four interviews with patients (n=23), carers (n=3), volunteers (n=24), staff (n=34) across 8 cases. All participants saw value in the services, but patients reported more subtle benefits than those perceived by volunteers or staff, such as companionship rather than reduction in negative feelings. Impacts were created both through an ‘instrumental’ focus on specific goals, and more altruistic ‘relational’ roles. Factors affecting impact included location (enabling patients to leave home), type of support (social vs practical), role restrictions (service boundaries), contact mechanisms (face to face), and regularity of contact.

Conclusion: Realistic expectations about service outcomes are required, together with shared and agreed understandings of the role and function of volunteers. Funder: UK Cabinet Office.
Describing the Size and Type of Care Tasks of the Volunteer Workforce in Palliative Care: A Nation-wide Survey

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Background: Governments expect the community to take up an increasing share of the palliative care provision, e.g. in the form of volunteerism. However, systematic insights into the total volunteer workforce in palliative care, their tasks and their involvement in the organization of care are lacking.

Aim: Describe the size and content of organized volunteerism involved in direct palliative patient care across the Flemish health care system.

Method: A postal survey was conducted among health care organizations providing care for patients with chronic, life-threatening conditions at the end of life in Flanders. The sample included every palliative care unit [PCU], palliative day care center, multidisciplinary home care support team, medical oncology department [MOD], sitting service, volunteer community home care organization [CHC], and a random sample of nursing homes [NH]. A questionnaire was sent to each organization’s volunteer coordinator.

Results: Response was obtained for 254 organizations. (Response rate: 79%) 201 (80%) had volunteers providing direct patient care, though numbers varied per organization type (7 to 1786 (mean)). PCUs had the highest average of these volunteers per patient (2.6), MODs and NHs the lowest (0.04 and 0.3). Psychosocial care (99%), fulfilling a signaling function (81%) and existential care (75%) were the most prevalent volunteer tasks. In some organizations volunteers even performed medical and nursing tasks (5%). CHCs reported the highest volunteer involvement, MODs the lowest.

Conclusion: Most organizations offering care to patients with chronic, life-threatening conditions in Flanders use volunteers in direct patient care. Still, their availability, tasks, and involvement differ greatly between organizations. This study is the first thorough mapping of palliative care volunteerism across a whole healthcare system and provides extensive information that can be useful for care organizations to benchmark themselves.
Effects of Implementation of PaTz-groups in which GPs and Community Nurses Cooperate in Primary Palliative Care

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Background: In PaTz-groups general practitioners (GPs) and community nurses have regular meetings to improve palliative home care, inspired on GSF. An important element of PaTz is the PaTz register of patients with palliative care needs.

Aims: To study effects of implementation of PaTz, including the PaTz register, on identification of palliative care patients, hospitalisations in the last month, place of death, start of palliative care and physician patient discussions.

Methods: In a pre-post evaluation GPs (n₁ = 195; n₂ = 166) of 38 PaTz groups filled in a questionnaire on palliative care provision in their practice and on recently deceased patients (n₁ = 460; n₂ = 305). Pre and posttest differences were analysed in multilevel analyses.

Results: Identification of patients with palliative care needs was done systematically by more GPS after implementation of PaTz compared to before (all patients 54% versus 18%). There were no differences before and after implementation regarding hospital as place of death (11%: and 10%) and the number of hospitalisations (none 64% and 61%). In posttest, patients included in the register were more often cancer patients compared to patients not included in the register (79% versus 53%); controlled for age, sex and cause of death they received palliative care earlier (more than 1 month before death: 80% versus 53%) and the GP more often discussed life expectancy (81% versus 61%), physical complaints (86% versus 69%), possibilities of palliative care (84% versus 61%) and existential issues (34% versus 23%) with them than patients not included in the register.

Conclusions: Implementation of PaTz improved systematic identification of palliative care patients within the GP practice. Especially when the PaTz register is used PaTz can improve timely palliative care. Further promotion of the proper use of the PaTz register is needed to further improve palliative primary care.
Developing a Computer Search in Primary Care to Systematically Trigger Early Palliative Care

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Background: The biggest barrier to providing early palliative care is being able to identify those who might benefit. General Practice databases provide a potentially valuable and up-to-date source of data that could be used to facilitate early identification. We had previously created a computerised search of GP databases to help systematically identify more people at risk of deterioration.

Aims: To further develop a primary care electronic record search to identify patients with early unmet palliative care needs and test it over an extended period.

Methods: We purposively recruited general practices based on urban/rural location and high/low percentages of patients already identified for palliative care. Quantitative data was collected over multiple runs of the search in each GP practice. The number of patients identified along with triggering codes was collected alongside demographic data. Qualitative data was collected through observing team meetings where the search results were discussed, and interviews with patients and GPs. Socio-technological theory was used to analyse the impact of the search and barriers to implementing it.

Results: The search identified 0.85% (n=433) patients out of a population of 51,874 in 8 practices. Being matched by the search results acted as a prompt to provide additional support in the majority of cases. Themes around resources, a contested understandings of palliative care and a deficit model of health care provision emerged. The process works best when it supports current practices rather than demanding changes.

Conclusion: An electronic search of primary care records can identify more patients for early palliative care. An “app-driven” approach where the search can be run on demand represents the method most likely to be adopted. Barriers to end-of-life conversations are significant but systematically identifying patients for early palliative or anticipatory care by computer searching can normalise this process.
Combining the Original and Alternative Surprise Question for the Early Identification of Palliative Patients: A Dutch Pilot Study

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**Background:** Palliative care is only provided to a small proportion of patients, mostly to those with cancer, not until the terminal phase, and mainly reactive. The Surprise Question (SQ1: Would I be surprised if this patient were to die within the next 12 months?), is an easy to apply tool to identify palliative patients. However, it's specificity is low. The aim of this pilot study was to explore if adding a second SQ (Would I be surprised if this patient is still alive after 12 months?) when SQ1 is answered negatively helps GPs to get triggered to thoroughly plan anticipatory palliative care.

**Methods:** 34 Dutch GPs were randomized in four arms and were send a questionnaire with four cases, representing respectively advanced organ failure (A), end stage cancer (B), frail elderly (C) and recently diagnosed cancer (D). GPs in the 1st arm did not receive additional information, the 2nd group received the SQ after each case, the third group the double SQ and the 4th a format to structure multidimensional, anticipatory care, in addition to the double SQ. We rated their answers based on essential components of palliative care, according to the WHO (RADIANT score).

**Results:** The third group gave higher RADIANT scores if they would be surprised if a patient would still live after 12 months (NO+YES). Group 4 had the highest RADIANT score on all cases. In all groups, case B had the highest RADIANT score, followed by cases A and C, and the lowest on case D. GPs most often explored somatic aspects and the least often social ones. Case D least often was multidimensionally explored.

47% of the GPs considered SQ1 a helpful tool and 71% SQ2.

**Conclusion:** Adding SQ2 seems promising in identifying palliative patients and providing multidimensional, proactive care.
Does Education in Palliative Medicine Make a Difference in End-of-Life Decision-making?

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Background: Decision-making in end-of-life (EOL) care is essential, but includes many challenging ethical, legal and medical aspects. The decisions may depend on doctors’ education.

Aim: To explore the differences in decision-making among doctors with and without specialty competency in palliative medicine (cPM).

Methods: A questionnaire with patient scenario of EOL care was send to Finnish physicians (500 GPs, 300 surgeons, 300 internists, 145 oncologists and 82 with cPM). The scenario presented a patient with advanced lung cancer in a comatose state. Decision to withdraw/withhold 10 life-prolonging therapies on a scale from 1 (definitely would not) to 5 (definitely would) were asked first without further information and then after family’s request for aggressive treatment and availability of advance directive.

Results: We achieved 699 responses. The mean result of the ten questions in the original scenario were 4.1 in physicians with cPM, 3.4 in GPs, 3.4 in surgeons, 3.5 in internists and 3.8 in oncologists (p < 0.05 for cPM vs. oncologists and p < 0.001 for cPM vs. others). On trajectory analysis, two groups with aggressive treatment-decisions were found. Younger age and being other doctor than oncologist or cPM were risk factors for belonging to these groups. Physicians with cPM were more willing to withdraw/withhold individual therapies. This difference was most striking with intravenous hydration, nasogastric tube and blood transfusions, while some therapies (e.g. antibiotics) showed quite similar results. Family’s request significantly decreased and advance directive increased palliative approach regardless PM education.

Conclusion: Education in PM decreases the willingness to use aggressive treatments in EOL care, although its’ impact differs between therapies. Education about decision-making should be mandatory for young doctors and in specialty training.

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FC15 | Primary Care

Location, Location, Location? Achieving Preferred Place of Care on Palliative Discharge from Hospital

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Background: Enabling patient choice around place of care at the end of life is increasingly recognised as an NHS priority by commissioners and policy makers. Understanding factors that influence rates of home deaths and achieving preferred place of care (PPOC) is vital to this process. It is recognised that there is disparity between those with malignant and non-malignant conditions in achieving PPOC. However little attention has been paid to the impact the oncology multidisciplinary ward environment may have on facilitating discharges to a patient’s PPOC.

Aims: To compare outcomes in those with malignant and non-malignant disease for patients at an acute hospital cared for on an oncology ward versus non-oncology wards, in terms of achieving PPOC on discharge and death at home.

Methods: Prospective case note review of patients identified to be in the final days, weeks or months of life who had expressed a preference to be cared for elsewhere.

Results: Data was collected for 218 patients. 110 were cared for on an oncology ward (mean age 70) and 108 (mean age 78) were cared for on non-oncology wards. Those cared for on an oncology ward compared with those cared for on non-oncology wards were significantly more likely to die at home (40% vs 18%, $X^2 = 13.316$ $p =0.0002$) and achieve their PPOC on discharge (77% vs 56%, $X^2 = 11.539$ $p =0.006$). There was not a significant association in achieving PPOC on discharge (69% vs 60%, $X^2 = 1.254$ $p > 0.05$ ) between those with malignant and non-malignant conditions. There was a significant difference in the rates of home death in the malignant and non-malignant groups (34% vs 14%, $X^2 = 7.09$ $p =0.0077$).

Conclusion: In this study, place of care during hospital admission appeared to be a more significant factor in achieving PPOC than whether a patient had malignant or non-malignant disease. We would suggest further investigation regarding the factors at a ward-based level that support favourable palliative discharge outcomes.
Evaluation of an Anticipatory Care Planning Tool for Care Home Residents and their Families

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Background: Creating robust anticipatory care plans for care home residents can be a time consuming process. When effective anticipatory/advance care planning for this population is inadequate, residents may be transferred to hospital and receive interventions that are burdensome and of little benefit.

Aims: To introduce an Anticipatory Care Questionnaire (ACQ) that is simple and quick to use and can be delivered by care home staff. This project evaluated the efficacy and acceptability of the ACQ in two contrasting care homes (one with nurses, one relying on external healthcare support).

Methods: A prospective audit of acute clinical events over an 8 month period was undertaken alongside qualitative interviews. Lothian Unscheduled Care Service (LUCS) GPs also discussed a range of scenarios that typically occur in a care home setting. Interviews were digitally recorded, transcribed and analysed thematically.

Results: A purposive sample of 27 relatives, care home staff and local GPs were interviewed. A convenience sample of 30 LUCS GPs considered four archetypical scenarios of frail care home residents whose health had deteriorated relatively acutely such that an out-of-hours call was made to NHS 24 by care home staff. 58 out of 69 acute clinical events were handled either in accordance with the ACQ or an appropriate decision was made by out of hours doctors. The system was most vulnerable when protocol driven decisions were made by out of hours service call handlers. Relatives and care home staff welcomed clear guidance about anticipatory care planning and how best to start talking about it before admission and once in a care home.

Conclusion: This questionnaire has formed the basis of robust anticipatory care plans in a care home population that improved management of acute events and were acceptable to those that used them. Following a patient/public consultation, the ACQ has now been revised and information leaflets developed for relatives and care home staff.
An Evaluation of the Impact of the Makerere Palliative Care Unit Research Network and Capacity Building as Part of a 5 Year Strategic Plan Review

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Background: The generation of palliative care (PC) evidence in low resource settings is essential & supported by the WHA resolution, but often limited by research capacity. One objective for a newly created academic PC unit was to encourage a research culture, support & initiate research nationally & internationally. Capacity building through development of research network, agendas, training, collaborations, supervision & mentorship instituted.

Aim: Evaluate the outcome of this research capacity building conducted in partnership with key stakeholders.

Method: Desk review of internal research capacity noting projects completed, abstracts presented, publications & research qualifications attained. Evaluation of 4 research trainings; advanced PC, modules for BSc in PC, short workshops. Surveyed all participants regarding research involvement, confidence in research process, dissemination & challenges.

Results: Academic PC unit; qualifications 5 BSc, 2 Masters, 1 Phd. 103 abstracts at national & international conferences & 11 papers published. Online survey with 56 (of 130) respondents; 27 nurses, 17 clinical officers, 5 doctors from 9 countries. 94% working in clinical PC with 32% government & 42% NGO. 63% attended no other research training. Significant improvement in confidence (p< 0.001) after training in all aspects of research process. Participants valued supervisors expertise (x=3.71), quality of relationships (x=3.63) & feedback (x=3.56) though reported challenges with ethical approval (x=3.46) access to the literature (x=3.21) & internet (x=3.41). Participants noted: ‘it was very rewarding, motivating & built my confidence as an upcoming researcher’. Further qualitative data will be available.

Conclusion: Results suggest the importance of research capacity building, & demonstrate changes in competence. Combining evidence based parties with clinical modelling is an important strategy within an integrated health systems approach for PC.
Unmet Existential Needs in Palliative Care Cancer Patients: The Potential of the QUAL-EC

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Background: We piloted the Quality of Life at the End of Life (QUAL-E) in Australian palliative care in-patients (N=52) and demonstrated feasibility, acceptability and face validity. An unexpected finding was the potential for the QUAL-E to prompt psycho-social-spiritual discussion when conducted as an interview, indicating opportunities for enhanced support.

Aims: We compared a 17-item QUAL-E-Cancer (QUAL-EC) to the Distress Thermometer Screening Tool (DT) and participants’ experience when the QUAL-EC was conducted as an interview.

Methods: A cross-sectional, mixed methods design was used. Convenience sampling recruited patients (N=50) with advanced cancer and a prognosis of less than 12 months from a tertiary hospital. Participants completed the DT, followed by the QUAL-EC which was digitally recorded as an interview.

Findings: Correlational and thematic analysis found that 39.6% of participants reported severe distress (score ≥7) while 40% reported moderate distress (score 4–6) on the DT. Levels of distress significantly correlated with two QUAL-EC domains: symptom control ($r=0.52, p<0.001$) and preparation for end of life ($r=0.32, p<0.05$). Qualitative analysis identified six themes: the health care team; family issues; approaching death; worry; coping and QUAL-EC experience. Feasibility: completion of the QUAL-EC ranged from 3–14 minutes ($M=7.37$ minutes, $SD=3.05$ minutes). Acceptability: Participants overwhelmingly found the questions to be clear and did not find the questions hard to understand, hard to answer or stressful. Ninety per cent of participants agreed or strongly agreed that they were glad they took part.

Conclusion: Patient distress was associated with either symptom burden or concerns about their family/loved ones. When distress is identified on screening, the QUAL-EC offers good potential for nuanced, versus vague, assessment of globalised distress (e.g., DT) as an aid in targeting patient-centered clinical/psycho-social interventions.
**One of the First Nation-wide Prevalence Studies in Palliative Care Needs: Palliative Care Indicator Tool**

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**Background:** An increasingly ageing population requires an approach that integrates palliative care in the health care system. However, identification of palliative patients and their care needs remains to be a challenge. Recently, the Palliative Care Indicator Tool (PICT) has been developed in Belgium to identify palliative patients and to assess the severity of their care needs.

**Aims:** To measure the prevalence of patients who need palliative care and the severity of these needs in Belgium, using the PICT.

**Methods:** To study the prevalence of palliative care patients in Belgium, adult patients were selected from hospitals (n=11), nursing homes (n=35), general practice (n=45), palliative home care teams (n=5) and palliative care units (n=27) and screened with the PICT.

**Results:** In total, 12,682 patients were screened with the PICT. One in 5 patients (19%) in hospitals, 14% of inhabitants of nursing homes and 4% of patients in primary care were identified as palliative patient, based on the surprise question. On average, 3.85 indicators were recorded per palliative patient. Forty percent (40%) of patients identified as palliative patients were given the ‘full statute’, 57% the ‘advanced statute’ and 2% a ‘low statute’.

**Conclusion:** This study is the first to show the prevalence of palliative patients across different health care settings in the whole of Belgium using one designated screening tool. The PICT can serve as a tool to identify health care needs in an earlier stage (regardless of the setting or condition), making referrals to the appropriate service possible. As such, patients can receive the right care at the right place in the right time.
Palliative Care Consultation in Dutch Hospitals: Reasons for Referral and Costs of Consultation

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Background/ aim: Recent research, mostly among patients with advanced cancer, shows that involvement of a Palliative Care Team (PCT) in patients’ care can lead to a better quality of life and satisfaction. In 2015, 77% of Dutch hospitals had a PCT. We assessed the most common problems for consulting a PCT and the costs of PCT consultation.

Methods: In 2014 and 2015 PCTs in 2 academic, 5 teaching and 3 general hospitals registered the reasons for which they were consulted and the time spent to provide their advice.

Results: Data were collected on 540 consultations. The majority (64%) concerned patients with an estimated life expectancy of less than 3 months. The main reasons for consulting a PCT were pain, the organization of care, fatigue and dyspnoea. All consultations involved a nurse or nurse practitioner who spent on average 183 minutes on a consultation. Physicians were involved in 94% of all consultations with a mean time of 84 minutes per consultation. Spiritual caregivers, psychologists and paramedics were involved in 53%, 22% and 14% of all consultations respectively, each with a mean time of 17 minutes per consultation. Pharmacists were involved in 8% of all consultations with a mean time of 22 minutes. There were substantial differences in average total time and average personal costs per consultation: in general hospitals a consultation took on average 2.7 hours and costed 172 euro, whereas these figures were 4.8 hours and 299 euro in teaching hospitals and 7.4 hours and 455 euro in academic hospitals.

Conclusion: PCT are most often consulted for patients with a life expectancy of less than 3 months. Consultation is mainly performed by nurses, nurse practitioners and physicians. Involvement of psychologists, spiritual caregivers, paramedics and pharmacists is limited. There are large differences between the average time spent per consultation, and thereby costs, between general, teaching and academic hospitals.

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What Casemix Criteria Best Predict Costs of Palliative Care Provision in the UK? A Casemix Development Study across Palliative Care Settings

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Background: Provision of palliative care is inequitable with wide variations across conditions and settings in the UK, but there is no standard way to classify complexity and no existing palliative care classification easily transferable to the UK to address unmet need and resolve the inequity.

Aims: To determine the best predictors of costs in palliative care in the UK, and to inform different levels of complexity and a casemix classification for palliative care.

Methods: A longitudinal survey was conducted in 9 palliative care services across settings. We collected data on patient demographics, potential complexity/casemix criteria, and patient-level resource use. Cost predictors were derived using multivariate regression, and casemix classification was based on Classification and Regression Trees (CART).

Results: 2,846 palliative care phases across community (n=1,492, 79% cancer), hospital (n=850, 75% cancer) and hospice (n=504, 88% cancer) settings were included in this preliminary analysis. In hospital and hospice settings, problem severity and phase of illness were the best predictors of phase costs, accounting for 14% of the variance. In community, functional status and phase of illness were the best predictors, accounting for 12% of the variance. CART analyses using trimmed data suggested 10 classes for hospital palliative care explaining 14% of the variance in phase costs, and 16 classes for community palliative care explaining 18% variation. Inpatient hospice care had 5 classes but explained 20% of the variance. Full analysis will be presented.

Conclusion: This is the first study in the UK to identify cost predictors, and inform complexity/casemix classes for palliative care. Similar to the Australian casemix classification, it demonstrates that phase of illness, functional status and problem severity are the main determinants of complexity, and underpin a potential casemix classification for palliative care.

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Informal Care, Satisfaction with Formal Care Service and Grief of Carers in England

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Background: The informal care provided by family/friends to patients at the end of life may influence carer satisfaction and grief.

Aim: To investigate the association between informal care and carer’s satisfaction with place of care and grief.

Design: Merged analysis of four mortality follow back surveys with bereaved carers (2009–2015, England) using validated measures on informal care in the last three months of life and carer satisfaction and grief

Method: Informal care costs calculated using time spent caring (Client Service Receipt Inventory); carer satisfaction at place of care (e.g. hospital, home) (1–6 low to high adapted from Life Before Death study); and grief at 3–6 month post bereavement (Texas Revised Inventory of Grief subscales). We used multiple regression analysis to examine the association between informal care costs and satisfaction and grief, adjusted for confounders.

Results: 1347 carers (67% women, mean age 61, 31% spouse or partner, 51% son or daughter) of patients (53% women, mean age 80, 64% cancer cause of death). During the three months before the patient died, carers spent a mean? of 128 hours/week (SD 121) caring for the patient (mean shadow price of £1,095/week, SD £1,082). Care satisfaction was highest for hospice (mean 5.6, n=286) and lowest for hospital (4.27, n=4.27). Informal care costs were associated with reduced satisfaction with hospital care and increased grief intensity.

Conclusions: Carers who provided more informal care seem less satisfied with care at hospital and may experience more intense grief. Whether it is causal needs to be tested.
Oral Health in the Dying Patient – An Analysis of Data Reported to the Swedish Register of Palliative Care

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**Background:** Oral health is often neglected in end-of-life care although important for the well-being of dying patients and their families.

**Aims:** To investigate two quality indicators of oral health during the last week in life and their association with gender, place of death and diagnosis.

**Methods:** Data were retrieved from the Swedish Register of Palliative Care in the Southern Region of Sweden, covering a population of 1.97 million inhabitants. 65.6% of the total number of 18131 deaths in 2015 were registered. The proportion of missing information in the register was 22.9% regarding assessment of oral health and 4.5% regarding presence of lesions. Distribution of assessments and lesions over age, gender, diagnosis and place of death were described and tested with chi-square test. Further, the association of 1) oral health assessment and 2) lesions, with relevant factors such as; presence of other person at death, nutrition, pain, anxiety, wheezing and nausea, will be assessed.

**Results:** Assessment of oral health was performed in 74% of all patients, assessment was statistically significantly associated with gender, but not with age (P< 0.01). Among the patients with assessment, lesions were statistically significantly more common among the younger patients and among males. Cancer patients were assessed to a larger extent, and also had more lesions, compared to the remaining patients (P< 0.01). Oral health assessment was also unevenly distributed over place of death, a significantly higher proportion of the patients in specialised palliative care were assessed, compared to the patients in hospitals (82% vs 67%). Of the patients in specialized palliative care with assessment >60% had lesions, compared to 26% of the patients in municipality care (P< 0.01).

**Conclusion:** Both assessment of oral health and presence of lesions differ statistically significantly depending on gender, diagnosis and place of death. Multivariate analysis will be presented at the Conference.
Dying as a Diagnosis: A Problematic Concept

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Aim: To explore the literature surrounding diagnosing dying.

Methods: Using a historical approach drawing on the work of Owsei Temkin and Charles Rosenberg this study aims to critique the clinical literature (largely narrative reviews) regarding the ‘diagnosis of dying’.

Results: The concept of the diagnosis of dying entered the palliative medicine literature in the early 1980s. This was seized upon by teachers and researchers as a means of engaging the wider medical and nursing community in the idea that diagnosis would be a prompt for clinical action and decision-making. There exists in medical historiographical literature, a significant body of work on the ‘framing’ of disease which does not sit easily with the idea of the ‘diagnosis’ of dying.

Conclusions: The concept of ‘diagnosis’ is not a value-neutral idea, but is a historically and contingent concept with implications for the treatment, prognosis, social status and behaviour of the patient and their families. In the historical literature diagnosis has been examined in considerable detail. The category of ‘dying’ has not formally been accepted in any formal scheme (ICD, DSM, etc) as a diagnosis and indeed is merely the final common pathway of a variety of heterogeneous pathophysiological processes. The literature surrounding the idea of the diagnosis of dying is similarly vague. Likewise give that the concept is an appeal to traditional modes of clinician thinking, it fails to give acknowledgement of the need to establish a differential diagnosis which need explored and/or excluded.

Also problematic in the literature is the lack of specificity of the diagnosis of dying. Being contingent, the symptoms cited most frequently in the literature surrounding the ‘diagnosis of dying’ are not sufficiently specific to be clinically useful. Likewise in an age of protocols and guidelines, a diagnosis will lead to a cascade of clinical decisions and treatment which may be clinically disastrous and ethically suspect.
Cancer Patients’ Preferred versus Actual Place of Death: A Review

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Background: Death at home is increasingly used as a key performance indicator of palliative care services, based on the assumption that home is the preferred place of death (PPOD) for most. This view has been based mainly on studies eliciting PPOD of the general public or bereaved caregivers, rather than of patients. Actual place of death (APOD) for patients with advanced cancer may depend on a variety of factors at the level of the individual, the illness and the environment. To determine the relationship between APOD and PPOD, it is necessary to compare these in the same population.

Aims: To review the literature directly comparing PPOD to APOD for patients with advanced cancer.

Methods: A literature search was conducted for studies that captured both patient-reported PPOD and APOD, published in English. Paediatric studies or studies of non-cancer populations were excluded, as were studies that utilized surrogate-reported PPOD. Quality of studies was assessed using the STROBE checklist.

Results: Ten papers met all criteria; 6 were from the UK. Seven were prospective, longitudinal studies; 3 were retrospective chart reviews. Sample sizes ranged from 41 to >5000. Three studies used specific questions to elicit PPOD; only 4 reported eliciting PPOD on more than one occasion. The most common PPOD was home in all but one study; when assessed longitudinally, this preference decreased over time, and often differed from preferred place of care before death (when elicited separately to PPOD). Missing data ranged from 7–55%. Congruence rates between PPOD and APOD were highest for hospice (range 93–100%) and lowest for home (range 37.5–94%).

Conclusion: Although home appears to be the PPOD for most patients with advanced cancer, the evidence base is limited. The methodology used to elicit PPOD, variation in frequency of questioning, and inattention to missing data make the current literature difficult to interpret. Larger scale, longitudinal studies are needed.
Place of Death of Cancer Patients (2009–2013) from a Comprehensive Cancer Center in Germany – Preliminary Data from a Feasibility Follow-up Study

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Background: To avoid unnecessary hospitalisation at the end-of-life (EOL) is a common wish of patients (pts) and their next. Therefore, the place of death (POD) is discussed as a quality indicator for EOL care. Data on POD of pts treated in a comprehensive cancer centre (CCC) in Germany is missing.

Aim: To follow up trends in POD of cancer pts from a CCC in Erlangen, Germany, in the years 2009–2013.

Methods: Deceased cancer pts treated in a CCC and registered in a regional cancer registry who died in years 2009–2013 were assessed in regard to their POD. Anonymized data collection from an electronic death registration system took place in 2016. Approval was given from the local ethics committee and the public registry. Data was analyzed descriptively using SPSS.

Results: Out of 9394 deceased pts, a follow up was possible in 7094, a POD determinable in 6316 pts (67.2%). More than every second cancer patient from the CCC (58.5%; n=3692) died in a hospital, another 22.2% (n=1401) at home, 14.4% (n=907) in a nursing home, and with 5.0% (n=316) only a minority in an inpatient hospice. The percentage of cancer pts dying in hospital (56.0% to 58.8%) or in an inpatient hospice (4.5% to 6.2%) increased slightly over time. Patients who died in hospital were significantly younger (68.2 vs. 73.7 years, p< 0.001) and in a significantly higher proportion male (60.7% vs 39.3%, p< 0.001) compared to private home/ nursing home/ hospices. In particular the percentage of female pts who died in a hospice increased over the years (4.7% to 8.8%), even though male cancer pts (55.9%) are overbalanced in the group under review.

Conclusions: Over the years, the proportion for cancer pts treated in our CCC dying in hospital has increased. Apparently, home as POD is less common for cancer pts from a CCC compared to a general population. Inpatient hospice care is increasingly utilized since 2009, especially in EOL care of women with cancer. More detailed analysis of the data will follow.
The Incidence and Impact of Implantable Cardioverter Defibrillator (ICD) Shocks in the Last Phase of Life: A Systematic Review

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Background: Although the implantable cardioverter defibrillator (ICD) is very successful in terminating life threatening arrhythmias, it might give unwanted shocks in a patient’s dying phase, which possibly leads to unnecessary pain and distress. Information about how often shocks occur in the last phase of life, and on the impact of these shocks on patients, relatives and professional caregivers is limited.

Aims: Provide an overview of studies reporting on ICD shock incidence and impact of shocks in the last phase of life.

Methods: In this systematic review, we searched for empirical studies on deceased patients who had an active ICD in the last month of life, reporting on the incidence and/or impact of shocks. We searched in Embase, Medline, Cochrane Central, Web of Science and Google Scholar.

Results: We found twelve studies relevant for this review, comprising a total population of 1112 (range 1–558) patients; 9 reported on incidence of shocks and 4 on impact. Eight studies were conducted in the USA and four in Europe.

Three studies specifically studied non-sudden deaths, showing a shock incidence of 6% and 14–22% in the last 24 hours and the last hour of life, respectively. The other six incidence studies did not discriminate in cause of death, and showed a shock incidence range of 17–32% in the last month (3 studies), 3–32% in the last 24 hours (4 studies) and 8–31% in the last hour (2 studies) before death. The four studies on impact demonstrated that shocks in dying patients are painful and very distressing for patients (3 studies), relatives (3 studies) and professional caregivers (1 study).

Conclusion/discussion: A substantial number of patients experience shocks in the dying phase. Little studies were conducted on the impact of shocks, but the available evidence suggests that shocks have a negative impact on patients, relatives and professional caregivers. Patients with an ICD at the of life might benefit from timely deactivation of the ICD.

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**“Let’s Bring her Home First.”**

**Patient Characteristics and Place of Death in Specialized Pediatric Palliative Home Care**

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**Background:** Specialized pediatric palliative home care (SPPHC) is the main pediatric palliative care structure in Germany. Detailed data on patient characteristics and care are sparse. Describing this population in terms of diagnoses and care needs is essential for further development of palliative care services for these patients.

**Aims:** We asked whether our population
(i) was representative compared to national mortality statistics;
(ii) showed differences among ACT (Association for Children with Terminal Conditions) categories, and
(iii) was different to published populations in pediatric palliative care in terms of diagnoses, care and place of death.

**Methods:** Retrospective single center chart analysis of 212 consecutive patients on SPPHC. We analyzed duration, intensity and intermission of care, and place of death, with relation to the four ACT categories.

**Results:** Main ICD-10 groups were nervous system, congenital abnormalities, neoplasia and metabolic disease, reflecting the mortality statistics for patients 1–20 years. 75% of the patients showed nervous system involvement. 36% of patients were assigned to ACT-3, 34% to ACT-4, 26% to ACT-1, and 4% to ACT-2. ACT-1 patients mostly needed high-intensity care for short durations, ACT-4 patients showed long survival times with mostly intermittent care; 84% of the patients died at home, 12% in hospital and 4% in a hospice, with 96% dying at their preferred place.

**Conclusions:** Our data on SPPHC show
(i) significant differences between ACT groups in terms of care needs and survival;
(ii) a very high prevalence of children with neurological problems, and
(iii) a vast majority of children dying at home.
Development of a New Tool for the Assessment of the Psychosocial Needs of End-of-Life Patients

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**Background:** Providing palliative care (PC) to end-of-life patients (EoLP) requires knowing which psychosocial aspects contribute to their well-being. Thus, reliable, simple and specific assessment tools are necessary.

**Aims:** To develop an instrument (Psychosocial Needs Evaluation; PNE) to assess and monitor the psychosocial needs of EoLP receiving PC and present its preliminary psychometric properties.

**Methods:** Six steps were followed to develop the scale:
1) bibliographical review;
2) build-up of experts panel;
3) agreement on the most relevant dimensions in psychosocial care;
4) description of key indicators and consensus on the questions for each dimension;
5) revision by external PC professional experts (including physicians, nurses, psychologists and social workers);
6) revision by expert patients.

Expert professionals and patients performed construct validity (Facie validity). To analyse properties, 148 patients participated in the study and four validated tests (HADS; 1 item of ORTC QL-C15 PAL; Suffering question; and Distress Thermometer) were administrated together with the PNE.

**Results:** For construct validity, 30 PC expert professionals included comments on the questions and made proposals for improvement. The tool was considered excellent. Additionally, 20 expert patients revised the tool and considered the questions very clear or clearly understandable. They also valued being asked about these issues.

Analysis showed a satisfactory intern consistency (Cronbach Alpha. 74) and a good concordance degree (intraclass index correlation 3.750, \( p < .000 \)). Factorial analysis showed four main factors that explain 58.4\% of variance: emotional and wellbeing, social support, spiritual and information.

**Conclusions and discussion:** The PNE tool allows assessing EoLP patients’ needs systematically and holistically. We believe the scale improves the understanding of the psychosocial needs of EoLP, and provides a more comprehensive, specific, individualized and effective PC approach.
The Cohen-Mansfield Inventory (CMAI) – Validating the Measure for Use with Frail Older People with Dementia in an Acute Hospital Setting

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Background: Increasing numbers of people admitted to acute hospitals have cognitive impairment or dementia and behavioural problems such as agitation. Many are reaching the end of their lives. The Cohen-Mansfield Agitation Inventory (CMAI) is the most widely used tool to assess agitation in people with moderate and severe dementia who reside in long-term care. However, no studies have evaluated the psychometric qualities of the CMAI in acute hospitals.

Aims: To validate the CMAI for use in people with dementia admitted to acute hospitals.

Methods: Patients were recruited (n=230) from two acute admission wards in Greater London, United Kingdom from 2011 to 2012. Pain, agitation and behavioural problems were recorded using a range of measurement tools, including the CMAI. Cross-sectional psychometric evaluation was performed, including an exploratory factor analysis and internal consistency checks.

Results: The initial 29 item version was reduced to nine items. A two-factor structure of aggressive and nonaggressive behaviours proved to be the best-fitting measurement model in this sample. The shortened CMAI showed similar associations with pain as the original version, in particular the link between aggressive behaviours and pain. The factor structure of the CMAI was broadly consistent with the original solution although a large number of items were removed and scales reflecting physical and verbal aggression were combined to form an Aggressive factor and physical and verbal nonaggressive behaviours were combined to form a Nonaggressive factor.

Conclusion: The short CMAI has been designed to assess agitation in people with moderate to severe dementia in an acute setting. This scale removed redundant items which are unlikely to occur in this environment where mobility is limited. The concise measure allows efficient assessment of agitation when admitted to a fast-paced environment like a hospital ward.

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The Relationship between Patients’ Views on the Impact of Palliative Care and Patient-reported Outcomes Using the Integrated Palliative Care Outcomes Scale (IPOS)

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Background: Although the IPOS measures patients’ main symptoms and concerns, it is not known how this relates to patients’ views on the impact of palliative care.

Aim: To analyse the relationship between patients’ Views on Care (VOC) and patient-reported outcomes using IPOS.

Methods: A multicentre longitudinal survey of palliative care patients in hospices, hospitals and community settings in the UK. Participants completed the IPOS alongside VOC questions, which are selected and refined from St. Christopher’s Index of Patient Priorities (SKIPP). Data was analysed using cross tabulations and chi-square tests of independence.

Results: 124 participants completed the survey (2.42% missing data). The first VOC question (VOC 1) assessed patients’ perceptions of change following palliative care intervention. 83.5% of participants reported that overall things were getting better. There was a statistically significant association between the participants’ scores on VOC 1 and changes in their total IPOS scores ($\chi^2=3.78; p=0.058$), with similar associations found for the IPOS physical ($\chi^2=6.64; p=0.010$) and psychosocial symptoms subscales ($\chi^2=2.73; p=0.98$). The second VOC question (VOC 2) assessed patients’ perception of the difference made by the palliative care team. 91.9% of participants reported that the palliative care team had made a positive impact. No significant association was found between VOC 2 and IPOS, with participants equally likely to report a positive impact if IPOS symptoms got better or worse ($\chi^2=1.86; p=0.172$). This finding was consistent for the IPOS physical ($\chi^2=0.515; p=0.473$) and psychosocial symptoms subscales ($\chi^2=2.24; p=0.134$).

Conclusion: VOC 1 works as expected to indicate patients’ perception of overall change. However, VOC 2 captures something different from patient-reported outcomes. Both patient-reported outcomes and views on the impact of palliative care need to be captured to improve the quality of care.

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Minimal Important Difference and Responsiveness of the Integrated Palliative Care Outcome Scale (IPOS) Using Multiple Anchor- and Distribution-based Estimates: A Longitudinal Study

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Background: Minimal important differences (MID) help clinicians interpret results from outcome measures. The MID is the smallest change in a score considered important by patients.

Aim: We aimed to determine the responsiveness of the Integrated Palliative Care Outcome Scale (IPOS), both for the patient-completed and the staff-rated version, and the clinical significance of changes in IPOS scores in both versions.

Methods: The IPOS is an outcome measure for palliative care patients. This national, multi-centre, longitudinal study included a representative sample of palliative care patients from two datasets (n=151 patients from the validation study and n=562 staff ratings from hospital palliative care unit and advisory teams). MIDs were calculated using distribution-based, Rasch and anchor-based approaches. Different anchors were used: patient and staff-reported global change, change in phase of illness and change in Karnofsky performance status. MIDs were estimated by the receiver-operating characteristics (ROC) curve method.

Results: Associations between anchors were moderate. Correlation between the anchors and IPOS change scores and Rasch responsiveness analysis demonstrated good responsiveness to change in both IPOS subscales, Physical symptoms and Psychological and information concerns. Combining results from all approaches, the MIDs ranged between 4–17 points for the total IPOS, 3–14 for the Physical and 3–10 for the Psychological/information concerns subscale. The MID for deterioration was smaller than the one for improvement.

Conclusions: We combined different methods to derive MIDs for the IPOS. These results will enable interpretation of treatment group effects in a clinical trial setting, and they can be used to help clinicians interpret the significance of changes in routine palliative care.

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Charting a Course to Develop and Validate a Patient Reported Compassionate Care Measure: Findings from a Narrative Synthesis Literature Review and an Overview of the COMPASS Study

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Background: Compassionate care is a reputed pillar of palliative care that is increasingly considered a practice competency and an indicator of quality of care. In order to evaluate and improve this core construct of quality care a valid and reliable patient reported experience measure is required.

Aims: To report on the findings of a narrative synthesis review of compassion measures within the healthcare literature and to provide an overview of an ongoing multi-centre study to develop and validate a patient reported compassionate care measure.

Methods: A narrative synthesis framework guided the review with identified measures being further evaluated using the Evaluating Measures of Patient-Reported Outcomes (EMPRO) tool. PubMed, Medline, CINAHL, PsychINFO, and the grey literature were searched. This review informed the design of an ongoing CIHR (Canadian Institutes of Health Research) funded multi-centre study to develop and validate a patient reported compassionate care measure.

Results: 1,200 articles were identified, with 91 studies being considered potentially eligible for inclusion after title and abstracts were screened, with a total of 9 studies, utilizing 6 measures, meeting eligibility after a full article review. 4 categories of compassion measures were identified: clinician-reported instruments, patient-reported measurements, measures of organizational support for compassionate care and educational measures. The 6 identified measures evaluated using EMPRO revealed significant limitations and poor psychometric results. Results informed the design of a robust 6 stage measure development and evaluation study, which will also be presented.

Conclusion: While measures of compassion exist, there are currently no valid measures that measure the construct comprehensively or are methodologically rigorous. To address this gap a Canadian research team is charting new frontiers through the development of a patient reported compassionate care measure.
A Pilot Study of Electronic vs. Paper-and-Pencil Completion of Proms in Cancer Care

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Background: Systematic use of Patient-Reported Outcomes Measures (PROMs) is essential for optimal patient care. Electronic PROMs collection may improve symptom assessment due to more efficient data capturing, immediate presentation of results and less response burden as opposed to paper forms.

Aims: Aims were to 1) investigate the equivalence of PROMs scores on common cancer symptoms collected in randomized order by paper forms and iPads, 2) assess patient preferences for one of the two assessment modes.

Methods: A parallel form agreement study was done at six Norwegian hospitals. Patients were approached when coming for a scheduled appointment at the cancer outpatient clinics. After consent they were asked to score the intensity of 19 common cancer symptoms on 0–10 numerical rating scales; 0: no pain, nausea etc. and 10: worst imaginable on paper and iPads. The symptoms were identical to the initial ones used in Eir, an electronic PROMs tool currently undergoing international validation. Patients were randomised to start with either the paper or iPad version, followed by the other version 30 minutes later. Intraclass correlation coefficients (ICC) were used to examine equivalence of paper/iPad scores.

Results: Of the included 114 patients, 110 (97%) completed both versions; 59 (54%) on iPad first, 51 (46%) on paper first. Mean age was 64.5 (27–86), median Karnofsky 90 (50–100). G1-cancer was most common (47%) followed by prostate (10%), breast and malignant melanoma (both 9%). 89% had metastatic disease. Overall, the median ICC was 0.815, ³0.75 for 14 items and ranging from 0.64 (vomiting) to 0.92 (tiredness). Interquartile range was 0.145.

Overall 41% of the patients preferred assessment on iPads, 19% preferred paper, while 40% had no preference.

Conclusion: The equivalence of PROMs scores was good, and the majority of patients preferred iPads or had no preference. This is promising, considering the many advantages of electronic assessments.

Wellbeing 0.73 Vomiting 0.64
Pain 0.89 Diarrhea 0.87
Numbness 0.87 Constipation 0.90
Shortness of breath 0.83 Lack of appetite 0.91
Drowsiness 0.89 Mouth sores 0.88
Tiredness 0.92 Dry mouth 0.82
Insomnia 0.74 Altered sense of taste 0.74
Anxiety 0.81 Altered sense of smell 0.77
Depression 0.79 Problems swallowing 0.71
Nausea 0.75 Median ICC, all items 0.815

[Intraclass correlation coefficients (ICC)]
**What Are the Barriers and Facilitators to Patient and Carer Recruitment to Randomised Controlled Trials in Palliative Care? A Systematic Review with Narrative Synthesis**

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**Background:** Adequately powered randomised controlled trials (RCTs) are required to evaluate the safety and effectiveness of health care interventions in palliative care. Why so many RCTs fail to achieve their recruitment targets is an important area of clinical practice that is poorly understood.

**Aims:** To identify and synthesise knowledge about barriers and facilitators to recruitment to palliative care RCTs to develop recommendations to increase recruitment.

**Methods:** A systematic review with narrative synthesis. Social marketing theory provided a theoretical framework for the review. Medline, Cinahl, PsycINFO and Embase databases (from Jan 1990 to early October 2016) were searched for papers containing narrative observations about the barriers and facilitators to recruitment to palliative care RCTs.

**Results:** 3832 records were screened and data extraction was carried out on 48 papers which included 10 papers that were identified from reviewing reference lists. The key barriers identified in the literature included: gatekeeping by professionals and family care givers, high refusal rates, the need for intensive resources and participants not meeting the eligibility criteria. The key facilitators included having the support of lead clinicians and the use of key messaging. Having research staff on site, regular contact with clinicians and the use of scripts / role play were seen as important recruitment strategies. The majority of the evidence is based on researchers own reports of their experiences of recruiting to palliative care RCTs rather than independent evaluation.

**Conclusion:** More methodological research is needed to try and reduce the waste of resources associated with RCTs that fail to reach their desired recruitment targets. Embedded clinical trials of recruitment strategies are a possible way forward to help to quantify whether potential strategies suggested in the literature truly have an impact.
Study Limitation or Important Information? Understanding Missing Data in Palliative Care Research

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Studies conducted in palliative care settings often suffer from high rates of attrition largely due to illness. Yet, little attention has been devoted to the best way to handle missing data in palliative care research when attrition is high due to disease progression and death. The goal of this study was to provide an example of the treatment of missing data in palliative care research.

Data for this study were drawn from a larger cross-sectional study of decision-making capacity and neuropsychological functioning in terminally ill cancer patients. Participants were 58 terminally ill adults (ages 50–89) receiving inpatient palliative care and 50 healthy adults. Study participation included a one-hour interview involving a semi-structured interview, measures of neuropsychological and psychological functioning. Multiple imputation was used to estimate the values of missing data.

Only 36.3% of the terminally ill sample (n = 20) provided complete data, notably 15.5% (n = 9) expired before completing the study, 15.5% (n = 9) became confused or too ill to continue. Five imputed datasets were created using a linear regression model. The variables included in the imputation process included the reason for incomplete data, demographic variables, neuropsychological variables, and outcome variables. This resulted in a more complete and accurate dataset that allowed for the conduction of planned analyses.

The high rates of attrition largely due to disease progression and resulting confusion, delirium, and death, led to a large amount of missing data. Multiple imputation analyses including the reason for missing data is a possible solution for better accounting for the experience of terminally ill patients. Rather than viewing this as a weakness of the study, efforts must be made to appropriately treat missing data.

The issue of missing data in palliative care research warrants further discussion.
Beyond Confidence Intervals (CIs) – Additional Value of Prediction Intervals (PIs) in Specialist Palliative Care Meta-analyses

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Background: Between-study heterogeneity is only partly described by the confidence interval (CI) of a random-effects meta-analysis. Prediction intervals (PIs) help to estimate where the true effect of a future study with similar settings might be expected. In contrast to I² or Tau², the clinical interpretation of PIs is more straightforward. Therefore, leading statisticians strongly recommend the reporting of 95% PIs in addition to 95% CIs.

Aims: To examine 95% PIs in meta-analyses that assessed the effect of specialist palliative care (SPC) on quality of life (QoL).

Methods: The underlying systematic review (CRD42015020674) included randomized controlled trials (RCTs) with adult in- or outpatients treated in hospital suffering from any advanced illness. MEDLINE, EMBASE, CENTRAL, PsycINFO, and trial registers were searched until July 2016. QoL was the primary outcome. All outcomes were analyzed with the random-effects model. PIs were calculated using R package “meta”.

Results: Of 3967 publications, 12 were included (10 RCTs, N=2454).

The main analysis for QoL showed a Hedges’ g of 0.17 in favor of SPC with a 95% CI from 0.01 to 0.32 (N=1223, 6 RCTs) and 95% PI from -0.24 to 0.57 (tau²=0.02, I²=41%).

In a sensitivity analysis, a study with extreme results was included which resulted in a Hedges’ g of 0.57 (95% CI -0.01 to 1.16, N=1390, 7 RCTs) in favor of SPC and in increased 95% PI from -1.54 to 2.69 (tau²=0.59, I²=96%).

A predefined subgroup analysis revealed a beneficial effect of SPC for cancer patients (g: 0.21, 95% CI 0.02 to 0.39, N=833, 5 RCTs). The prediction interval ranged from -0.32 to 0.73 (tau²=0.02, I²=42%).

Conclusion: The 95% CIs indicate a small but consistent effect of SPC on QoL. However, the 95% PIs of all QoL analyses include both positive and negative values. Therefore, we can expect that a future study with comparable settings might have an effect in both directions but with a clearly higher probability of an effect in favor of SPC.
Conducting a Double Blind Randomized Controlled Trial (DBRCT) in Palliative Care: Lessons Learned from a Feasibility Study of Exogenous Melatonin to Prevent Delirium in Advanced Cancer Patients

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Background: Feasibility studies are highly recommended in the context of RCTs in palliative care (PC).

Aim: To evaluate the lessons learned from a feasibility study for a DBRCT on the recruitment, retention, randomization, blinding process, acceptability of study procedures and institution infrastructure in a single centre, 31 bed PC unit.

Methods and approach taken: An exploratory, descriptive qualitative methodology was utilized drawing on content-based and thematic analysis of the recruitment log, executive committee minutes and research nurse/assistant log diary and field notes.

Results: Recruitment of 60 adult PC inpatients with advanced cancer and a Palliative Performance Scale (PPS) ≥ 30% took 16 months (average recruitment of 3.75 patients/month). 396/616 (66%) of patients admitted on weekdays were ineligible. The most common reasons for ineligibility were: delirium on admission (31%), PPS < 30% (17%), communication problems including aphasia, deafness and emotional distress (15%), and non-cancer diagnosis (13%). Initial patient verbal consent to be contacted by a research team member was obtained for 138/220 (63%) eligible patients. Study procedures were acceptable to recruited patients and staff. There were 9 study withdrawals, no unexpected SAEs or indication to unblind any participant. Thematic findings highlighted 3 core domains which informed all facets of the study: communication, training and education at trial start-up and ongoing; infrastructure and resources throughout the trial including predicted/unpredicted changes in study and clinical personnel; and learning by doing.

Conclusion: Infrastructure, resources and processes needed navigating within a process of kinaesthetic (emerging and revising) learning. Our feasibility study indicates the need for multisite collaboration for a future DBRCT to improve recruitment rates. Ongoing training and education efforts and clear communication are vital.

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Exploring Staff Self-report Questionnaires for Use in Future Multidisciplinary Training Evaluations: A Cognitive Interview Study

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Background: Robust evaluation of training for generalists in end-of-life care (EoLC) requires the use of acceptable and appropriate validated measurement tools. There is little consensus regarding which self-report questionnaires are suitable for this task.

Aims: To explore the acceptability and appropriateness of three staff-completed questionnaires used to test the impact of EoLC training.

Methods: Face-to-face cognitive interviews explored three questionnaires: the Maslach Burnout Inventory (MBI), the End-of-Life Professional Caregiver Survey (EoLPCS) and the Frommelt Attitudes Towards Care of the Dying Scale (FATCOD). These tools have previously been identified as relevant to EoLC training via a systematic review, but have not been explored with UK staff. Interviews explored acceptability and appropriateness across four areas of processing: comprehension, retrieval, judgement, and response; plus relevance and user-friendliness. Framework Analysis was used, paying attention to non-confirmatory cases.

Results: Participants (n=24) comprised nurses, doctors, and a range of allied health professionals. Most were female (n=20), worked in inpatient settings (n=22), and explored 2 questionnaires per interview. MBI items were generally acceptable and appropriate. FATCOD items with double negatives (e.g. “not a non-family caregiver responsibility”) were difficult to understand, and at times participants were hesitant to agree/disagree ‘strongly’ as they felt the item did not account for individual differences. Many items on the EoLPCS had multiple interpretations, affecting the validity of scores across individuals.

Conclusion: Adequate measurement tools are a core component of training evaluation quality. Whilst issues with the MBI were minor, the FATCOD and EoLPCS require revisions and retesting to ensure that participants’ understanding and responses translate into meaningful scores when testing the impact of training.

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Increasing Opportunities for Two-way Dialogue for Patient, Family, and Public Involvement in Palliative Care Research

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Introduction: Patient and public involvement (PPI) in research is increasingly recognised. Such collaboration can inform research priorities and increase research relevance.

Aim: To re-design PPI and strengthen two-way dialogue between PPIs and researchers, to enhance impact of palliative care research on services.

Methods: A consultation workshop using nominal group technique to identify and rank recommendations on improving PPI. We implemented the two highest ranked recommendations working with our PPI members as co-designers to evaluate and refine the innovations.

Results: The two recommendations comprised: enabling involvement across the whole research cycle; and widening engagement. Working with PPIs, we implemented these recommendations developing face-to-face workshops and online discussion forums. Our PPI work has gained national recognition.

Face-to-face workshops: used a ‘Dragon’s Den’ format where researchers presented their project to PPIs, seeking to broaden critical discussion and invite collaboration. Project presentations encompassed the research cycle from initial research ideas through to dissemination.

Online Forum: The forum is the first of its kind in palliative care research. The forum sought to enable wider national PPI in research in palliative care by creating accessible space for members to engage in discussion and share ideas. The forum comprises: discussion forums, idea generation board and document-sharing facility.

Conclusion: Working with our PPI members has enabled a radical re-design of our approach to PPI in research. This has strengthened the two-way dialogue between PPI members and researchers, and the calibre and relevance of our research to patients and families.
‘You’ve got to Integrate it into your Life’: Growth and Resilience in the Context of Expected and Unexpected Bereavement

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Background: The distinction between uncomplicated and complicated grief has been a contested area of bereavement research and practice. Much of this discourse maintains a psychopathological focus in interrogating issues pertaining to defining, predicting and treating grief that becomes complex. However, the nature of resilience and growth have also been conceptualised as meaningful elements of adjustment following bereavement.

Aim: To understand the experiences of growth, resilience and adjustment in the context of bereavement, after both expected and unexpected deaths.

Methods: 80 family members bereaved after a palliative or coronial death participated in an on-going mixed method, longitudinal study. Participants completed a range of validated scales including the Brief Grief Questionnaire, the Post Traumatic Growth Inventory-Short Form, and the Experiences in Close Relationships Scale at 6, and 13 months post death. Additionally, in depth interviews were undertaken at the same time points. Thematic narrative analysis of interview data explored the relationship with the deceased, family context, loss history, and narratives of caregiving, death, and adjustment. Scores from the scales were triangulated with themes arising from the narrative analyses to give an in-depth picture of participant’s experiences.

Results: Findings reflect upon levels of growth and grief reported by participants and reveal the meaning of growth constructed by bereaved caregivers post loss. Experiences of post loss growth are subjective and influenced by a range of factors including the individual’s loss history, attachment context and perception of internal and external resources.

Conclusion: This study furthers an understanding of resilience and recovery in light of current theory. Findings inform approaches to the development of psychoeducational resources about adaptive grief, and highlight ways in which unique patterns of coping and needs for additional support are self-identified.
Distrust in the End-of-Life Care Provided to a Parent Has a Long-term Negative Influence on Bereaved Children: A Population-based Survey Study

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Background: Previous research shows that the death of a parent places children at risk for a number of negative outcomes and even death. The role of trust in the health care at the end of life has been acknowledged to be crucial for patients and family members. However, the long-term consequences of children’s distrust in the end-of-life health care provided to their parent remains unknown.

Aim: To explore negative outcomes in the long-term of cancer-bereaved teenage children’s distrust in the care that was provided to a dying parent.

Methods: We used a population-based nationwide survey to investigate self-reported distrust in the care provided and possible negative outcomes in 622 (73%) children who six to nine years earlier at age 13 to 16 years lost a parent to cancer.

Results: Most participants had trust in the provided care. However, in those 18 percent who reported to have had no or little trust (i.e. distrust) in the health care provided to their dying parent six to nine years earlier we found statistically significant higher risks for various negative outcomes at time of survey: bitterness towards health-care professionals for not having done everything that was possible (adjusted relative risk ratio (adjRR): 3.5; 95%CI: 2.3–5.1) and for having stopped treatment (adjRR: 3.2; 95%CI: 1.7–6.1), self-destructivity (e.g. attempted suicide (adjRR: 2.6; 95%CI: 1.2–5.5)), eating problems (adjRR: 2.4; 95%CI: 1.4–4.3) depression, and other psychological problems. We did not find any statistically significant associations with grief-related variables.

Conclusion: Distrust is associated with various negative long-term outcomes, such as bitterness towards the health care and self-destructivity. The professional caregivers involved in the care of the (dying) parent might play an important role to safeguard the children’s trust in the provided care. A suggestion might be to include children into the family-meetings especially at the end of life.
**Why Is it so Hard to Discuss Spirituality?**

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**Background:** Despite known benefits of spiritual care and high levels of patient support for discussing spirituality with their physicians, the frequency of spiritual discussions in the medical consultation is low. Surveys have shown that physician discomfort is a significant contributing factor. Spiritual care is a recognized part of palliative care provision and particularly important as spiritual needs are known to be high at the end of life.

**Aims:** We wanted to understand the attitudinal barriers to conversations about spirituality in the medical consultation: specifically, why are these conversations so difficult for doctors; and what are the underlying challenges for them in discussing spirituality with patients.

**Methods:** We conducted a qualitative study of doctors caring for advanced cancer patients. Participants were initially invited to participate by email, then purposefully sampled, and included physicians from two secular countries. Semi-structured interviews were taped and transcribed verbatim. The text was analyzed using Thematic Analysis according to the method of Braun and Clarke.

**Results:** Thematic saturation was reached after 23 participants had been interviewed. The following themes were identified:

1) confusing spirituality with religion and concerns about proselytising;
2) peer pressure;
3) influence of personal spirituality, at both extremes of importance;
4) institutional factors such as availability of chaplaincy services;
5) historical factors.

**Conclusion:** This study explored the underlying attitudes contributing to the reluctance doctors have to discuss spirituality in the medical consultation. Underlying confusion regarding the differences between religion and spirituality, and the current suspicion with which religion is regarded in medicine needs to be addressed if discussion of spirituality in the palliative medicine consultation is to become routine. Historical opposition to a biopsychosocial-spiritual model of the human being is problematic.
Multidisciplinary Training on Spiritual Care in Palliative Care Improves the Attitudes and Competencies of Hospital Medical Staff: Results of a Quasi-experimental Study

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Background: Patients value healthcare professionals’ attention to their spiritual needs. However, this is undervalued in medical and nursing education. Additional training for healthcare professionals is essential for the implementation of a national multidisciplinary guideline on spiritual care (SC) in palliative care (PC).

Aims: The aim of this study is to explore and measure the effects of a specific multidisciplinary training programme on barriers for and competencies in SC in PC.

Methods: A pragmatic multicentre trial on healthcare professional-reported outcomes using a quasi-experimental pre-test-post-test design as part of an exploratory mixed methods action research study. Eight multidisciplinary teams in regular wards and 1 team of PC nurse ambassadors, in 8 Dutch teaching hospitals, received questionnaires before the training about perceived barriers for SC, spiritual attitudes and involvement, and SC competencies. The effect on barriers on SC and SC competencies were measured both 1 and 6 months after training. Our sample describes 214 nursing, 41 medical, and 15 other healthcare professionals.

Results: For nurses, 7 out of 8 barriers to SC were significantly decreased after 1 month, but only 2 were still decreased after 6 months. For physicians, the training had no effect on the barriers to SC. Nurses improved in 4 out 6 competencies after both 1 and 6 months. Physicians improved in 3 out of 6 competencies after 1 month but in only 1 competency after 6 months.

Conclusion: Concise SC training programmes for multidisciplinary teams in hospitals can make an important contribution to improve quality of care because they can have a significant effect on hospital staff competencies and on the barriers they perceive. Differences in the effects of the training on nurses and physicians in this study show the need for further research for quality indicators of SC training and research on physicians’ educational needs on SC.

Funding: Health insurer Zilveren Kruis.
What Do Palliative Care Practitioners Understand to Be Spiritual Care? Results from an International Survey on Behalf of the EAPC Spiritual Care Taskforce

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Background: Little is known of the detail of the activities which palliative care practitioners understand as spiritual care (SC). The Implementation subgroup of the EAPC Spiritual Care Taskforce therefore designed and conducted a survey to explore practitioners’ current understandings.

Aims: To explore how clinicians and others working in palliative care understand SC, and investigate relationships between respondents’ understandings and their professional and sociodemographic characteristics.

Methods: After initial piloting, an online survey ran for one month. Respondents were sourced via a circular email to all EAPC members, social media, and “snowballing” (individuals sharing the link with colleagues). Quantitative data were analysed using descriptive statistics, and free-text responses thematically. We then tested hypothesised relationships between respondents’ characteristics and emergent themes.

Results: On survey closure 528 palliative care professionals had responded, working across the world, from Northern Europe (42%), Australasia (6%), Central/South America (3%) to Africa (1%). Respondents were 68% female, 35% aged 46–55, and 66% said they engaged in personal religious and/or spiritual practices. Most, regardless of their own faiths or religious or spiritual activities, addressed the issue of similarities and differences between religion and spirituality in their responses; mainly distinguishing between these, although a few equated them. A wide variety of other themes emerged, including engaging in personal conversations with patients and/or their families, through collective or individual prayer or provision of religious or other pastoral or counselling services, to music or art therapy, or complementary therapies. Only 28% followed any guidelines for SC.

Conclusion: SC is a key element of palliative care, but even members of the EAPC have widely varying understandings of which activities comprise SC, and relatively few follow guidelines for its provision.
Background: The relief and prevention of grief related suffering in bereavement is a central tenet of palliative care practice. The potential for traumatic stress in bereaved caregivers has been recently recognised as a concern that requires further investigation. There is a need for a comprehensive understanding of the nature and symptoms of traumatic stress in bereavement.

Aim: To explore the experience and symptoms of grief, traumatic stress and growth for family caregivers in the context of palliative care bereavement over time.

Methods: A longitudinal, mixed method design examined the experience of 60 family caregivers bereaved after a palliative care death. Participants completed psychometric measures of grief, traumatic stress, and psychological growth at 6 and 13 months post loss. At the same time points, in-depth interviews focussed on the positioning of trauma within the experience of caregiving, the dying process and death event. Data from validated scales was triangulated with thematic narrative analyses of interview data.

Results: Around 27% of participants reported high and medium levels of symptomatology, including traumatic stress and grief. Narrative analysis revealed themes related to the impact of grief and suffering including difficult memories of the dying process, ruminative thoughts about aspects of care, and the impact of the management of the death event that resonated across the two time points post loss. Alongside this participants also experienced a sense of growth and adaptation.

Conclusion: Findings highlight the clear presence of traumatic stressors experienced by family members in the landscape of palliative care. The extent to which approaches to interdisciplinary palliative care provision are informed by an understanding of this potential for trauma requires further consideration. Additionally, there are implications related to assessment and intervention for bereavement services in coordinating post death follow up and counselling.
Older People Living Alone and their Perspectives on Advance Care Planning – Qualitative Secondary Analysis of Data from the Austrian Interdisciplinary Study on Very Old Age (ÖIHS)

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Background: Planning for the end of life has become increasingly important to ensure autonomy regarding type and place of care. This is especially true for older people living alone, who are most vulnerable with regard to achieving death at home. Yet, little is known about the attitudes of these people to Advance Care Planning (ACP) in Austria.

Aims: The aim of the study is to better understand how older people living alone think about planning for their future/end-of-life care and how they deal with these issues.

Methods: Secondary analysis of qualitative data from a subsample of the ÖIHS-study, which provides a broad data set on health, care and living conditions of very old people in Austria. Data which were assessed for secondary analyses included qualitative interviews with 25 people living alone at home or in institutions in rural and urban areas in Austria; Transcribed interviews were analyzed using an open coding procedure applying MAXQDA software.

Results: We found a broad diversity regarding social inclusion and networks within the sample. Only a minority had no nearby friends or relatives Most interviewees were highly aware of the need and importance of planning ahead. However, we discovered a lack of information about different forms of ACP as well as a willingness to confront themselves with issues like a potential increase of care needs in future proactively. Among those who had a living will, several people had a clear notion of what should (not) happen to themselves or their property, in case of a serious decline of health.

Conclusion: Although the idea of ACP is favored by older people living alone, multifaceted barriers hinder its implementation in practice. Living alone does not mean lacking any kind of social support, however, more research is necessary to better understand their capacities towards the end of life.
Advance Care Planning in Palliative Care for People with Intellectual Disabilities: A Systematic Review


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**Background:** Advance care planning (ACP) is defined as a person-centered, ongoing process of communication that facilitates patients’ understanding, reflection and discussion of goals, values, and preferences for future care. There is evidence for the general palliative care population that ACP strengthens the patient’s autonomy and improves quality of care near the end of life. However, more insight is needed into whether and how ACP is applied in palliative care for people with ID and what the effects of ACP are in this specific group.

**Aims:** To gain insight into what is known about the use and effects of ACP in palliative care for people with ID.

**Methods:** Four databases were systematically searched: Pubmed, PsycINFO, Embase, and CINAHL. A stepwise procedure was used to identify relevant studies. Included were empirical quantitative, qualitative, or mixed methods studies, concerning people with ID who receive palliative care or who non-acutely died, and describing (elements of) ACP. Methodological quality was graded by a critical appraisal tool.

**Results:** Fourteen studies were included, of which seven quantitative, three qualitative, and four mixed method studies. Most studies described the perspective of professionals and/or relatives. No studies focused on the perspective of the patient with ID. Studies concerned different elements of ACP: end-of-life decision-making, decision-making about medical interventions, decisions about place of palliative care, decision-making in palliative care, organizational policies, collaboration in ACP, communication around advance directives, inclusion of family, documentation of wishes for future care, and start of ACP. No intervention studies on effectiveness of ACP were found.

**Discussion:** There is a need to further investigate how ACP can be implemented within the palliative care for people with ID, how to address the needs and preferences of patients with ID, and what the effects of ACP are.

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The Model of Advanced Care Planning in Catalonia (Spain)

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Background: Care models for advanced chronic patients present two key aspects: early identification and advanced care planning (ACP). In 2014, Catalonia arranged the ACP Model (ACPM), addressed to chronic patients’ complex needs, into a public health-social system (HSS).

Aims: To describe the implementation process (IP) of an ACPM.

Methods: A core group of professionals (n=55) was convened to develop the ACPM with the co-participation of patients, caregivers, social agents and healthy persons. Inclusion criteria included: solid professional trajectory, equal representation as for territory and professional profile.

Four work levels were defined: conceptual document (CD) and implementation guide (IG) elaboration; training program (TP) development; building-up of patients, discussion groups (DG) of professionals and healthy persons.

The CD and IG were written with the agreement of expert professionals in legislation, ethics, medical specialties, nursing, anthropology, social work and psychology. The materials for the TP have been elaborated by academic experts and professionals.

Results: CD and IG have been published as open-access documents. The TP is being implemented over all Catalonia (online and face-to-face courses). Its contents focus on communication skills; legal and ethical aspects; patient and family needs and shared decision-making. These documents and materials have been reviewed by around 100 professionals from the Catalan HSS.

Conclusion/discussion: ACP is a challenge for the model of care towards advanced chronic patients. The Catalan Model of ACP establishes the conceptual and pragmatic foundations of ACP and develops the training of the professionals daily taking care of such type of patients.
Assessing the Impact of Advance Care Planning in Dementia Nursing Homes

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**Background:** In dementia care a large number of treatment decisions are made by family carers on behalf of their family member who lacks decisional capacity, Advance Care Planning (ACP) can support such carers in the decision-making of care goals.

**Aim:** To evaluate the effectiveness of ACP with family carers of people with Dementia.

**Methods:** Paired cluster randomised controlled trial of 24 dementia nursing homes located in N.Ireland, UK. Participants were family carers of nursing home residents classified as having dementia and judged as not having decisional capacity. The intervention included a trained nurse facilitator; family education; family meetings; documentation of ACP decisions; and orientation of GPs and nursing home staff about the intervention. The primary outcome was family carer uncertainty in decision-making about the care of the resident (DCS scale). Other outcomes included family carer satisfaction with nursing home care (FPCS scale); family carer psychological distress (GHQ); admission to hospital; completed “do not resuscitate” (DNR) orders, and place of death.

**Results:** 12 nursing homes were allocated to each group. There was evidence of a reduction in the total DCS score and of an increase in the total FPCS score in the intervention group compared with the usual care. There was little evidence of a difference between the intervention and usual care group on the total GHQ score. Although there were increases in DNRs, reductions in hospital admissions and hospital deaths, none of these differences had statistical significance.

**Conclusions:** The ACP was effective in reducing family carer uncertainty in decision-making concerning the care of their family member and improving perceptions of quality of care in nursing homes. Given the global significance of dementia, the implications for clinicians and policy makers include recognising the importance of family carer education and improving communication between family carers and formal care providers.
Development of a Complex Intervention to Support the Initiation of Advance Care Planning by General Practitioners in Patients at Risk of Deteriorating or Dying: A Phase 0–1 Study

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Background: Guidelines suggest that ACP should be initiated in primary care. Most patients with life-limiting illnesses are cared for over a long period of time in primary care. However, a practical model to implement ACP in general practice is lacking.

Aim: To develop an intervention to support the initiation of ACP in general practice.

Methods: We conducted a Phase 0–1 study according to the Medical Research Council (MRC) Framework. Phase 0 consisted of a systematic literature review about the barriers and facilitators for GPs to engage in ACP, focus groups with GPs were held about their experiences and attitudes regarding initiating ACP in general practice and a review of ACP interventions to identify potential components for the development of our intervention. In Phase 1, the complex intervention and its components were reviewed and refined by two expert panels.

Results: Phase 0 resulted in the identification of the factors inhibiting or enabling GPs' initiation of ACP and important components underpinning existing ACP interventions. Based on these findings, an intervention was developed in Phase 1 consisting of: a training for GPs in initiating and conducting ACP discussions, a register of patients eligible for ACP discussions, an educational booklet on ACP for patients to prepare the ACP discussions that includes general information on ACP, a section on the role of GPs in the process of ACP and a prompt list, a conversation guide to support GPs in the ACP discussions and a structured documentation template to record the outcomes of discussions.

Conclusion: Taking into account the barriers and facilitators for GPs to initiate ACP as well as the key factors underpinning successful ACP intervention in other health care settings, a complex intervention for general practice was developed, after gaining feedback from two expert panels. The feasibility and acceptability of the intervention will subsequently be tested in a Phase II study.
Advance Care Planning in frail older people, results from a cluster randomised controlled trial

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Background: Advance Care Planning (ACP) is a formalised communication process, that empowers people to identify preferences for future healthcare, and share these with professional caregivers and relatives. Evidence for its positive effects predominantly originates from the US and Australia. Furthermore, evidence on the effects of ACP programmes on people of advanced age, who reside in care homes or are community dwelling, is scarce.

Aims: To assess the feasibility and effectiveness of ACP in Dutch frail older people.

Methods: In a cluster-RCT among older people living in care homes or receiving home care, the intervention group received an ACP programme (Respecting Choices\textsuperscript{®}) in addition to usual care, whereas the control group only received usual care. Outcomes (at 12 months) were the patient activation measure (knowledge and confidence to manage one’s health, PAM), advance directive (AD) completion, surrogate decision-maker appointment and quality of life (SF-12). We conducted multilevel analyses.

Results: Of 653 eligible people, 201 (31\%) participated in our study. Their mean age was 87 years (range 73–102). 97/101 (96\%) intervention participants engaged in the ACP programme, often with their relatives. At 12 months, 92\% of intervention participants vs. 32\% of controls had completed an AD (p< 0.001) and 97\% vs. 65\% had appointed a surrogate decision-maker (p< 0.001). Change scores did not differ between intervention and control groups for the PAM (-0.26 vs. -1.43, p=0.43) and the SF-12 (physical scale: 0.95 vs. 1.15, p=0.98; mental scale: -4.63 vs. -4.20, p=0.72).

Conclusion: One third of eligible frail older people participated in our study and those in the intervention condition almost all completed the ACP programme. Intervention participants significantly more often completed an AD and appointed a decision-maker than controls. We found no effect of ACP on patient activation or quality of life.

Main study funder: ZonMw.
Six Evidence-based Recommendations for Improving Care and Support In Advanced Chronic Obstructive Pulmonary Disease (COPD)

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Background: National guidance calls for quality end-of-life care in any condition, yet non-malignant disease relies on frameworks developed for cancer which are inappropriate. An alternative approach is required recognising the slow relentless progression of non-malignant disease, and its effect on patients and carers.

Aim: To develop evidence-based recommendations to improve care and support of patients and carers living with advanced COPD.

Methods: The Living with Breathlessness Study was a multiple-component, population-based, mixed-method, longitudinal, multiple-perspective study. It followed more than 500 patients and carers for up to 18-months using interview and survey methods, and collected qualitative data on barriers and facilitators to care from clinicians. Programme-wide evidence was synthesised to identify recommendations. Stakeholder views of recommendations were collected through a workshop and online survey.

Results: Six inter-related recommendations emerged, linked by the concept of person-centred care, supported by action points to enable delivery:

1) Stop focusing on challenges of prognosis and unpredictability as barriers to meeting needs;
2) Change targets to incentivise person-centred care within existing services;
3) Enable identification of and response to patient support needs (through evidence-based tools and approaches);
4) Identify and support patients’ carers (through evidence-based tools and approaches);
5) Identify and respond to patient and carer psychological morbidity;
6) Change societal attitudes to and understandings of COPD, breathlessness, palliative care and carer support.

The recommendations were broadly endorsed by stakeholders, with caution regarding ease of implementation.

Conclusion: The recommendations could inform a new framework for care and support in advanced COPD likely to have resonance for those living with other advanced non-malignant conditions, and clinicians striving to support them.

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The Use of Palliative Care Services among COPD Patients versus Lung Cancer Patients: A Population-based Survey

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Background: It is demonstrated that palliative care (PC) services improve the quality of life. Although COPD patients have PC needs similar to those of lung cancer patients, research on PC service use focuses mainly on lung cancer patients and far less on COPD patients.

Aims: To describe rate and timing of referral to PC, reasons for non-referral and other indicators of end-of-life care in COPD patients, and to compare these outcomes with those of lung cancer patients.

Methods: We performed a large-scale survey among physicians certifying a representative sample of deaths in 2013 (n=6871) in Belgium regarding PC and end-of-life practices. We selected deaths from COPD (n=251) and deaths from lung cancer as comparison group (n=192).

Results: COPD patients (23%) were less often referred to PC services compared to those with lung cancer (55%) (p<0.001). The median timing of referral for COPD was six days prior to death (interquartile range (IQR): 3–14) and 17 days for lung cancer (IQR: 7–54) (p<0.001). Physicians whose COPD patients had not been referred cited PC not being meaningful in 36% of cases, compared to 18% of lung cancer patients (p=0.059). For COPD patients the proportion of deaths labeled as sudden and unexpected by the reporting physician was higher (p<0.001), and the treatment goal in the last weeks of life was less often aimed at comfort/palliation (p<0.001) compared to lung cancer patients.

Conclusion: While PC services are still used mainly as terminal care services in both COPD and lung cancer, our study also unequivocally shows unequal PC service use for COPD patients compared to lung cancer patients. This is likely due to COPD patients’ unpredictable illness and dying trajectory and caregivers not viewing PC as meaningful for COPD patients. These barriers may be overcome by focusing on early integration of PC for COPD patients and demonstrating its benefits and meaningfulness in the pre-terminal phase.

Funding: SBO/IWT
Can Really Early Introduction of Specialized Palliative Care Limit Intensive Care, Emergency and Hospital Admissions in Patients with Severe and Very Severe COPD? A Pilot Randomized Study

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Background: COPD is a progressive lung disorder with high rates of mortality within 2 years after admission for an acute exacerbation. Very few palliative care intervention studies are available. This trial seeks to determine the effectiveness of the introduction of specialized palliative care on hospital, intensive care unit (ICU) and emergency admissions of patients with severe COPD.

Methods and design: Pilot randomized controlled trial using a 2 arms parallel groups design. For the intervention group, an early palliative care consultation (EPCC) is added to standard care (SC). Patients with COPD defined according to GOLD criteria with a stage III or IV disease and/or long term treatment with domiciliary oxygen and/or home mechanical ventilation. 36 were hospitalised during previous year. 8 patients died at the end of the study. There was no effect in the EPCC group on Hospital, ICU and emergency admissions (P>0.05). Both groups demonstrated a statistically significant improvement in quality of life (SF-36 and COPD Assessment Test) 3 and 6 months after inclusion, but there was no group effect and no effect overtime after 6 months. There was no effect of EPCC on mood and anxiety (HADS) and on the use of antibiotics. Number of Ads completed at the end of the study were respectively in the EPCC and SC 6 and 12 (P= 0.064).

Discussions and conclusion: The results of this pilot study do not allow to confirm the effectiveness of a EPCC, but may provide directions for future palliative care interventions in this particular population.
Proactive Palliative Care for Patients with COPD (PROLONG): A Pragmatic Cluster Controlled Trial

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Background: Patients with severe Chronic Obstructive Pulmonary Disease (COPD) have poor quality of life (QoL). Palliative care (PC) is not common in this patient group. We assessed the effects of proactive PC on the well-being of patients with COPD.

Design: A pragmatic cluster controlled trial was performed with hospital as cluster. Six hospitals participated, three in the control and three in the intervention condition. For pragmatic reasons no randomization on hospital level took place. Hospitals were selected for the intervention condition based on the presence of a specialized palliative care team (SPCT). To control for confounders a pre-trial assessment was performed in which hospitals were compared on baseline characteristics.

Methods: Patients with COPD with poor prognosis were recruited during hospitalization for an acute exacerbation. All patients received usual care while patients in the intervention condition received additional proactive PC through monthly meetings with an SPCT. Our primary outcome was change score in QoL measured with the St George Respiratory Questionnaire (SGRQ) at 3 months. Secondary questionnaire outcomes were measured at 3, 6, 9 and 12 months. Other outcomes concerned readmissions, survival and having made advance care planning (ACP) choices. All analyses were by intention-to-treat.

Results: Between Jan 6, 2014 and Jan 8, 2015, 228 patients were recruited and at 3 months, 163 patients completed the SGRQ. There was no significant difference in change scores for SGRQ total at 3 months between groups (-0.79 [95% CI -4.61 to 3.34], p=0.70). However, patients who received proactive PC experienced less impact of their COPD (SGRQ impact subscale) at 6 month (-6.22 [-11.73 to -0.71], p=0.04), and more often made ACP choices (adjusted OR 3.26 [1.49 to 7.14], p=0.003).

Conclusion: In this study proactive PC did not improve QoL of patients with COPD. Secondary outcomes were promising. Further research is necessary.

Funder: ZonMw.
Planning for the Future: Addressing the Information Gaps for People Living with COPD

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Background: COPD is recognised as a life limiting illness. There is growing acknowledgement that people want to have conversations, are willing to record their end-of-life preferences and feel relieved when issues have been discussed. This is coupled with more recent trends indicating that people with illnesses can and should contribute to research and quality improvement initiatives that affect them, as promoted by the Health Research Board Ireland.

Aim: The aim of this work was to determine existing information gaps in relation to planning for the future for people living with COPD and to develop practical measures to fill this gap.

Method: Five participatory workshops took place over 7 months with 7 people with COPD, 3 family carers and the authors. The workshops were framed on a continuous process of engagement, reflection and feedback. The authors worked to create a space where those attending the workshops felt comfortable to explore, reflect and express their thoughts and feelings with regard to COPD, palliative care and advance planning. Between workshops participants engaged with others and were facilitated to represent the views of the wider COPD community as well as other people in their lives.

Result: Information gaps and barriers to this topic being discussed were identified. This led to the development of a draft information booklet entitled ‘Planning for the future with COPD’.

Conclusion: The process of engagement with patients and carers about this difficult topic has the potential to inform future patient – health carer collaboration. Dissemination of the booklet has the potential to inform many people affected by COPD.
Tackling the Rhetoric: An Evidence-based Support Needs Tool to Enable Supportive and Palliative Care in Advanced Non-malignant Disease

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Introduction: Delivery of supportive and palliative care to patients with advanced non-malignant diseases such as COPD is hampered by the challenge of prognostication and unpredictability of disease trajectories. An alternative approach is delivery of appropriate care and support in response to patient-identified need.

Aim: Informed by the evidence-based Carer Support Needs Assessment Tool, this study aimed to develop a support needs tool for patients with advanced COPD, to enable patients to identify and express their support needs with generalist clinicians.

Methods: Two-stage qualitative study.

Stage 1: domains of support need in advanced COPD were identified through a rapid review of the literature, analysis of qualitative data from the Living with Breathlessness Study (n=20 purposively sampled patients with advanced COPD) and patient focus groups.

Stage 2: the draft Support Needs Approach for Patients (SNAP) tool was developed from the identified domains of support need, then reviewed and refined in stakeholder workshops with patients, carers and clinicians to ensure acceptability and suitability for clinical practice.

Results: A comprehensive set of evidence-based support domains were identified and reformulated as questions. The draft tool asks patients to consider whether they need more support in relation to 16 broad areas of support need e.g. knowing what to expect in the future, getting out and about, and support for their carer. Patients, carers and clinical stakeholders broadly endorsed the content and wording of the draft SNAP tool and the proposed person-centred approach which it underpins. Clinical stakeholders noted the tool’s potential to be used with patients from other disease groups.

Discussion: The new SNAP tool has the potential to help patients with advanced COPD, and other non-malignant diseases, to identify and express their support needs to enable delivery of supportive and palliative care. Future work will test tool validity and feasibility.
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Supporting People with Advanced Ill Health Who Are Homeless In London – How Can we Promote Dignity and Choice at the End of Life?

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Background: Chronic homelessness is a growing problem associated with poor health and premature death. Prior to death, homeless people often experience multiple challenging unplanned hospital admissions, with poor discharge planning and aftercare.

Aims: To identify gaps in current services and develop recommendations to promote high-quality, compassionate care at the end of life for homeless people in London.

Methods: Focus groups and interviews were completed with currently homeless people (n=28), formerly homeless people (n=10), health care professionals (n=32), drug and alcohol workers (n=4), hostel staff (n=29) and outreach staff (n=10) from three London boroughs. Thematic analysis of verbatim transcripts was completed to identify key themes across participants’ accounts.

Results: The real or perceived fragility of many homeless people, difficulties developing trusting relationships, denial and concerns about the removal of hope, meant that conversations about end-of-life preferences were rare. Illnesses such as advanced liver disease have uncertain prognoses, and are influenced by behaviour, making identification of who may benefit from palliative care complex. Many homeless people with support needs remain in hostels. Yet these environments were not designed to support dying residents resulting in poor pain and symptom control and high emotional and practical burdens on staff. Furthermore, mainstream services were often unable to support individuals continuing to use substances, challenging access to many services including care homes and hospices.

Conclusions: Current care is often fragmented, within and between sectors and boroughs. Given the unique and complex needs of homeless people, specialised and flexible services are key in promoting compassionate, coordinated and dignified end-of-life care. A pan-London approach to commissioning services would be hugely beneficial to homeless people with advanced ill health.
Do Staff Talk to People with Intellectual Disabilities about Dying? An Interview Study

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Background: Many people with intellectual disabilities (ID) live in settings supported by ID staff. Most will be affected by death, and will need support around death, dying and bereavement. Previous studies suggest that ID staff tend to protect clients from knowing about death and avoid communication about death.

Aims:
(1) To gain further insight into the individual, organisational and contextual factors that affect the communication of death-related bad news to people with intellectual disabilities by ID staff;
(2) to develop, trial and evaluate a staff training course on communicating death-related bad news to people with ID.

Method:
(1) Semi-structured interviews with 20 staff in residential/supported living services, who had recent experience of supporting a person with ID at the end of life;
(2) three one-day courses were attended by 114 staff and evaluated through questionnaires.

Results: Staff found supporting people with intellectual disabilities around death and dying extremely difficult, and often preferred to protect the person with ID from knowing that they were going to die. The following factors had a particularly strong influence on staff practice around communicating death-related bad news: fear and distress around death; life and work experience; and organisational culture. The training days consisted of World Café sessions, presentations and feedback by people with ID, and an expert teaching session. Evaluation was overwhelmingly positive.

Conclusions: Palliative care services can play an important role in supporting ID staff, many of whom lack experience of dying and are uncomfortable around discussing death-related issues. ID staff need to be enabled to reflect on their practice, through emotional support, supervision and team discussions. Future work should focus on the development and testing of strategies to enable ID staff to support their clients in the areas of dying, death and bereavement.
What Are the Barriers to Accessing Holistic Care for Lesbian, Gay, Bisexual and/or Trans People Facing Advanced Illness: Accesscare – A UK National Qualitative Interview Study

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Background: Lesbian, gay, bisexual and/or trans (LGBT) people have unique healthcare needs, higher risk of certain life limiting illnesses, and unmet care needs when facing advanced illness and bereavement.

Aims: To examine experiences of LGBT people facing advanced illness to identify barriers to care, and examples of good practice, to inform healthcare professional education and supportive materials for patients.

Methods: National in depth qualitative interview study with recruitment through clinical teams, media, and community networks. Interviews were analysed using thematic analysis.

Results: N=40 LGBT patients (n=20) and current (n=6) or bereaved (n=14) unpaid carers were interviewed. Experiences related to care for: cancer (n=21); non-cancer (n=16); and both cancer and non-cancer conditions (n=3).

LGBT Participants described universal needs associated with advanced illness: comfort; safety and being pain-free. However, they experienced barriers to accessing holistic care at multiple levels. In consultations participants described heteronormative assumptions and trans/homophobic behaviours, such as refusal to acknowledge relationships. They described lack of societal recognition of relationships, and loss in bereavement, and inadequate awareness of support services. Experiences of discrimination shaped preferences for identity disclosure; participants described ‘risk assessments’ associated with disclosure due to fears of how care would be affected. Positive experiences were associated with overt acknowledgement of the depth and nature of relationships, and recognition of the need for intimacy.

Conclusion and discussion: LGBT people experience health disparities when facing advanced illness. Simple adjustments to practice, such as avoiding heteronormative assumptions and sensitive exploration of relationships, and public health initiatives to increase access to services, can improve care for LGBT people.

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The Phases of Illness Guide for People with a Learning Disability (PIP-LD)

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Aim: To develop and implement a guide for care staff to recognise changes and decline in a person with a learning disability’s health.

Background: People with a learning disability are living longer due to improvements in both physical and mental health care. However, compared to the general population life expectancy is still significantly reduced. The CIPOLD 2013 report found the main reason for people with a learning disability dying prematurely was a delay or problem with their treatment. It also highlighted that decline and dying was not recognised, therefore limiting access to good end-of-life care.

Method: The Phases of Illness Guide for People with a Learning Disability (PIP-LD) was developed by reviewing the literature, meeting experts in the field and organisations which had implemented a palliative care programme for people with a learning disability. The PIP-LD has five phases: Stable, unstable, deteriorating, dying and care after death. Each phase has specific goals and key care objectives. Twenty Learning Disability Residential Homes were recruited. Care staff were asked to use the PIP-LD to review their residents on a quarterly basis over a one year period.

Findings: The PIP-LD was used in all 20 homes. It enabled care staff to understand and document a person’s medical condition and so identify their current health status. This empowered staff to not only meet people’s immediate health needs but to recognise change and plan appropriate care for their expected future decline.

Conclusion: People with a learning disability may be living with a life limiting or develop a life threatening illness and it is vital that staff caring for them recognise the signs and symptoms of such illness early, so they can receive optimum care, treatment and access to good end-of-life care. The PIP-LD may be one way which enables care staff to do this.
Self-reported Health and Care Consumption of Older Homeless People in the Netherlands

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Background/ aims: Previous research has shown a substantially reduced life expectancy for homeless people compared to the general population, indicating that they have an increased need for palliative care at a relatively young age. This study describes the perceived health, care needs and care consumption of older homeless people, and compares these characteristics to those of younger homeless people.

Methods: Using data from the 2.5-year follow-up measurement of a cohort of homeless people in the four major Dutch cities (CODA-G4; n=378), we compared participants aged ≥55 years (n=51) to younger participants (n=327) with regard to self-reported measures of health, social support and service use.

Results: Older participants reported more cardiovascular (24% vs. 12%) and respiratory (28% vs. 18%) diseases than younger participants; in both older and younger age groups, self-reported cancer prevalence was low (0% and 1%, resp.). Many older (29%) and younger (27%) participants reported to perceive a high level of psychological distress. Almost one third of the older participants never or only rarely received social support from friends (29%) and family (31%), as compared to 16% and 22% of the younger participants. Analgesic use in the past month was reported by 31% (on average on 20 days) of the older participants and 24% (on average on 9 days) of the younger participants. Proportions of older vs. younger participants that reported service use were 10% vs. 19% for ambulant psychiatric care, 28% vs. 39% for social work, 43% vs. 52% for GP care, and 37% vs. 28% for somatic hospital care.

Discussion: These preliminary results suggest that older Dutch homeless people suffer from considerable health problems and have complex care needs. As compared to younger homeless people, their care consumption seems to be targeted to a smaller extent at psychosocial care and to a larger extent at somatic hospital care. They might benefit from multidisciplinary palliative care.

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How the Social Determinants of Health Shape End-of-Life Experiences for Vulnerable Populations and their Care Providers

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Background: It is increasingly recognized that the health of individuals and communities is shaped by their social and environmental conditions, otherwise known as the social determinants of health (SDOH). Those who are economically exploited, socially excluded, and politically subordinated experience the poorest health and greatest suffering, as well as inadequate access to health services and early death. People living in poverty for example, and who are homeless, die in places where they do not receive quality end-of-life (EOL) care – on the street, in cars, in shelters, and in hospital.

Aims: The purpose of this ethnographic study was to provide a contextual description of the EOL experiences of structurally vulnerable people and how these experiences are shaped by the SDOH.

Methods: We conducted > 300 hours of participant observation and interviews with homeless people (n=25), their ‘chosen’ family (n=24), and service providers (n=74), and interviews with key decision makers (n=20). Data were subjected to interpretive thematic analysis guided by a social justice and equity lens.

Results: Analysis of data suggests that meeting basic needs for survival are prioritized over getting EOL care needs met resulting in negative outcomes such as uncontrolled pain. Within the community, desensitization and normalization of death has made EOL needs invisible, and when made visible, these vulnerable populations are often deemed “unfit for palliative care” due to stigmatizing attitudes. The ‘silo-ing’ influence of care systems and resultant navigational barriers also create fractured care delivery which result in poor quality EOL Care.

Conclusion: Systems of care currently in place to support EOL care do not always meet the needs of structurally vulnerable people. Evidence is required to develop policy, health services, and practices that consider how SDOH shapes access to quality care at EOL.
An Interprofessional, Simulation-based End-of-Life Care Training Programme for Hospital Healthcare Professionals

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Background: With more than 50% of UK deaths occurring in hospital and one third of acute admissions thought to be in the last year of their life, education and training for hospital-based healthcare professionals around end-of-life care remains imperative. Interprofessional simulation in end-of-life care has been successful in the undergraduate setting but is uncommon in postgraduate education.

Aims: To design, implement and evaluate an interprofessional simulation-based end-of-life care training programme in a London hospital trust.

Methods: A multidisciplinary steering group developed the programme which uses actors to simulate communication based scenarios of common end-of-life cases. Training was attended by ward teams made up of a consultant and a registrar level doctor, a nurse and a therapist. Course evaluation was carried out through a self-rated confidence questionnaire, specific questions about the fidelity and impact of the course and a post-course reflective account to demonstrate behavioural change. Results were analysed by three researchers using SPSS software. Consent was obtained for sharing of data.

Results: Fifty-seven healthcare professionals attended the pilot sessions with representation from several disciplines across a range of medical and surgical specialties. Preliminary results demonstrate a positive impact on participants’ confidence in managing end-of-life care scenarios. 88.7% felt the course met their expectations either quite a bit or very much and 87.3% would recommend the course to a colleague. Post-course reflective accounts describing an end-of-life care case that has occurred since the training, have also demonstrated behavioural change amongst course participants.

Conclusion: This innovative interprofessional, end-of-life care training programme has been successful in improving healthcare professionals’ confidence in managing end-of-life care scenarios and has demonstrated an impact on participants’ behaviour.
Development and Evaluation of an e-learning Programme for Children’s Palliative Care

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Background: Education is an essential component of children’s palliative care (CPC), however, it is not always accessible, with least accessibility in areas where it is needed most. Thus training needs to be accessible as well as fit for purpose to develop a trained & skilled workforce in line with guidelines such as the EAPC competencies for CPC.

Aim: To develop, implement & evaluate the impact of international elearning training programs on CPC.

Methods: The development, implementation & evaluation of the CPC elearning program was carried out in four phases: (1) development & piloting of initial courses; (2) refining of the courses following recommendations from pilot study & developing a bespoke elearning site; (3) expansion of the courses available in English, along with translation to other languages; (4) evaluation of the impact of the elearning program.

Results: 186 participants from 31 countries undertook the pilot in 2012. Following the pilot the program was expanded to 7 courses available in English. Some courses have been translated into French, Spanish, Portuguese, Serbian, Russian, Manderin, Hindi & Dutch. To date, 1,700 participants have accessed the training from more than 105 countries. 373 participants who had accessed the elearning program by October 2013 were invited to participate in an online evaluation, with this being repeated in October 2016 for remaining participants. 55 participants completed the initial survey (15%) thus showing a higher than anticipated conversion rate. Over 8% of participants found the training clear & understandable, useful & rated it highly. Over 70% noted that due to the course they had increased knowledge, skills & attitude change, with 61% stating change of practice due to the elearning program.

Conclusion: Elearning is a useful tool in extending training in CPC globally. Work to update & revise the programmes is ongoing & training through elearning is having an impact on the provision of CPC around the world.
A Training Programme to Deal with the Desire to Die in Patients: Evaluation of Two Pilot Courses

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Aims: Although health professionals (HP) in palliative care (PC) are regularly confronted with desires to die (DD), considerable uncertainty concerning how to deal with them exists. In this study a needs oriented training programme was developed and evaluated.

Methods: A training programme with six modules including: reflecting own experiences, knowledge on types and reasons for DD, legal background, ways of responding, practice (roleplay) and self-care was developed. A self-developed guidance document on discussing DD was provided. Two pilot courses were held and evaluated using pre/post self-reporting questionnaires on participants’ confidence in dealing with DD at three times: before the course, directly after the course and 3 months later.

Results: 60 persons were interested in participation. 12 HP from different professional backgrounds were chosen for each course. Good marks were given to all modules, especially for the module concerning background knowledge and the module providing a practical approach (roleplay) to deal with DD. The multi-professional composition was highlighted. Self-reported confidence improved after the course. Participants reported also improved knowledge on: recommended ways to respond to DD, possible reasons for DD and the legal and psychiatric background. Levels for self-care did not improve. Potential for improvements of the course were also mentioned: participants expressed the need for deeper reflection on their attitudes and the incorporation of spiritual and cultural aspects and the phenomenon of a strong wish to live in patients. First results of the follow up indicate sustained change and practice transfer.

Conclusion: A training course on dealing with DD meets a need of HP in specialized and non-specialized PC. The course improved self-reported confidence, follow up evaluation indicates sustainability of improvements and integration into practice. Still, some important issues around DD were missed or not addressed sufficiently.
How to Design and Evaluate a Student-selected Component in Palliative Medicine for Medical Students

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Background: The new medical school curriculum at our university opens up for student-selected components (SSC) in clinical subjects. We wanted to design a two week SSC in palliative medicine to complement the mandatory education of about 40 hours.

Aim: To review published reports on palliative medicine courses/rotations/SSC in medical school as a basis for planning our own SSC.

Methods: Systematic literature review. Searches in Medline, inclusion criteria were courses/rotations in palliative medicine in the clinical part of medical school with duration longer than one day and published assessment of learning.

Results: Searches yielded 1183 hits. After screening of abstracts and reading 62 full text papers, 29 articles presenting 28 courses were included; 15 from the USA. The courses lasted from 8 hours over 3 days to 4 consecutive weeks. 17 courses were mandatory, 11 selective. The most common topics were principles of palliative medicine, pain and symptom management, ethics, and communication. A variety of teaching methods were used, but interactive small group teaching dominated. 22/28 courses included patient contact or placement in home care, hospice, or palliative care inpatient unit. The most common assessment methods were pre-post self-evaluation of skills and attitudes, pre-post knowledge tests, and qualitative analysis of reflective notes, diaries or case reports. Self-efficacy in Palliative Care Scale (SEPC) and Thanatophobia Scale (TS) were the most commonly used questionnaires. General outcomes were increased knowledge, increased confidence in facing and communicating with severely ill patients, and reflections on own attitudes.

Conclusion: The results show that in addition to knowledge and skills, palliative medicine is well suited to teach a person-centred approach. Encounters with patients and family members give the highest learning outcome. When evaluating the module and assessing students’ learning, mixed methods should be used.
Evaluating Staff in London Hospitals to Make Care in the Last Days of Life Everyone’s Business: An Evaluation of Learner’s Confidence

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Background: Approximately 460,000 people die in England each year making end-of-life care (EOLC) a high priority. Concerns about poor quality of EOLC have been raised through a number of recent reports. The EOLC Team at UCLPartners was awarded funding to produce educational material to upskill clinical staff in caring for patients in the last days of life within the acute hospital setting. Milestones was developed to give trainers a comprehensive set of materials (17 minute video and five structured educational sessions) referencing the five priorities of the care of the dying patient.

Aims: The aim of the evaluation was to assess the impact of the material on learner’s confidence, used as a proxy measure for Kirkpatrick level two evaluation; learning.

Methods: Confidence of learners was demonstrated asking learners to rate their confidence (1 to 7) for 9 questions, covering the five priorities of care.

Trainers collected confidence questionnaire data before and after a session from all learners taught for than an hour or more. Learners were asked to indicate if they were willing to take part in further evaluation. Contact details given were used to approach learners at least 3 months later with a 30% response rate.

Results: Responses from the questionnaires were compared with a paired t-test to evaluate the statistical significance of the difference between confidence ratings. The educational material has improved learners’ confidence in all five priorities of care. The increase in confidence was statistically significant for all categories and was sustained up to 8 months after training (p-values across categories and timeframes < 0.001).

Conclusion: Ideally, the evaluation would have covered all Kirkpatrick levels, however, manpower and time limited this. Despite this the evaluation demonstrates that Milestones can be used by multiple trainers with varying teaching experience across multiple trusts to consistently increase learner’s confidence.

The text is about an educational program called Milestones, which was developed to provide trainers with comprehensive materials to upskill clinical staff in caring for patients in the last days of life within the acute hospital setting. The program was evaluated to assess its impact on learner’s confidence, and the results showed a statistically significant improvement in confidence across all five priorities of care, which was sustained up to 8 months after training. The evaluation highlights the potential of Milestones to be used consistently across multiple trusts to increase learner’s confidence in end-of-life care.
How to Increase Public Participation in Advance Care Planning: Findings from a World Café to Elicit Community Group Perspectives

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**Background:** In 2014, Alberta, Canada broke new ground in having the first provincial healthcare policy and procedure for advance care planning (ACP), the process of communicating and documenting a person’s future healthcare preferences. However, to date public participation and awareness of ACP remains limited.

**Aim:** To elicit community group perspectives on how to help people learn about and participate in ACP.

**Methods:** Targeted invitations were sent to over 300 community groups in Alberta (e.g. health/disease, seniors/retirement, social/service, legal, faith-based, funeral planning, financial, and others). Sixty-seven participants from 46 community groups attended a “World Café”. Participants moved between tables at fixed time intervals, and in small groups discussed three separate ACP-related questions. Written comments were captured by participants and facilitators. Each comment was coded according to Michie et al.’s Theoretical Domains Framework, and mapped to the Capability, Opportunity and Motivation behavior change system (COM-B) in order to identify candidate intervention strategies.

**Results:** Of 800 written comments, 77% mapped to the Opportunity: Physical COM-B component of behavior, reflecting a need for access to ACP resources. The most common intervention strategies identified pertained to Education, Environmental Restructuring, Training, and Enablement. We synthesized the intervention strategies and qualitative comments into eight recommendations for engaging people in ACP. These pertain to access to informational resources, group education and facilitation, health system processes, use of stories, marketing, integration into life events, inclusion of business partners, and harmonization of terminology.

**Conclusions:** There was broad support for the role of community groups in promoting ACP. Eight recommendations for engaging the public in ACP were generated and have been shared with stakeholders.

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“*I Think One May Be Seen as the Symbol of What Was Bad, while the Funeral May Be Celebrating What Was Good*”: Health Professionals’ Perceptions of Attendance at Patient Funerals

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**Background and aim:** Following the death of a patient, health professionals (HPs) face the decision of whether or not to attend the patient’s funeral. In a recent quantitative study, we reported on a range of factors influencing funeral attendance and provided support to long-held assumptions about why HPs attend patient funerals; chiefly as a form of self-care and/or as a bereavement follow-up practice.

The findings led us to perform a more in-depth analysis of the factors underlying the HP’s choice to attend or not a patient’s funeral.

**Methodology:** As part of a survey completed by 1098 Australian physicians, nurses, psychologists, and social workers, we asked participants to describe their views on funeral attendance. This study provides the qualitative content analysis of the responses from the 465 participants who answered the question.

**Results:** Differences between professions, gender and years of practice were identified. Among those who had attended funerals (n=335) the main categories were an emphasis on self-care, honoring the relationship with the patient, and attendance as a personal choice. Among participants who had not attended funerals (n=126), we identified two subgroups: those who did not discount attendance in the future, and those who would never attend a funeral.

The main reasons were issues of professionalism, respect for a space reserved for family and friends, employing alternative mechanisms to grieve, cultural differences, and a lack of guidance about what is appropriate. Not wanting to be seen as a reminder of the worst days of a person’s life was a widespread attitude towards non-attendance. Self-care was also a reason for those refraining from attendance.

**Discussion:** This study probed in more depth the dilemmas and reasons why HPs choose to attend or refrain from attending patient funerals. Our study validates the need for a more open discussion about the role of HPs after their patients die; an imperative discussion in all health professions.
Understanding the Barriers to Introducing Early Palliative Care for Cancer Patients in France

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Background: Palliative care which amounts to more than simply medical care for end-life-patients is not sufficiently available in France. It has been observed in many countries that medical teams are reluctant to introduce EPC although there is some evidence of benefit outcomes of the continuum of care in advanced cancer.

Aims: To analyze the barriers to introducing EPC in the treatment of patients with advanced cancer and suggest means of overcoming these barriers in French hospital settings.

Methods: This study based on ethnographic methods was conducted at several hospitals. The methods used consisted in 1) collecting data on the decision-making practices and the timing involved in patients’ referral to palliative care; 2) conductive semi-directive interviews (n=40) with palliative care providers and oncologists.

Results: The following reasons were identified to explain the barriers to introducing EPC: the fact that palliative care is associated in people’s minds with the end of life; the social and/or symbolic “value” attached to some patients; the professional logics of oncologists, who tend to favour the idea of survival rather than quality of life; not wanting to interfere with coping strategies used by patients and their families; the fact that oncologists often find it difficult to broach the topic of the end of life with their patients; the effects of local (institutional and regional) cultural traditions on how much emphasis is given to palliative care at each hospital.

Discussion: The main barrier to the introduction of EPC seems to be the fact that the social representation of palliative care is closely associated with the end of life. The anthropological approach that aims to determine how this social representation is formed and sustained should help health professionals to overcome these barriers.
Social Representation of Palliative Care in the Spanish Newspapers: A Qualitative Analysis

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Background: Coverage of palliative care (PC) in Spain is still insufficient and a lack of social awareness is a major barrier to development of these services. Mass media are the main agents in the process of building public opinion and frequently deal with PC thereby contributing to its image and public understanding.

Aims: To analyse how PC is portrayed in the Spanish press, as well as the contribution made by the press to the social representation of PC.

Methods: Based on the criteria of scope and editorial plurality, four printed newspapers were selected (ABC, El País, El Mundo and La Vanguardia). All the articles published between 2009 and 2014 containing the words “palliative care” or “palliative medicine” were identified. Sociological discourse analysis was performed on the identified texts on two levels: a) contextual analysis; b) sociological interpretation considering discursive positions.

Results: A total of 262 articles were analysed. During the study period, bills in which PC was referenced were discussed, there was public debate regarding some controversial cases involving euthanasia, and end-of-life care became a topic of general discussion. Politicians and healthcare professionals were the main parties responsible for transmitting messages on PC. The discourses identified were characterized by their strong ideological and moral content focusing on social debate, strong ties between PC and death and, to a lesser degree, PC as a healthcare service. The term “palliative care” was used as a metaphor in some opinion pieces, where PC is identified with situations in which there was a lack of eagerness to address problems or where problems had dramatic consequences.

Conclusions: There is a substantive presence of PC in the Spanish press, generally in connection with discussions that were far removed from its own healthcare reality and that provided an ideologized image of PC, which was partially mitigated by the contributions of professionals and patients.
Fact or Fiction: The Findings of Two Comprehensive and Critical Meta-narrative Reviews of Self-compassion and Compassion Fatigue

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Background: The constructs of compassion fatigue (CF) and self-compassion (SC) are replete in the healthcare literature, particularly in palliative care where suffering is prevalent. While these constructs have raised awareness about burnout and self-care, they remain largely unchallenged.

Aims: We conducted separate reviews to appraise conceptualizations, measurements, interventions and outcomes associated with SC and CF within the healthcare literature in order to identify gaps and future research directions.

Methods: Both literature reviews used a meta-narrative approach in accordance with RAMESES standards. An initial scoping review of each construct within Pubmed, CINAHL, Medline, PsychINFO and the grey literature was conducted. Comprehensive maps of each body of literature were built with a narrative approach being used to synthesize and critically appraise the literature.

Results: The SC review identified 939 articles, with 62 studies being reviewed, mapping into 4 categories: conceptualizations; measures; affect; and interventions. The construct of SC was highly theoretical, liberally employed and has significant limitations, including its construct validity and specificity with related concepts. The CF review identified 1054 articles, with 89 studies being reviewed, mapping into 6 categories: definitions; conceptual analyses; symptoms; measures; prevalence; and interventions. The nature of CF and the premise that is compassion depleted through the provision of compassionate care is not supported by the literature.

Conclusion: While the importance of SC and CF cannot be diminished among palliative care providers, subsuming these constructs under the rubric of compassion lacks an evidence base. Subsequently, there are significant limitations with associated measures, interventions and research, requiring both constructs to be reconsidered and delineated from compassion which involves an action orientated response to the suffering of another.
The Use of Benzodiazepines (BDs) in a Specialist Palliative Care (SPC) Unit: A Focused Ethnography Study


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Background: BDs are used extensively in SPC and typically prescribed alongside other drugs increasing the risk of adverse events such as impaired memory, dizziness, drowsiness and increased falls particularly as people become frailer. Given the wide variations in practice there is a need to better understand the social, cultural and affective factors concerning the use of these drugs to improve patient safety.

Aims: To explore health professionals’ (HPs) values, beliefs, knowledge and feelings, in situ decision-making and actions concerning BD use.

Methods: A focused ethnography (FE) was conducted. Fieldwork was undertaken by an experienced ethnographer and took place intensively over 6 weeks in a large SPC unit in Australia. Qualitative data included 18 semi-structured interviews and 150 hrs of field observations and interviews (HPs, patients and families). Analysis proceeded at the same time as data collection using an established FE framework and led by two senior researchers.

Results: The majority of in-patients were prescribed at least one BD on any given day for management of symptoms including anxiety, insomnia, breathlessness, and ‘agitation’. BD use was driven by organizational and cultural factors and underpinned by what HPs considered a moral imperative to relieve distress at all costs. Patients were not always aware of what they were prescribed and why and often expressed a wish to remain alert.

Conclusion and discussion: In other health care settings BD protocols underscore the need for short courses, low doses and avoidance of ‘anticipatory’ prescribing. There is significant risk of over-prescribing of BD in SPC. Attention to organizational and cultural influences is critical if SPC HPs are to become less reliant on BDs. Further research is needed to evaluate the neurocognitive effects of BDs in palliative care. A study of community palliative care may also reveal important differences to the way BDs are used.
Medical Collaboration during ICU Admission Decisions for Seriously Ill Patients: A Qualitative Study of Internists’ and ICU Physicians’ Perceptions

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Background: Intensive care (ICU) admission decisions are complex particularly for seriously ill patients. They involve collaboration between the referring internists and ICU physicians. Good collaboration is associated with patient health-related outcomes and healthcare providers’ satisfaction with the decision-making. How physicians perceive each other roles can influence the quality of collaboration.

Aims: Explore internists’ and ICU physicians’ perceptions of their roles and how perceptions relate to experience of collaboration during admission decisions.

Methods: In-depth interviews with ICU physicians (n=12) and internists (n=12) working in a Swiss tertiary care hospital. Interviews were analyzed using an inductive thematic approach.

Results: Internists and ICU physicians had the same perception of their various respective roles. Both groups of physicians estimated that their colleagues usually performed their roles satisfactorily. Shortcomings were reported in complex situations involving seriously ill patients and gave rise to tensions. Sources of tension related to:
1. Imparting information about the patient: ICU physicians complained that internists did not provide the relevant information, thus making the decision more difficult. Internists complained ICU physicians did not trust them and expected to be convinced of the appropriateness of intensive care.
2. Choosing comfort care: ICU physicians felt that internists did not take their responsibility and let them make a comfort care decision.
3. Misunderstanding about ICU physicians’ expected role: Internists reported they sometimes only wanted ICU physicians’ advice, whereas ICU physicians assumed the internists wanted the patient to be admitted to intensive care.

Conclusion: ICU admission decisions involving seriously ill patients can give rise to tensions between internists and ICU physicians. Further research should determine if physicians’ dissatisfaction leads to inappropriate admission decisions.
Poster Exhibition
(Poster Set 1)

Audit and Quality Improvement
Bereavement
Breathlessness
Cancer
Communication
Education
Fatigue / Weakness / Cachexia
Other Patient Groups
Other Symptoms
Palliative Care in Children and Adolescents
Policy
Primary Care
Psychology and Psychiatry
Public Health and Epidemiology
Research Methodology
Spirituality
Miscellaneous
**GSF in Community Hospitals – Findings from the First Gold Standards Framework (GSF) Accredited Community Hospital Wards Delivering Proactive Person-centred End-of-Life Care**

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**Aims:** Community Hospitals are ideally placed as the hub of their local community to give quality end-of-life care. The Gold Standards Framework (GSF) is a quality improvement programme used in a variety of settings, delivering proactive personal care for people in the last years of life in all settings. We report on the introduction of the Community Hospitals Programme, and the impact of the first 20 accredited wards.

**Method:** The structured 12–18 month GSF Hospital training programme includes training, tools, support and evaluation at organisational, patient and staff level, including measures of progress and attainment and some independent evaluations. Training leads to formalised GSF Accreditation and an Award. GSF encourages teams to identify patients earlier (aiming for the 30% figure), assess their needs (offering all initial advance care planning discussions) and proactively planning care aligned to preferences, enabling more to die at home if that is their wish.

**Results:** Evaluations from GSF Accreditation indicate significant progress in several key areas in many hospitals and a ‘culture change’ on the wards. The first GSF Accredited wards show embedded good practice including earlier identification (average 47%), more proactive needs-based approach, more offered advance care planning discussions (average 79%), better communication with GPs and reduced acute hospitalisation (Acute hospital bed days reduced), enabling more to live and die where they choose.

**Conclusions:** Findings from GSF trained community hospitals and recently accredited wards show significant changes, with proactive, better coordinated, person-centred care. Earlier recognition is key and can be attained, leading to better planning, more proactive care and improved communication with the community. Community hospitals can improve end-of-life care for their patients, and reduce crises acute admissions, enabling more to live and die where they choose.
Abstract number: P01-002  
Abstract type: Poster Exhibition

Effectiveness of the Psychosocial Intervention to Ease Suffering of Persons with Advanced Illness in Spain: Evidence from a Cohort Study (2015)

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**Background:** The Programme of Integral Care for People with Advanced Illnesses aims at adding quality and put in value the task of palliative care teams towards individuals in end-of-life situation. It has implemented 42 Psychosocial Care Teams (PSCTs) in Spain formed by, mainly, psychologists and social workers. PSCTs offer support to the existing palliative care services. They provide care to advanced patients in regards to emotional, spiritual and social issues and contribute to their integral care. The knowledge about intervention effectiveness is important to improve quality of care.

**Aims:** To assess the effectiveness of PSCTs’ interventions to ease suffering and discomfort of end-of-life and palliative care patients.

**Methods:** The evolution of psychological and spiritual parameters of 10,506 patients across 34,724 visits has been analyzed in a quasi-experimental, prospective, multi-centered, one group and pre-test/post-test study for the period comprising 1st July 2014 to 30th June 2015.

Patients were visited by 210 professionals. We have analyzed the evolution of the following seven dimensions: mood, anxiety, emotional distress, meaning, peace and forgiveness and suffering referred by the patient in each visit with the psychosocial team and the global assessment made by the professionals.

**Results:** The descriptive analysis shows that the majority of patients improve in relation to basal visit in all the dimensions analyzed. Mean average increase of those variables range from 2.6% to 38%. ANCOVA’s statistical analysis, controlling for the basal value, sex, age and pathology, systematically attributes to the intervention a significantly statistical improvement (p< 0.001) in all dimensions.

**Conclusion and discussion:** PSCTs’ interventions have a positive effect for patients already receiving conventional palliative care as for the psychological and spiritual parameters evaluated. Thus, incorporating psychosocial and spiritual care improves patients’ wellbeing.
Assessment of Hydration in the Last Days of Life

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Background: Reduced oral intake is common in the dying phase. Decisions surrounding clinically assisted hydration (CAH) are complex and emotive for patients and those important to them, as well as for healthcare professionals. The NICE guidance on Care of Dying Adults in the Last Days of Life (2015) states that the need for CAH should be reviewed daily and considered where the patient is symptomatic of thirst or there is evidence of dehydration, independent of the care setting.

Aim: To review current practice in the assessment of hydration and the use of CAH for patients in the last days and hours of life in Cheshire and Merseyside.

Method: A retrospective case note audit carried out between August and October 2015, including dying patients managed across community, hospice and hospital settings. Data was collected to compare current practice with Cheshire and Merseyside regional standards.

Results: 321 patients were included in the audit across all settings. 11% of patients had their wishes with regard to CAH documented prior to their deterioration. Benefits and burdens of CAH were discussed with 13% of patients and 45% of their relatives. Documented evidence that patients were supported to take oral fluids was present in 73%, and an assessment of mouth care was documented in 71%. 56% of patients had their care supported by an end-of-life care (EOLC) record. The use of an EOLC record was 19% higher in a hospice setting. Daily assessment of hydration status was 43% higher when an EOLC record was used. Initial administration of CAH was most often via the intravenous route, and subsequent episodes were more often subcutaneous.

Conclusion: This audit highlights an increased documentation of hydration assessments when an EOLC record was used. EOLC records were used more frequently in a hospice setting. Further education and training is required across all care settings (especially hospital and community), if patients are to receive care in keeping with national guidance.
Implementing an “Aid to Decision-making Form” (ADF) for the Stratification of Care in Cancer

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Background: During care for cancer patients, life-threatening conditions may suddenly appear turning healthcare choices into tough decisions. When anticipated directives regarding end-of-life issues are unknown, maximum therapeutic engagement is usually the preferred choice, but is not always the best solution for the patient and his/her relatives. It is therefore essential to anticipate therapeutic strategies. Until now, no document has met with widespread approval in oncology.

Aims: The present work proposes to implement an “Aid to Decision-making Form” (ADF) for the stratification of care in cancer inpatients in a large comprehensive cancer center.

Methods: Multidisciplinary focus groups composed of doctors (oncologists, palliative and supportive care team, intensive care specialists...), and senior nurses had worked for 3 months at the beginning of 2015 to design this ADF. The form was then submitted to the Internal Ethics Committee.

Results: The ADF contains information on who filled out the form, when and in which circumstances, describes the patient’s current clinical status, the stratification of care decided, and how this decision was shared with the patient. The form was pilot-tested over 2 months in several units with patients receiving palliative care. Then, it was rapidly extended to the whole hospital. It is now updated at each oncology and palliative care joint staff meeting and systematically included in the patient’s medical record.

Conclusion: The ADF clarifies medical decisions in complex situations, promotes a multidisciplinary approach, facilitates the traceability of the stratification of care and ensures that the information imparted to the patient and his/her relatives is documented. The first results of an ongoing audit will be available for the congress and should confirm these promising qualitative results. Prospective evaluation will also compare the decisions made in emergency situations to those recommended by the ADF.
Aim: Breathlessness is a common and distressing symptom of advanced illness. In a previous study a breathlessness support intervention was shown to improve confidence, function and control over breathlessness. The intervention included a breathlessness pack, pacing guidance, a hand-held fan, and a crisis plan. This work evaluates sustained changes in practice 4 years after the original study was conducted.

Design: Retrospective case note review of patient episodes for a Palliative Care Hospital Advisory Team over 6 months. Patient episodes were identified according to predetermined criteria; diagnosis of cancer, chronic respiratory disease or heart failure, with a score of ≥2 for breathlessness on the Integrated Palliative Outcome Scale (IPOS) equating to moderate, severe or overwhelming shortness of breath. A subset of case notes was randomly selected for detailed review against agreed standards.

Results: 206 patient episodes met the inclusion criteria between April and September 2016. 49% were male (n=101). Age range was 21–93 years (median 72). 73% diagnosis of cancer (n=150), 18% chronic respiratory disease (n=37) and 9% heart failure (n=19). 66% had an IPOS score of 2 (n=136), 32% a score of 3 (n=66) and 2% a score of 4 (n=4). 21% (n=43) had multiple episodes during the 6-month period. Detailed case note review was completed for 30 episodes. 3 (10%) had been offered a breathlessness pack, 11 (37%) a hand-held fan, for 15 (50%) an assessment of anxiety had been completed, 23 (77%) had a documented future care plan, and 24 (80%) had documentation of a pharmacological management plan.

Conclusion: More than two thirds of suitable patients are being offered one or more components of the breathlessness support intervention 4 years after its introduction. This demonstrates sustainability within a hospital palliative care setting. An action plan including increased awareness of available resources will support better quality patient care as part of the ongoing audit cycle.
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Person-centred Anticipatory Care Planning in the Acute Hospital: From Concept to Cultural Norm

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Background: Effective anticipatory care planning (AnCP) has been reported as improving the process and outcomes of care including appropriate treatment options, medications for symptom control and achieving preferred place of death. Implementing AnCP is high on policy agendas internationally however, there is a lack of information defining person-centred AnCP within the acute hospital setting and how this can be achieved.

Aims: To explore, develop and test approaches to support reliable, person-centred anticipatory care that improves the experience and outcomes of care for patients, families and healthcare staff.

Methods: Quality improvement
Pilot areas from Medicine of the Elderly, Stroke, Acute Medicine and Oncology supported by a Quality Improvement Collaborative with 41 members from across hospital and primary care settings.

Process, balancing and outcomes data were collected by the pilot areas. The project team conducted case-note audit at baseline, end year 1 and year 2 (n=115); observation of ward rounds (n=5), multi-professional meetings (n=8), nursing handovers (n=5); 1-1 interviews with patients (n= 20) and family (n=15);Focus groups with clinical staff (n= 4)

Results: Exploratory work identified key elements of person-centred AnCP processes, contextual factors and levers for improvement. Development of the Information Reconciliation Model provided a conceptual vehicle for systems level change whilst the Anticipate & Respond to Change (ARC) bundle reflecting five point of care priorities evolved from small scale testing. Series data demonstrates a number of improvements including reliability of AnCP; engagement with patients and families including in Do Not Attempt Resuscitation decisions and appropriate clinical response to deterioration.

Conclusion/discussion: Person-centred AnCP within the acute hospital requires system wide thinking, supporting processes and attention to culture and contextual factors within different specialties.
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End-of-Life Care in the Acute Hospital Setting Following the Removal of the Liverpool Care Pathway (2015)

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Background: The Liverpool Care Pathway (LCP) was removed from use in Northern Ireland in October 2014. The Five Principles of End-of-Life Care (EOLC) were adopted regionally at this time. These reflect good practice in holistic assessment, communication and care at the end of life for the patient and their family.

Aims: To audit current end-of-life care against the regional principles.

Methods: Retrospective analysis of the first 40 adult patients who died across the hospital from 1/4/15. Unexpected, sudden deaths, or deaths within 24 hours of admission were excluded. A proforma was designed to reflect the 5 Principles of Care and this was used to analyse the notes.

Results: 25 patients included (age range 47–94). The majority (58%) of EOLC was delivered by generalist palliative care teams. Compliance with the Principles:
1. Timely identification that a person was dying: 92% recognition.
2. Patient’s awareness of dying documented in 36% [n=8] of patients. Care plan explained to patients in 60% [n=15].
3. Varying identification of physical 92% [n=23], psychological 28% [n=7], spiritual 36% [n=9], and social 24% [n=6] needs. Less than 75% of patients had anticipatory prescribing for end-of-life symptom management.
4. 14 aspects of EOLC were evaluated to encompass symptom control, comfort management and psychological, social and spiritual needs. Of note, 52% [n=13] had a review of their drug charts, 36% [n=9] had a frequency change in routine observations, DNACPR completed in 88% [n=22].
5. Support for family and carers was documented in 88% [n=22] before death and 28% [n=7] after death.

Conclusion: Communication with family, daily reviews by a senior doctor and timely referral to the specialist palliative care team were all good. Holistic assessment, anticipatory prescribing, and documentation of conversations with patients can all be improved. This audit has triggered a regional audit of practice to inform decisions on the best way to improve EOLC regionally.
Reviewing the Culture of Advanced Care Planning and Referral to Specialist Palliative Care in the Lung Oncology Clinic

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Background: Metastatic NSCLC is the leading cause of death from cancer worldwide. It often leads to a high burden of symptoms and poor quality of life (QOL). A need to facilitate communication of patient preferences when a poor prognosis is diagnosed is widely acknowledged. This is not systematically assessed and if preferences expressed, rarely recorded or sought too late. Advanced care planning (ACP) is a mechanism to discuss future care and record patient preferences. In addition, early integration of specialist palliative care (SPC) with standard oncological care has been shown to prolong survival with meaningful improvements in QOL. However, SPC is traditionally delivered late in the course of the disease.

Aim: To determine the proportion, timing of ACP discussions, and referrals of patients with metastatic NSCLC to SPC.

Method: Retrospective audit reviewing electronic medical records of 60 patients who had died with metastatic NSCLC and were seen in the lung OPD.

Results: A total of 48 eligible patients included. 66.7% had an ACP discussion offered and documented. Median time period between first clinic attendance and ACP was 334.5 days; between ACP and death 54 days. 89.6 % of patients were referred to SPC. Median time period between first clinic and referral – 161 days; between referral and death was 79 days.

Conclusion and discussion: The majority of patients were referred to SPC, however, the average period between referral and death was 79 days, reinforcing the notion that patients are often referred late in the patient’s disease trajectory. Approximately 2/3rds of patients had ACP, with almost a 1/3 of ACP discussions in the last 30 days of life. This suggests a clear need for an ACP framework to trigger timely SPC referrals and early ACP discussions. There is a danger of unmet SPC needs in this patient group, and a need to define what the SPC needs are for patients with metastatic lung cancer as late referrals may result in denial of the benefits of SPC services.
Audit on the Usage of Medication for the 5 Key Symptoms of Dying in a Palliative Care Unit

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Background: Symptom control is an important part of terminal care. Although hard evidence is lacking for most medication, they play an important role in this process. An audit on the use of medication during the terminal phase in a palliative care unit (PCU), gives a global view on this subject to the unit and offers possibilities for comparison with the acute hospital.

Aims: Collecting data on the usage of medication for the 5 key symptoms of dying (pain, dyspnoea, death rattle, nausea and restlessness) in a palliative care unit in Belgium in 2015.

Methods: Patients that had been admitted to the PCU in 2015 and died in the PCU were included in the audit. The medication of each patient in the last 3 days of life was analysed in the patient files. For each key symptom it was examined whether medication was prescribed and whether it was effectively administered. The type, dosage and administration form was further specified for administered medication. Excel was used for storage and analysis of the data.

Results: 184 patients were included in the audit. 100% of the patients were prescribed prn medication for pain, 97% effectively received this medication. Most used were morphine and fentanyl with a mean dose of 114 morphine-equivalents/24u orally. The prescription and administration rate for the other symptoms were respectively 70% and 43% for restlessness, 65% and 43% for death rattle, 64% and 23% for nausea, 52% and 45% for dyspnoea. Midazolam was most used for restlessness, hyoscine butylbromide and hyoscine hydrobromide for death rattle, alizapride for nausea and morphine for dyspnoea. Most used form of administration was subcutaneous injection.

Conclusion: With this audit we documented which medication is used and how it is used for each of the 5 symptoms of dying during the last days of life in a PCU. It is a first step in the comparison of end-of-life care in the PCU and the acute hospital.
An Audit on the Adequacy of Pain Assessment Documentation, in Paper and Electronic Records of a Home Palliative Care Unit

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Background: Accurate assessment and documentation is a perquisite for effective pain management of patients referred to palliative care units. The ONTARIO Pain Management Guidelines provides a best practice framework for pain characteristics assessment documented either in paper or electronic format.

Aim: Assess
a) whether patients with pain admitted in a home palliative care unit, were fully assessed using the ONTARIO algorithm shortly before and after the implementation of an electronic patient file and
b) whether the way of documentation influenced its adequacy.

Methods: Within a six months period before and after the implementation of an electronic patient file, 30 patients’ records (paper or electronic) were searched for pain documentation, according to these factors of ONTARIO Pain assessment algorithm (onset, provoking/palliating factors, quality, region/radiation, severity). Before the second audit round, four result feedback meetings and electronic documentation group training sessions were initiated, as the implementation strategy for improvement.

Results: 20 out of 23 consecutive patients within two months and 10 out of 16 within one month presented with pain had their records, paper or electronic respectively reviewed. 204 pain assessment episodes (mean 10.2, range 2–21) were retrieved and analysed from paper files, while 53 (mean 3.92, range 1–18) from electronic records. None of the patients were fully assessed with the 13 items of the ONTARIO algorithm, while the mean number of characteristics documented was 2.49 (1–10) in the paper and 5.94 (1–12) in the electronic file (p=0.002). Severity was the item most frequently documented in electronic files (62.3%), and region (69.6%) in paper.

Conclusion and discussion: Pain assessment documentation was more adequate in electronic than in paper patient records. Both methods documentation failed to comply with best practice recommendations and highlight the need for further staff training.
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“Resuscitation: Adequate Consultation or Not” – An Audit of Resuscitation Discussion in Patients at the End of Life

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Background: Court of Appeal judgement on 17th June 2014, found that Janet Tracey’s human rights had been breached when a DNACPR form was written about her without her knowledge. Prior to this judgement, studies suggested that only 40–50% DNACPR forms were documented as having been discussed with patient or their relatives. Other articles have suggested that decision-making and communication of DNACPR decisions with patient, family and other professionals need to improve. Discussions on CPR will naturally be distressing for any patient, but the court ruling advised not exempting patients from these discussions on the grounds that it may cause distress.

Aims: To check if DNACPR discussions were taking place with the patient and or their relatives and that were documented adequately.

Methods: Retrospective audit of all patients admitted consecutively to the inpatient unit for symptom control and terminal care over a 6-month period, specifically looking for evidence of DNACPR discussion by healthcare professional and adequate documentation.

Results: 170 patient admission, excluding 9 readmissions, 20 missing notes, 8 lacking capacity and 5 missing DNACPR forms, reduced sample size to 128 patients, showing only 88% DNACPR forms were discussed. From 12% undiscussed, 25% were completed by hospital junior doctors, and 37.5% by hospice and hospital senior doctors. The reason given was “due to distress” or “likely to cause anxiety”. This analysis concluded that both the hospice junior/non consultant grade hospice doctors and the community palliative care nurses were discussing and filling forms appropriately, while senior hospital and hospice doctors could improve in their approach.

Recommendations: Checking form during rounds with verbal reminders on discussion. To incorporate updated ruling into teaching and induction. Assess during staff appraisals. Checking patient and relatives understanding of discussion has not taken place and could be a project for the future.
Abstract number: P01-012
Abstract type: Poster Exhibition

Description of the Situation of Patients with Advanced Disease Treated with Chemotherapy in the Last 30 Days before Death

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Background: ASCO recommends don’t use cancer-directed therapy for solid tumor patients with low performance status. Implementation of this approach should be accompanied with appropriate palliative and supportive care.

Aim: To described the situation of patients with advanced disease treated with chemotherapy in the last 30 days before death.

Method: In 2015, specialists from the Oncology, Haematology, and Palliative Care departments PCD were tasked with assessing the interventions in inpatients that died during that year and treated during 30 days before death. The study variables included: the patient’s general conditions at the time of intravenous chemotherapy prescription; early PCD intervention and level of therapeutic intervention (LTI: scale agreed internally classify the intensity of therapeutic intervention). In 2016, the analysis was expanded to include oral chemotherapy.

Results: Of the 199 cases in the year 2015, 52% presented a high probability of death within admission, 93% were expected due to deterioration during the admission; 16% were attributed to chemotherapy-related toxicity. In 94% of cases, the patient’s general condition was registered at the last admission; in 55% of cases, the patients received PC intervention, and in 68% of cases LTI was indicated.

In the year 2016 (through June), 216 deaths were evaluated. In 84% of these cases, the patient’s general condition had been registered at the time of chemotherapy prescription; in 75% the PCD intervened, and in 85% of cases LTI was indicated.

Conclusions: These findings show that although many patients receive adequate PC, a sizeable percentage is under-referred. The patient’s general condition is a key indicator of prognosis and should be carefully considered when prescribing chemotherapy in patients who may be close to EOL. We found that disseminating these results among staff helped to increase physician awareness of the importance of registering and taking into account such variables.
Abstract number: P01-013  
Abstract type: Poster Exhibition

Nationwide Evaluation of the Quality of Hospital Palliative Care Services Using the Q-PAC Quality Indicators

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Background: Palliative care teams need to know whether they are delivering quality palliative care (PC) and what aspects need improvement. In Belgium, a comprehensive quality indicator set for all types of palliative care services has been implemented between November 2014 and May 2016.

Aim: To describe the quality of care delivered by hospital-based palliative care teams and the variation between teams using a validated quality indicator set.

Methods: We use quality indicator data collected using a repeated cross-sectional measurement design within 10 hospital mobile palliative support teams (PSTs) and 15 palliative care units (PCUs) in Flanders, Belgium. Over 3 measurement periods a questionnaire-based survey was conducted in patients receiving support from one service, their palliative care providers, the closest family member of deceased patients, and their care providers.

Results: The PCUs and PSTs gathered data on 498 patients, 621 care providers, 1084 family members and 1864 care providers after death (RR between 48% and 96%). Both PCUs and PSTs scored high on performing a pain assessment (98% and 94%) and asking the patient how he is feeling (99% and 93%). Both scored low on contact with GP (22% and 30%) and talking to relatives about informal care for the patient (10% and 28%). A large variation between different PCUs was found for eg care objectives discussed with a physician (0–88%) and weekly multidisciplinary consultations about the patient (10–100%). A large variation between different PSTs was found in all domains of care except communication and care planning.

Discussion: Our study indicates good quality of palliative care in Flanders in certain aspects but room for improvement in others. The lower scores overall for care aspects related to coordination and continuity and support for family particularly require attention. The large variation between teams for certain indicators suggests that teams can learn from each other to improve their care.
Developing and Implementing an End-of-Life Care Programme in Residential Care Homes in the UK

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Aim: To enable staff in residential care homes to provide demonstrable high-quality end-of-life care.

Background: The Department of Health’s End of Life Care Strategy (2008) in England highlighted the need to provide good quality end-of-life care in all settings. A Care Home Project Team developed the ‘Steps to Success’ end-of-life care programme. Implementation of the programme provided staff with a framework to develop and deliver high-quality end-of-life care. Prior to introducing the programme anonymous audit data was collected by the care home staff from all deceased residents records for the previous year for place of death, completed advance care plans (ACP) and completed do not attempt cardio-pulmonary resuscitation orders (DNACPR). This data collection then continued monthly.

Results: Within this initiative all residential care homes (RCHs) implemented the Steps to Success programme and remained engaged with it through the sustainability programme. From 2011/12 to 2014/15 there has been an increase of deaths in the care home from 54% (n=8/18) within four residential care homes to 64% (n=74/115) in 23 RCHs with corresponding increase in ACP discussions from 11% (n=2/18) to 58% (n=67/115) and completion of DNACPR from 6% (n=1/18) to 63% (n=73/115).

Discussion: Improvement was demonstrated across all outcome measures with those homes completing the implementation of the programme successfully maintaining it in practice. Six factors enabled this to occur and these should be considered when implementing other such initiatives in RCHs. These were: staff gaining a basic understanding of palliative care; regular meetings within the home; collection of audit data; provision of certificates; contributing towards and on-going learning through a sustainability initiative.

Conclusion: The development and implementation of the Steps to Success Programme was enabled by six factors including on-going learning which was possible through collection of audit data.
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Abstract type: Poster Exhibition

Optimising Day Therapy Services for Patients with Non-malignant Disease

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Background: Day therapy forms a common aspect of UK hospice outpatient care. Patients are able to access multi-disciplinary professionals to address their holistic needs in the face of deteriorating health. Patients with non-malignant disease are increasingly using day therapy services. However, it is not known if day therapy services, initially created for patients with malignancy, effectively meet the needs of patients with non-malignant disease.

Aims: Conduct a quality improvement project aimed at optimising day therapy services for patients with non-malignant disease.

Methods: Baseline data including diagnoses, re-referral rates and outcome measures was gathered using a one year retrospective case note audit. Focussed interventions were subsequently adopted, including increasing the period of day therapy attendance from 12 to 17 weeks, and using the MYMOP tool to deliver more individualised care. A one year prospective study commenced in August 2015, assessing for changes in outcomes and re-referral rates for patients with non-malignant disease. X² analysis was used to analyse nominal data.

Results: 185 patients were seen in 2014–15, 29% of whom had non-malignant disease. These patients received 12 weeks non-targeted day therapy, resulting in a 17% improvement in outcome scores. Following discharge, 36% were re-referred and 13% died during the study period. Reasons for re-referral included new physical symptoms and reduction in functional ability.

In the post-intervention year, 83 patients were seen. The proportion of patients with non-malignant disease was identical. The MYMOP intervention resulted in an additional 10% improvement in outcome scores, and re-referral rates dropped to 8% (p < 0.01) with no change in mortality.

Conclusions: Patients with non-malignant disease benefit from longer periods of day therapy which are targeted specifically at their own identified needs. The MYMOP scoring system aids individualised care and improves patient outcomes.
Opioid Analgesics Medication Adherence in Japanese Outpatients with Cancer Pain at a Comprehensive Cancer Center: A Survey of Opioid Analgesics Medication Adherence in Clinical Practice (SOAP)

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Background: Cancer pain is one of the most common symptoms in cancer patients. While opioid analgesics are used to treat it, the improper use of opioid analgesics disturbs enough pain control.

Aims: We aimed this study to evaluate medication adherence of opioid analgesics in Japanese outpatients with cancer pain, and to explore the predictive factors of medication adherence.

Methods: Outpatients who have treated cancer pain using opioid analgesics at the National Cancer Center Hospital East from February to September 2015 were recruited. A self-administered questionnaire was used to investigate opioid analgesics usage. The Japanese version of the Morisky Medication Adherence Scale-8 (MMAS-8) was used to assess medication adherence.

Results: In all, we analyzed 348 responses. According to the classification of the MMAS-8, opioid analgesics medication adherence level was rated as high (=8.0), medium (6.0 to < 8.0), and low (< 6.0) in 134, 152, 62 patients (38.5%, 43.7%, 17.8%, respectively). Determinants associated with low level in multivariate analysis were as follows: absence of medical staff who can be consulted about opioid analgesics (p=0.037), barriers toward the physiological effects of opioid analgesics (p=0.001), lack of explanation about cancer pain reduction by opioid analgesics (p=0.043), and continuation of driving (p=0.009).

Conclusion: We validated the factors affecting medication adherence of opioid analgesics in Japanese cancer patients. Providing medication teaching tailored to the barriers to opioid analgesics and social life situation of each patient might improve pain control.
Difficult Conversations – A Workshop to Improve Nursing Staff Confidence in Talking to Patients and Families about Death and Dying

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Background: The Transforming End of Life Care Team (TT) at UCLH is implementing a 5 year education programme to improve care and communication for patients in the last year of life. The TT has identified that nursing staff find it difficult to talk to patients about dying and could benefit from practical training.

Aims:
1. Improve nursing staff confidence and willingness to engage in conversations about death and dying with patients and their families.
2. Encourage staff to take responsibility for these conversations within their professional remit.

Methods: One day ‘Difficult Conversations’ interactive workshop developed to provide training for up to 12 nurses per session, facilitated by multidisciplinary members from TT and Palliative Care teams. Topics related to death and dying covered include: fears and concerns (with personal stories about death & mourning explored), professional beliefs, after-death care, the importance of discussing death and dying and self-care and support. Practice sessions to facilitate beginning and ending conversations around death and dying are held. Feedback on confidence and willingness to participate in such conversations is collected pre and post workshop, with additional qualitative interviews conducted 6 weeks post attendance.

Results: 8 workshops have been attended by 64 staff, attracting staff of all grades across trust sites. Feedback demonstrates increased confidence in discussing dying (mean of 2 points on 5 point Likert Scale) and a reported change in practice. Willingness to engage in such conversations increased by 1 point. Staff report feeling empowered to discuss death and dying. Evaluation feedback indicates that nurses would recommend the workshop to colleagues. Specialist hospital teams have since requested tailored workshops.

Conclusion: One day workshops can improve staff confidence and willingness to engage in conversations around death and dying, which may improve end-of-life care for patients and their families.
Statin Stopping – A Review of Statin Therapy in Patients Admitted to a Specialist Palliative Care Unit

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**Background:** There is increasing evidence to suggest that statin therapy discontinuation can be a safe means of reducing tablet burden, adverse effects and cost in the context of life-limiting illness while also potentially improving quality-of-life.

**Aim:** To retrospectively review the prevalence of statin prescribing and discontinuation rates amongst patients admitted to a Specialist Palliative Care Inpatient Unit over a three-month period.

**Methods:** All patients admitted to a Specialist Palliative Care Inpatient Unit over a three-month period were included in the review. Pharmacist-led medication reviews were used to identify the numbers of patients who, on admission, were currently prescribed statin therapy. Subsequently those patients underwent further chart review to identify other patient characteristics including diagnosis, outcomes and if and when statin therapy was discontinued.

**Results:** 180 patients were included in the review. 12% (n=21) of patients admitted were on statin therapy at the time of admission. Over 80% (n=17) of those patients on statin therapy died within the course of the admission to the Specialist Palliative Care Inpatient Unit. Only 2 patients continued statin therapy throughout the course of their admission and both were subsequently discharged home. The discontinuation of statin therapy occurred on the day of admission in over 60% (n=12) of cases. In over 40% (n=8) of cases where statin therapy was discontinued the decision was not documented in the medical notes. Over 80% (n=17) of the patients on statin therapy had a malignant diagnosis.

**Conclusion:** Statin therapy remains a frequently discontinued therapy on admission to our Specialist Palliative Care Inpatient Unit. Although prompt discontinuation was the norm, the reasons for same were often poorly documented in medical notes.
**Abstract number:** P01-019  
**Abstract type:** Poster Exhibition

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**A Third of Hospital Patients Are in their Final Year of Life – Can we Give them Better Care? Findings From the First Gold Standards Framework (GSF) Accredited Hospital Wards Delivering Proactive Person-centred End-of-Life Care**

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**Aims:** A third of hospital patients are in their last year of life; almost 50% of people die in hospital, yet most still do not die where they would choose. Poor end-of-life care in UK hospitals has received much recent attention and is recognised as a key area for improvement. With earlier recognition and a more tailored approach, more might be discharged home earlier, receive better care with fewer hospital deaths.

Gold Standards Framework (GSF) is a quality improvement programme delivering proactive personalised care for people in the last years of life in all settings. We report on the introduction and impact of the first 8 years of the GSF Acute Hospitals Programme, with findings from the first GSF Accredited wards.

**Method:** The structured 2 year GSF Hospital training programme includes training, tools, support and evaluation at organisational, patient and staff level, including measures of progress and attainment and some independent evaluations. GSF encourages teams to identify patients earlier (aiming for the 30% figure where appropriate), assess their needs (offering all initial advance care planning discussions) and proactively planning care aligned to preferences, enabling more to die at home.

**Results:** Evaluations indicate significant progress in several key areas in many hospitals and a 'culture change' on the wards. Most progress but we discuss why some do not complete the programme. GSF Accredited wards show embedded good practice including earlier identification (average 35%), more proactive needs-based approach, more offered advance care planning discussions (75–95%), better communication with GPs and reduced hospitalisation (hospital bed days reduced), enabling more to live and die where they choose.

**Conclusions:** Findings from the first phases of GSF trained hospitals and the first accredited wards show significant changes, with proactive, better coordinated, person-centred care. Earlier recognition is key and can be attained.
Abstract number: P01-020
Abstract type: Poster Exhibition

**Initiating Strong Opioids: Introducing the SO-IPT Tool**

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**Background:** Opioids are an essential part of pain control in palliative care and their initiation in the UK should adhere to the 2012 National Guideline. This guideline makes recommendations about the choice of opioids, prevention of side effects and the communication of information about opioids to patients. However, adherence to these guidelines can be challenging, as demonstrated by our audit.

**Aim:** To audit adherence to the National Guideline on the initiation of strong opioids. Based on the findings, to develop a tool to support adherence to the Guideline.

**Method:** A retrospective cross-sectional survey of patients initiated on strong opioids during a period of two months in 2015 at a tertiary cancer centre was carried out. Medical records for 37 patients were examined, and performance in 25 different criteria recorded. Of these criteria, five were available from audits carried out in two previous years for direct comparison.

**Results:** Morphine was used as the first-line strong opioid in 89% of patients. Appropriate breakthrough doses were prescribed in 44%, prophylaxis for nausea was prescribed in 70% and for constipation in 49%. Evidence of communication with patients about strong opioids was present in 11% of cases. As a result of these findings we developed the SO-IPT tool (Strong Opioid- Initiation Prescription Template) to support clinicians in adhering to the National Guideline.

**Conclusion:** Our study identified poor documentation as the main limitation to adherence to the National Guideline on the initiation of strong opioids. The introduction of the SO-IPT tool, a template containing the key guideline recommendations on the safe prescription of strong opioids, aims to improve adherence to guidelines on the safe introduction of these drugs. We recommend an evaluation of the SO-IPT tool be carried out to establish if it improves documentation of communication and decisions around strong opioid prescribing.
**Abstract number:** P01-021  
**Abstract type:** Poster Exhibition

# Data from a National Hospice and Palliative Care Registry for Benchmarking in Pain Relief

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**Background:** Quality management tools have been increasingly used in palliative care in the last years to examine and improve performance and services.

**Aim:** The aim of the study is to exemplary perform a benchmarking for pain relief by using symptom intensity changes from the beginning to the end of support by palliative care services.

**Methods:** The German Hospice and Palliative Care Registry (HPCR) has been initiated as a quality management system in Germany. Among other data, it consists of a validated symptom and problem checklist proxy assessed by staff. We analyzed data sets from 2011 till 2015 of institutions that provide both pain values of admission and of discharge for at least 10 patients. Initial pain scores were compared with final pain scores by Wilcoxon signed-rank test. The percentage of patients with pain relief was then calculated per institution.

**Results:** The analysis includes data sets of 85 palliative care service providers. Each institution provided from 10 to 269 data sets that could show the changes in pain during the period under review. Overall, the pain scores from the beginning and the end of the treatment were available for 4748 patients. The median of patients with pain reduction was 47.8%. The calculation revealed that 21 institutions are in the upper quartile with the number of patients for whom pain relief was documented. In 12 institutions, this calculation resulted in pain relief for more than 90% of their patients.

**Conclusions/ discussion:** Benchmarking shows differences in pain relief between providers of palliative care. If quality data are made available to participating institutions, they could compare their performance quality with that of others. Thus, they could identify improvement potentials, and could be motivated by data of other institutions. In the future, further research on defining and evaluation of threshold for “good / bad quality” is recommended.
Abstract number: P01-022
Abstract type: Poster Exhibition

**Exploration of Nurses’ Perception on Palliative Care in a District Public Hospital in Hong Kong**

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**Background:** Quality palliative & end-of-life care in Palliative Care Unit is unique and the department has initiated to extend palliative care services to all clinical units with 416 in-patient beds include acute, ventilator, and rehabilitation, renal and palliative in Department of Medicine and Geriatrics in Hong Kong from 2012. A series of professional palliative care training was conducted with collaboration of the palliative care specialists.

**Methodology:** This is a quasi-experimental pre- and post-test study conducted to assess the nurses knowledge on palliative care before and after the specialized designed training program. Before and immediately after the intervention, the participating nurses were anonymously assessed by filling up a validated Palliative Care Nursing Quiz (PCNQ).

**Results:** More than 80% of nurses returned the pre-test questionnaire as baseline PCNQ (227 out of 280). Half of the nurses (n=112) stated self-perceived inadequacies in end-of-life care. Among the respondents, 109 nurses (48.0%) attended the lectures and completed the post-test questionnaire. “Philosophy of palliative care” improved from 2.41 +/- 1.00 to 3.01 +/- 1.04 (full mark: 4). “Psychosocial & spiritual aspect of palliative care” improved from 1.04+/-.83 to 1.89+-/-.86 (full mark: 3). “Pain and symptom management” improved from 7.02+/-.97 to 9.81+/-.214 (full mark: 13). The domain with the lowest percentage of correct answers was the “Psychosocial & spiritual aspect of palliative care”. See Table 1. The total score improved from 10.47+/-.79 to 14.69+/-.95 (full mark: 20). All scores improved significantly statistically with p value less than 0.05.

These studies concluded that the knowledge gaps and education needs that exist amongst nurses in non-palliative care setting. Special designed palliative care training as intervention significantly improved nurses’ PC knowledge. To provide quality palliative care, continuing nursing education is highly recommended.
Involving Children as Next of Kin in Adult Palliative Care Is a Crucial Challenge

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The Swedish National Board of Health and Welfare has a stated policy requiring health care units to involve children as next of kin to parents with serious illness in daily practice. To implement this policy, a project was performed in two palliative care units to develop local evidence based action plans.

The aim of the research project was to study the development and implementation of evidence based local action plans to support children as next of kin in adult palliative care units. Four research questions guided the research:

(i) Were there changes in health care professionals’ awareness and action from before the development of local action plans and after one year?
(ii) How was the child perspective, the child's perspective and the UN Convention on the Rights of the Child taken in to account?
(iii) What characterized the health professionals' reflections encountering and making children as next of kin visible?
(iv) What characterized the knowledge transformation and the learning processes?

A questionnaire was distributed at base line and after one year (i) and analyzed statistically. The discussions in work group sessions were recorded, transcribed and analyzed by qualitative content analysis (ii-iv).

The structured data did not provide any significant differences between baseline and follow-up in terms of awareness among health care professionals concerning children’s rights as next of kin to adults in palliative care (i). There was an obvious awareness among the professionals of the need to integrate a child perspective into the action plans (ii). The value of a more family-focused care was evident but could increase the demands on the organization (iii). The learning process was characterized by diverse visions between developing personal action preparedness and designing an action plan (iv).

This type of tailored implementation gave both a conceptual and instrumental learning.
Abstract number: P01-024
Abstract type: Poster Exhibition

Medical Device Related Pressure Injury in Palliative Care. Are Oxygen Masks Really that Safe?

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Background: One-third of pressure injuries that develop during hospitalization are device-related. The most common site of medical-device related pressure injuries (MDRPI) is the ear. Pressure Injuries are associated with increased morbidity and mortality. One device common to hospitalized palliative care patients is the oxygen mask. Pressure injuries can result from the mask or its elastic strap. Little research has been conducted on the issue of MDRPI from a palliative care perspective.

AIMS To describe the incidence of pressure injuries, related to the use of oxygen masks in palliative care patients in an acute hospital.

Methods: This is a descriptive study of all in-patients, aged 18 or above, in an acute hospital in Singapore who were referred to the palliative services over a 2-week period in April 2016. All patients using an oxygen mask (non-rebreather mask, NRM or venturi mask, VM) were recruited into the study. Patients who presented with pressure injury on admission were excluded. Baseline patient demographic data were collected as part of a quality improvement initiative. Descriptive statistics were used.

Results: Eleven patients on oxygen masks were referred to the palliative services. Eight (72.7%) were male. Median age was 81 years. One third had a cancer diagnosis (36.4%). Most patients were on non-rebreather masks (81.8%). Three patients had protection applied over the ears to reduce pressure and friction from the elastic strap.

All patients developed pressure injuries (Stage I and II) over the ears resulting from the elastic strap of the oxygen masks. All, except one, were too unwell to express discomfort.

Conclusion: In our review, the incidence of pressure injury resulting from the use of oxygen masks is 100%. Within the hospital, we have no standardized preventive or management strategy in place resulting in inconsistencies in practice. We need to combine research, training & clear communication to standardize practices to reduce MDRPIs.
Prescribing Diclofenac – Navigating the Landmine of Risks and Benefits in the Palliative Oncology Setting

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**Background:** Amongst the non-opioid analgesics, NSAIDs are more effective than placebo for cancer-related pain. However, the addition of cardiovascular contraindication and strengthening of the precautions regarding usage of Diclofenac have heightened concerns about its role in palliative care. Furthermore, the UK reclassification of Diclofenac as a prescription-only medicine (POM) in January 2015 has intensified the conundrum of risk versus benefits stratification in palliative cancer patients who may benefit from the use of Diclofenac.

**Aims:** This is a retrospective documentation audit at a tertiary cancer centre, examining the prescription of Diclofenac against recent UK and European Medicines recommendations. It aims to examine current prescribing practice against these standards with a view to improving the risk versus benefits stratification for clinicians considering the use of Diclofenac for palliative cancer patients.

**Methods:** Data was extracted from several sources including electronic and pharmacy patient records of patients admitted to the in-patient unit. We compared 2 groups of patients: Patients prescribed Diclofenac in November and December 2014 (post the UK Drug Safety Update); and Patients prescribed Diclofenac in May and June 2015 (post the reclassification to POM).

**Results:** In total 38 case records were examined. Cardiovascular history was recorded in 13% of patients in 2014 and none in 2015. Gastrointestinal history was recorded in 20% of patients in 2014 and 4% in 2015. Documentation of medication review was evident in 26% in 2014 and 13% in 2015.

**Discussion:** The safe use of Diclofenac as an opioid sparing medication in cancer pain, necessitates rigorous pre-assessment and documentation of renal, GI and cardiovascular risk factors. We propose the development and evaluation of a tool: NSAID PC as prescription checklist to support clinicians with the challenge of risk versus benefits stratification on a named-patient basis.
Outcomes of Patients Receiving Inpatient Radiotherapy on the Palliative Care Unit

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Radiotherapy is a frequently used treatment in advanced malignancy and palliative care units are often enlisted to support these treatments. Anecdotally, patients that require admission are frailer and appear to have more complications of treatment than those treated as outpatients. This is yet to be reviewed in the Australian setting.

**Aim:** To review the outcome of these patients with regards to; toxicity, discharge location and mortality at 14 and 30 days post finishing radiotherapy.

**Methods:** A Retrospective audit was undertaken of all patients who received Radiotherapy whilst an inpatient on the Palliative Care Unit (PCU) from January 1st 2013 to December 31st 2015. Ethics gained through hospital ethics department.

**Results:** A cohort of 119 patients was captured in this audit. Of this 33.6% returned home, 12% to residential care, 9.6% to inpatient rehabilitation and 43.2% died during that admission. 44.5% died within 30 days of finishing/ceasing radiotherapy, 29% within 14 days. A notably higher rate than previously documented.

Despite attempts to find correlating factors for poor outcome (death< 30 days) the only positive correlation was staff recognition of deterioration prior to cessation of radiotherapy.

**Limitations:** Include that it is a single centre retrospective audit, which excluded inpatient radiotherapy on other units.

**Conclusions:** patients requiring admission to PCU at the same time as receiving RT are a frail population who have poor functional status, multiple co-morbidities and have a high risk of 30-day mortality. Ongoing communication between the palliative and radiation oncology teams is essential to ensure the most appropriate treatment for patients in this specific population.
Implementing a Palliative Care Service in a Private Hospital – A 3 Year Experience and the Institution’s Learning Curve

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Aim: Evaluate a 3 year experience of implementing a palliative care consultation team (PCT) in a private hospital with 327 inpatient and 85 intensive care unit (ICU) beds that had no structured Palliative Care service before and most clinicians weren’t familiar with this approach.

Methods: Review of administrative data from July 2013 to August 2016.

Results: 248 patients, average age 75 (28–101 years), 46% men. The main diagnosis presented was cancer (62,2%), followed by dementia and/or frailty (15,2%), neurological conditions (6,8%), and cardiovascular (5,2%).

In 2013/2014 Oncology presented an average of 3,6 calls per month while the other medical specialties together had an average of 1,5 calls. In 2015/2016 a higher number of calls occurred both in the oncology department (6,8 per month, 189% increase) and in the other specialties (6 per month, 400% increase).

The length of stay in the hospital before calling the PCT varied from 0 to 272 days. However, while in 2013/2014 the PCT was called after an average length of stay of 23 days, in 2015/2016 this number lowered to 17 days.

PCT was mostly called for end-of-life care, the average follow up with the PCT was 13 days, 80% of the patients died in the hospital within the stay that de PCT first evaluated them and 20% were discharged with home care or transferred to a nursing facility.

A significant number of calls (38%) were for patients already in the ICU, PCT approach managed to discharge from the ICU 29% of these.

Conclusion: An ascending learning curve about palliative care in the institution could be noticed. At first the majority of calls were from the oncology department, which already had more familiarity with palliative care, as the PCT got more known through its work and educational activities an increasing number of calls, especially from other medical specialties occurred. Although, the PCT keeps on being called mainly for end-of-life care a smaller length of stay before calling the PCT was observed.
Can a Home Palliative Service Increase the Number of Home Deaths?

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**Background:** The majority of deaths occur in hospital, even for patients who receive palliative care services. A Health Quality Ontario report of over 54,000 patients who received palliative care services between April 2014 and March 2015 showed 64.9% of palliative care patients died in hospital versus 23.5% who died in the community.

**Objectives:**
1) To compare the rate of hospital and community deaths of our local home palliative care program with the provincial statistics.
2) To determine if age or final diagnosis are factors that affect the place of death.

**Methods:** Retrospective data of patients who died between September 1, 2013 and October 22, 2016 (n=644) was obtained from the electronic medical record of a five physician home palliative care team. Chi-Square analysis was conducted comparing the number of patients who died at home based on age, diagnosis, and length of stay on service prior to death.

**Results:** Overall, 46% of patients died at home, 35% of patients in the local palliative care unit, 9% of patients in the local acute medical unit and 9% at an outside facility which includes hospice or an outside acute care facility. Patients age 50 and over were more likely to die at home versus those who were younger (48% vs 29%, p=0.0075). Those referred for home palliative care within the last 30 days of life were more likely to die at home compared to those who stayed on service for over 30 days (57% vs 40%, p< 0.0001). Patients with a pulmonary diagnosis (lung cancer, COPD, pulmonary fibrosis) were less likely to die at home versus patients with other diagnoses (34% vs 50%, p=0.0009).

**Conclusions:** The local home palliative care program has been successful in supporting patients wishing to die at home. Younger patients and patients with a pulmonary diagnosis were less likely to die at home. More study is required to identify factors in these populations that reduce the likelihood of dying at home.
Evaluation of the Practice of Palliative Sedation Therapy in a Rural Hospital

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Aim of the study: Palliative sedation therapy (PST) can be used as a measure of last resort in the end-of-life care of patients with terminal illness when a patient suffers without adequate symptom control. We want to evaluate the practice of PST in our hospital.

Study design: In a retrospective way we examined the medical records of all patients who died between 2014 and 2016. Those who died during PST have been analysed. In the analysis we focused on the decision-making and documentation process of PST, the existence of refractory symptoms, the patient’s life expectancy and unwanted rise of consciousness.

Results: A total number of 570+ patients died in our hospital. In 2014 61 out of 189 were treated with PST. Average age was 75 years, 32 were male.

Refractory symptoms were adequately documented in 43 cases, life expectancy in 14. Documentation of PST being discussed with patients was found in 19 cases. In 4 cases an unwanted rise of consciousness was described.

Results for 2015 and 2016 will be available before May 2017.

Conclusions: A third of all patients dying in our hospital suffered from refractory symptoms which were treated with PST. Duration of the PST-treatment was short and the maximum administered dose of sedatives moderate. Documentation of the decision-making process and the success of the PST was inadequate.

Lessons learned: Better documentation of the decision-making process is desirable.

The patients role needs to become more prominent and visible in the decision-making process.

Effects of PST need to be documented in an objective and verifiable way.

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<th>Patient characteristics and results</th>
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<td>Adequate documentation of refractory symptoms</td>
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The Real World Effects of Prescribing in Palliative Care – RAPID

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Abstract number: P01-030
Abstract type: Poster Exhibition

Background: Palliative care has sought to improve its evidence base for clinical prescribing in many ways. Randomised controlled trials (RCTs) are being undertaken to inform clinical decisions. In addition to RCTs, pharmacovigilance studies provide data on the effects of treatments outside the controlled trial environment by systematically collecting prospective data they assist in defining the attributable benefits and harms from treatments. They are cost effective, timely and add to knowledge by defining the net benefit based on real world use.

Aim: To prospectively collect information on the therapeutic benefit and harms of treatments.

Methods: This research network has developed an international, web-based initiative to collect prospective data to document the net clinical benefit and safety of frequently prescribed palliative care medications. Three time points are assessed and include: baseline; a point at which clinical benefit should be experienced; and a point at which short-term harms may occur. In addition, harms can be recorded at any time. Only de-identified data are collected and the time impost on clinicians is minimal. Clinical outcome data are aggregated for reporting with RAPID turnaround of results.

Results: Fifty sites in 10 countries are now participating. The results from these completed series will be presented: Metoclopramide for nausea; Haloperidol for delirium; Gabapentin/Pregabalin for neuropathic pain; and Dexamethasone for anorexia.

Conclusion: This low tech high impact program is demonstrating both tangible – research data, and intangible – clinical reflection, outcomes not previously been captured in palliative care. The program continues to grow in the: number of interventions being studied; number of contributing sites; gathering of real world data to inform clinical decision-making; building of research capacity; and improvement of patient outcomes. Infrastructure funding for the network is provided by the Australian Government.
Abstract number: P01-031
Abstract type: Poster Exhibition

Effective Handover: Re-audit of Palliative Medical Handover

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Background: The Royal College of Physicians (RCP) set medical handover standards to ensure patient care & safety. It states “handover, particularly ‘on-call responsibility, has been identified as a point at which errors are likely to occur”. Junior Doctors Committee recommended that handover be supported by information systems identifying all relevant patients. The RCP standards were locally adapted resulting in 24 items, including demographics, diagnostic, holistic assessment, drugs & allergies, communication, progress & plans.


Results: Demographic, diagnostic, reason for admission, physical assessment/management, current progress details, co-morbidities Gold Standards Framework registration & Preferred Place of Care well handed over (>90%). Source of admission, treatment, social assessment & allergies/sensitivities less well transmitted (80–89%). Spiritual & psychological assessment, discharge plans, patient & family insight & conversations needed improvement (< 70%), with Advance Care Planning (42%) & date of last chemotherapy needing to improve significantly (20%).

Conclusions: Quality of handover not as good as last audit in June 2014. This could be linked to omission of audit in 2015 and a new team of doctors joining the team, without a formal training session given. To try & improve quality further, results were presented with recommendations. These included use of prompt cards, prompt structured handover, using computer record to support the process & avoidance of interruptions. The second cycle has been planned (Feb 2017), & results shall be available for this poster.
Abstract number: P01-032
Abstract type: Poster Exhibition

**Costs-analysis of Care at the End of Life in Cancer Patients. Comparative between a Palliative Care Unit (PCU) to Other Hospitalization Units (No_PCU)**

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**Background:** Palliative care teams may be efficient at saving costs compared to conventional care in the end of life attention.

**Aims:** To analyze the clinical characteristics, health resources use, costs of hospitalization, therapies and pharmacy costs of patients in their last 15 days of life. We compare the PCU to other units.

**Methods:** Retrospective study of cost analysis.

**Setting:** Universitary Tertiary Hospital.

**Subjects:** All oncologic palliative patients dead in the hospital during a 6 months period. Costs were studied in last 15 days of life.

**Results:** n= 56, mean age:65,71(SD13,303)Gender M:64.3% F:35.7%,Charlson Comorbidity Index: average 7.25 (SD1.5)Spread cancer 71.8%. Pain was present in 83% patients.

**Place of Death:** PCU43%,Oncology23.2%, Intensive Care Unit 9%, Radiotherapy7%, Internal Medicine5.3%, Haematology 5.3%. The PCU was consulted in 60.7% cases, 68% of them were moved to the PCU ward.There were no differences regarding age, gender and Charlson index between patients of PCU and No_PCU.

There were significant differences with less medical tests in patients of PCU, adjusted by days of stay.

**Laboratory:** PCU: 0.192 vs NoPCU:0.422 (p< 0.001).
**X-rays:** PCU: 0.09 vs NoPCU: 0.24 (p< 0.009) and
**CT scan:**PCU:0.011 vs NoPCU:0.0936 (p< 0.042).

There were also differences in the Pharmacy costs: PCU with 10.77€/day vs NoPCU 34.87 €/day (p=0.018).

The sanitary cost average by patient was:PCU 2507,09 € (CI 95% 3021,80 1992,38) while it was 4873,5 € (CI95% 3777,27–5969,72) No_PCU.The costs difference, adjusted by days of stay, was significantly lower in PCU 259,84 €/day (CI 95% 316,4–450,13) compared to 383,26€/day in No_PCU units (CI 95% 239,97–279,71) compared to 383,26€/day in No_PCU units.

**Conclusions:** The oncologic palliative patients admitted to PCU had lower health costs compared to other hospital units. The costs saving by the PCU was in average 123 €/patient/day.

The model of attention in PCU focused on the patient needs at the end of life can improve the rationalization of health resources use, with the resulting cost savings.
Increased Waiting Time for Transfer to Medium-stay Palliative Care Units

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Background: The transfer from an acute care hospital to a Medium-stay Palliative Care Unit (MPCU) is helpful for terminal patients that need to be hospitalized for several weeks-months and can take advantage of this specialized care resource.

A long wait for transfer has a negative impact on both patients and caregivers and in addition a greater economic cost. Our perception is that waiting time has increased in the last years.

Objectives: Analyze whether there is an increased waiting time during the period observed and if it is related to an increased number of patients transferred or to a longer survival in the MPCU or otherwise to a less choice of MPCU available.

Methods: Observational analytical study. Patients included was over 18 years with terminal disease criteria (WHO/SECPAL), admitted in the Emergency Room or in hospital wards, and considered suitable by the hospital Palliative Care team to transfer to a MPCU. Observation period was the same four-month period from 2012 to 2016. Descriptive analysis and linear regression model of waiting time, number of transfers, survival and MPCU requested was performed by using SPSS 11.0 and Stata program.

Results: 378 patients were transferred. Mean age was 76.6±11.6 years, 54.8% were men and 75.1% had cancer. An annual increase of waiting time 0.76 ± 0.22 days (p=0.001) was observed with no significant changes (< 10%) by the number of transfers (0.78 ± 0.26 p = 0.002) and solicited MPCU (0.77 ± 0.21 p=0.000). By study design we can not conclude that variation of survival explains the increased waiting time (1.90 ± 0.49 p=0.000).

Conclusions: We confirm an increase in the waiting time for transfer to the MPCU which seems not related to the number of referrals or with the choice of destination Units. Further studies would be needed to assess whether this rise is related to the improvement of palliative patients survival in the MPCU.

No funding was allocated for this work.
Heart Failure and Palliative Care: A Multidisciplinary Perspective

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Background: The Heart Failure (HF) is a disease of unpredictable developments and low rate of survival, and is considered the supreme manifestation of all heart diseases. It represents a high level of physical and psychological stress, which strengthens the importance of the palliative care practice for affected patients.

Aims: Check the knowledge of a multidisciplinary health care team in charge of patients with HF on the topic Palliative Care.

Methods: We conducted semi-structured interviews with doctors, nurses, nursing technicians, an occupational therapist, a nutritionist and a psychologist of a specialized service at a federal hospital in Rio de Janeiro city (Brazil) in June and July 2016. The interviews were recorded and later transcribed. The corpus of analysis were processed on IRAMUTEQ® software. The choice method to describe and analyze the thematic generated was the Bardin content analysis. The study was approved by the ethics committee of the research site.

Results: Data analysis generated three conceptual categories: Ideal time to start palliative care therapy; Concepts of palliative care, and; Family integration in the care process.

Discussion / conclusion: The data indicated that the inclusion of palliative care is necessary in heart failure treatment, however there is no consensus concerning the moment when such inclusion should interfere. It was noticed that although the professionals were aware of this care philosophy, a training team is necessary for the theme to become widespread. Even if professionals do not declare to practice palliative care with patients, they recognise the urgent need of inserting this approach on the researched scenario and they consider the integration of the family in the care process fundamental to the practice of palliative care. This study was funded with author’s resources.
Abstract number: P01-035  
Abstract type: Poster Exhibition

Development of a Care Guide for the Palliative Trajectory

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Background: In Sweden, a request from health care professionals, has been put forth for a more structured and personalized support for patients with palliative care needs throughout the palliative trajectory. Today such a support exists only for the dying patient.

Aim: To develop a person-centered structured care guide for adult patients with palliative care needs throughout the palliative trajectory, regardless of age, diagnosis and care facility.

Methods: Developing and testing the care guide began in 2014 and follows the Medical Research Council framework. The guide was developed based on research, collected clinical experience, expertise of patients and families and a multidisciplinary advisory committee and regulatory documents issued by the Swedish health care authorities. Feasibility and revision of the guide was accomplished through three subsequent pilot studies in about 50 municipal, acute and specialized palliative care settings. Intertwined with the pilot studies, feasibility and evaluation of the guide involved interviews with patients and family, focus groups with and written comments from the staff and review of medical records.

Results: The results showed that the care guide provide a clear and structured support and can be used either as support to assure the care given is based on the principles of good palliative care or in addition as a documentation record from early to late palliative care, including end-of-life and after death care. A first version of the Swedish palliative care guide was released in September 2016. The guide consists of three parts, including decision supports and suggestions for interventions related to the most common needs and problems at the different stages in the palliative trajectory.

Conclusion: The care guide is designed to improve palliative care by supporting a personalized palliative approach. Implementation, surveillance and follow up of the care guide is currently being undertaken.

Funding: The Kamprad Family Foundation
Abstract number: P01-036
Abstract type: Poster Exhibition

A Simple Intervention Can Go a Long Way: Improving the Quality of Junior Doctors’ Prescriptions in Palliative Care

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Aims and goals: In the hospital setting, prescriptions for patients with palliative care needs are largely written by non-speciality doctors. Training can be variable; as a result, prescription errors occur, leading to delays in receiving medication and further patient discomfort. To combat this, we produced a palliative medication lanyard card for junior doctors’ use.

Methodology: In November 2014 we assessed doctors’ simulated prescriptions and their confidence in prescribing via an online survey at two London hospitals. In 2015 with a new cohort, we introduced a lanyard card displaying key information including the names and doses for medications and syringe drivers and an opioid conversion table. At 6 months we assessed its success with a further survey.

Results: ‘As required’ medication prescriptions improved in all areas (analgesia by 31%, nausea/vomiting by 40%, secretions by 28% and agitation by 4%). Moreover, prescription quality improved for; medication ‘start up’ doses for a syringe driver (analgesia by 14%, agitation by 31%, nausea/vomiting by 33% and secretions by 32%), prescribing a syringe driver correctly (27% to 56%), opioid conversion (73% to 88%), and dosing in liver and renal failure (18% and 17% less errors respectively).

Confidence levels for prescribing in palliative care showed improvement in all domains assessed (prescribing ‘as required’ medications, when and how to prescribe syringe drivers and managing patients with poor oral intake).

Conclusions: The introduction of this simple and cheap intervention provides accessible prescribing information for doctors managing patients with palliative care needs. It has improved prescription quality and doctors’ confidence prescribing, and is therefore likely to better the speed at which patients receive the correct medication. This improvement has been demonstrated despite the presence of already present intranet guidelines in both hospitals.
**Abstract number:** P01-037  
**Abstract type:** Poster Exhibition

## Palliative Indicators in a University Hospital – A Cross-sectional Prevalence Study Combined with ESAS-r Symptom Assessment

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**Background:** The frequency of need for palliative care among patients is determined by the indicators you choose and varies considerably. At the University Hospital of North Norway we are planning a palliative care unit and this prompted an audit to explore local palliative care needs.

**Aims:** We aimed to explore the prevalence of various palliative care indicators and the symptom burden of patients admitted into the main hospital departments.

**Methods:** We did a cross sectional study, attending the pre-rounds of included departments. Palliative care indicators like “cancer as underlying disease” (cancer), “current opioid prescription” (opioid) and “would you be surprised if the patient dies within the coming 12 months”? (surprise), were addressed. In addition, we sought to assess the symptom burden by ESAS-r. Differences between patient groups and departments were tested with chi square statistics, Mann-Whitney and Kruskal-Wallis non-parametric tests.

**Results:** 87 patients were admitted at included departments, 18 from oncology, 37 from surgery, 26 from medical and 6 others. Regarding palliative indicators; 51 patients (58.6%) had the indicator “cancer”, 36 (41.4 %) had the indicator “opioids” and 43 patients (49.4%) had the “surprise” indicator. Only 8 (9%) did not have any of the indicators, which was as many as those who had all indicators. 64 patients completed an ESAS-r. There were no differences in symptom burden between cancer and non-cancer patients (p > 0.05 for all symptoms) and the highest symptom burden scores were found at the department of lung diseases (n=13), mean ESAS-r 3.36 vs 2.43 (p = 0.22).

**Conclusions:** By assessing palliative care indicators we found a majority of admitted patients to have an indicator for palliative care and lung patients to have the highest symptom burden. The frequency of palliative care indicators points to the need of organized palliative care and that palliative care should be distributed to non-cancer patients as well.
Abstract number: P01-038
Abstract type: Poster Exhibition

Improving the Quality of Documentation for Patients thought Likely to Be Dying on Critical Care

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Background: ‘More care less pathway’ (2013) review highlighted clinician and family communication issues regarding nutrition, hydration and concerns documentation. Our Critical Care Unit uses Trust individual plan for care of those thought to be dying (2014) and supplementary Critical Care individual treatment escalation limitations (Oct 15).


Results: 24 patients identified. Individual care plan used in 58%, of these; both documents used in 79%. Marked difference in documented treatment escalation limits in those using individual care plan and those not. (Ventilation 100% vs 73%, Vasoactive medication 92% vs 72%, Renal Replacement Therapy 85% vs 55%, Routine bloods 85% vs 27%). Difference in documented assessment of mouth, hydration and nutritional needs. (Mouth care 100% vs 0%, hydration 100% vs 36%, nutrition 92% vs 36%). Nutritional needs discussed with relatives 67% vs 23%. Use of individual plan showed greater documentation of patient needs (spiritual 90% vs 21%, religious 90% vs 14%, practical 90% vs 7%, cultural 90% vs 0%). Similar found in addressing needs (spiritual 90% vs 14%, religious 90% vs 14%, practical 80% vs 0%, cultural 80% vs 0%). Prognosis and expectations discussed with patients or their family in 100% of cases.

Discussion: Good documentation of the care for those thought to be dying is essential. Individual care plan results in substantial difference in documentation quality. Discussion with patients and families about prognosis and expectations 100%; but noticeable difference in more holistic discussions. “If it’s not documented it didn’t happen” – any aid to achieving good Critical Care documentation should be encouraged. Small sample size is main limitation; but statistics show benefits of using individual care plan and we encourage other units similarly.
Abstract number: P01-039
Abstract type: Poster Exhibition

**Systematic Quality Monitoring for Specialized Palliative Care Services: Development of a Minimal Set of Quality Indicators for Palliative Care Study (QPAC)**

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**Background:** A feasibility evaluation of a comprehensive quality indicator set for palliative care identified the need for a minimal selection of these indicators to monitor quality of palliative care services with short questionnaires for the patients, caregivers, and family carers. Therefore we aimed at developing a minimal indicator set for efficient quality assessment in palliative care.

**Methods:** We performed a 2 round modified Research ANd Development corporation in collaboration with the University of California at Los Angeles (RAND/UCLA) expert consultation with Thirteen experts in palliative care (professionals and patient representatives). In a home assignment, the experts were asked to score 80 developed indicators for “priority” to be included in the minimal set on a scale from 0 (lowest priority) to 9 (highest priority). The second round consisted of a plenary meeting in which the minimal set was finalized.

**Results:** Thirty-nine of the 80 indicators were discarded, while 19 were definitely selected after the home assignment, and 22 were proposed for discussion during the meeting; 12 of these survived the selection round. The final minimal indicator set for palliative care consists of 5 indicators about the physical aspects of care; 6 about the psychosocial aspects of care; 13 about information, communication, and care planning; 5 about type of care; and 2 about continuity of care.

**Conclusion:** A minimal set of 31 indicators reflecting all the important issues in palliative care was created for palliative care services to assess the quality of their care in a quick and efficient manner. Additional topic-specific optional modules are available for more thorough assessment of specific aspects of care.
**Abstract number:** P01-040  
**Abstract type:** Poster Exhibition

## Advance Care Planning in an Irish Acute Hospital Setting

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**Background:** Early identification and discussion of poor prognosis helps patients and their families engage with healthcare professionals. A patient centered approach permits healthcare professionals to work together with patients in planning for future care. Effective communication and documentation is essential for good patient care.

**Aim:** To promote timely communication & documentation of discussions between healthcare teams, patients & their families in regards to advanced care planning in an acute hospital setting.

**Method:** Retrospective review of medical records was conducted of all inpatient deaths over a 1-month period (n=27). Data collected included resuscitation status, ceiling of care, Specialist Palliative Care Team (SPCT) referral, family & patient awareness, prognosis & communication.

**Results:** Documentation of resuscitation status was recorded in 91% of charts, which was performed by the primary team in 77%, or the out of hours team or consulting team in 23%. Ceiling-of-care (escalation plans), along with patient & family awareness was documented in 100%. In several cases, however, documentation remained unclear: Ambiguous or non-defined terms encountered included “full ward management,” “comfort measures,” and “palliation.” Referral to SPCT was made in 88% of cases, of which 42% occurred within 1 day of patient death. 52% were made within 5 days of patient death. Rates of documentation with regards to patient prognosis in 45%, and liaison with General Practitioner following death, was low at 30%.

**Conclusion:** Early awareness of poor prognosis, and early referral to the SPCT can aid both patients and their families in making informed decisions about future care, and can assist the coordinated development of a comprehensive advanced care plan. Documentation is imperative to support appropriate care planning and a consistent approach from all healthcare professionals involved. Liaising with the General Practitioner maintains communication across care settings.
Mirroring the Standards: Auditing Hospital Care of Those Approaching the End of Life

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Background: In 2014 the local District Nursing (DN) service reviewed the level of support provided for those approaching end of life (EoL). 36 standards relating to documentation of the care of those recognised to be approaching EoL were identified throughout whole illness & initial bereavement. Recognising those approaching EoL, recording GSF registration & implementing a Clinical Care Plan for each patient appeared to enable significant improvements in documentation of community care. The aim was to review acute care against similar standards & ensure patients received a seamless service, in order to compare the locally agreed standards of care & documentation received in the community compared to that received in hospital & identify areas of failure to meet standards in an attempt to introduce appropriate teaching & support for staff to demonstrate an improvement in quality of care & documentation.

Methods: Transform clinical lead reviewed 20 consecutive case notes of patients recognised approaching EoL/GSF prior to hospital admission, who subsequently died (Mar 16). Data, retrospectively gathered from medical & nursing notes of each patient & collected on excel spreadsheet, was analysed.

Results: Only one standard, relating to the initial bereavement visit, was met in 100% patients, 5 were met in >80% patients, two were met in 60–79% patients, but 28 were met in less than 60% patients with a few standards not met in any.

Conclusion: In a trust where so much emphasis has been put on, & education put into, end-of-life care, it is very disappointing to see the results of this initial cycle of audit. However, when the original DN audit was undertaken, the results were similarly poor & dissemination of those results, education & reaudit, resulted in significant improvement over a period of a couple of years. It is hoped that by the time this poster is presented, similar education & intervention will result in improved documentation proving the work that is being done.
Care Decisions for the Last Days of Life: A Welsh Perspective

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Background: Care of the dying patient remains a sensitive issue; the challenges for healthcare professionals can be diverse and care interventions complex. Guidance to support the delivery of quality care in the last days of life has been implemented in all care settings in Wales for the past 16 years. Continuous central monitoring contributed to ongoing changes in response to service user feedback and quality review. Recent developments and recommendations for care of the dying patient in England provided the added impetus to undertake a thorough overhaul of the Welsh guidance.

Methods: Consensus review of existing guidance in light of national recommendations of the NHS Leadership Alliance for care of dying people, supported by outcomes of an electronic survey, resulted in prototype guidance being drawn up. The new guidance was tested in a controlled way across a variety of care settings and agreement reached it was fit for purpose. The guidance was assessed for equality and diversity issues and given full quality assurance assessment prior to national implementation.

Outcomes: This paper reports on the progress of reviewing the previous process-led guidance to address the current focus on providing individualised care for the patient and those important to them at the end of life. The new guidance resulting from this process is discussed, audit and quality monitoring systems are described and the national progress with implementation across Wales reported.
Assessing Prescription of Anticholinergic Medications for Inpatients Known to the Palliative Care Team

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Background: Drugs which increase anticholinergic (ACh) load can cause increased morbidity. Their prescription is common in palliative care patients. NICE guidelines for Falls and Delirium require that a medication review is conducted following such events.

Aim: To assess whether palliative care patients experiencing delirium or falls have their drugs reviewed in keeping with guidelines; and to establish ACh burden in this population.

Methods: This is a retrospective audit of all inpatients known to palliative care at a tertiary cancer hospital at 2 discrete time points. Electronic / bedside records were used to identify falls, delirium and documentation of medication reviews. Drug charts were reviewed with the validated Anticholinergic Risk Scale (ARS). This gives drugs 0 to 3 points based on ACh activity, with the sum giving patients a total ARS score (ARSS).

Results: 49 patients were included. Mean age was 58. 55% were women. The most common cancers were upper gastrointestinal (17%) and breast (17%). Median ARSS was 0 (range 0–5). 39% were on at least 1 ACh drug, most commonly metoclopramide.

8 patients had delirium; their median ARSS was 1.5 (range 0–5). In 77.8%, the patient was on between 1 and 3 ACh drugs (in 2 patients, started within 72 hours prior). In 5 cases there was a documented drug review. 1 patient had ACh drugs decreased. 4 patients had a fall during admission, 1 of whom had an ACh drug started within 72 hours prior. This was subsequently stopped.

Conclusion and discussion: Over a third of patients were on ACh drugs. In those with delirium the proportion is far higher, with an increased ARSS. In only half of falls and delirium is a drug review documented, falling below the standard of 80%. There were few cases where ACh drugs were specifically reviewed or changed. Further work is now needed to review all patients with falls / delirium over 1 year to assess their ACh burden, and adherence to NICE guidelines regarding medication reviews.
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Abstract type: Poster Exhibition

A Palliative Care Consultation Service in a Large Cancer Hospital – Main Actions Developed and the Outcomes Achieved

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Aim: Describing the main actions developed by and the outcomes achieved by a palliative care team (PCT) in its inpatient consultation service.

Design: Retrospective analysis of consults realised in between June and September 2016 (3 months).

Results: In cancer hospital with 407 beds in Brazil a palliative care service has inpatient specialized care (12 beds), ambulatory (80 appointments per week), a consultation service for inpatient of different specialties.

In the 3 month period analysed 529 consultations were asked (5,9 new patients per day), patients average age was 62 (17–97 years), 55% male. The vast majority had low performance-status, only 24% KPS of 50 or more. The vast majority of the patients were in exclusive palliative care, but 12,5% were still receiving chemo and/or radiotherapy, 36% were already followed by the PCT in the ambulatory setting. Half of the patients were in the ER when the PCT was called.

The PCT most frequent actions after evaluating those patients were related to: symptom control (78%), prognostic evaluation (32%), improving communication issues (22%), organizing follow-up (21%), discharging procedures with ambulatory follow up (15%) and proposing to hospice (14%). The outcomes of those patients while being followed by the PCT via consultation were: 38,5% dyed within the hospital after an average of 4,2 days after the PCT evaluation, 26,3% were discharged after an average of 5 days, 24% were admitted in the PCT inpatient unit after an average of 3,15 days, and 10,6% were transferred to hospice after average of 6,6 days.

Conclusion: A consultation service could be a way of optimizing PCT resources in an inpatient setting of cancer hospital as in less than a week of PCT follow up it was possible to achieve major definitions in terms of therapeutic planning: ambulatory care, hospice care, end-of-life care and necessity of more specific approach in an inpatient unit specialized in palliative care.
Administration of Drugs by the Subcutaneous Route in a Palliative Population of Hospice In-patients. A Quality Assessment Survey of Subcutaneous Administered Medicine. Course Project for Nordic Specialist Course in Palliative Medicine

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Subcutaneous (sc) drug administration is preferred for most patients in late palliative stages. Off label sc drug administration is common.

**Aim and objectives:** Register use of sc drug administration, label and off-label and evaluate safety and tolerability in our in-hospice patients.

**Material and methods:** Retrospective data randomly collected from records of 100 in-hospice patients treated with sc drugs (100/105).

Prospective data of sc drug administration from in-hospice patients (20/22).

**Results:** 95% of our patient received at least one drug sc and a total of 9027 bolus doses were registered.

Midazolam 91% Haloperidol 57% Morphine 45% Oxycodone 32% Glycopyrrolate 20% Metoclopramide 13% Ketamine 7%. 30 different drugs were administered sc 10 (33%) licensed for sc administration 14 (47%) licensed for intramuscular use 6 (20%) licensed for intravenous use only In 7 patients 11 side-effects were registered. Side effects were all minor like short lasting redness or local pain 1 led to direct termination of the drug (pantoprazole) 2 were solitary incidences of stinging pain 4 incidents were solved by needle replacement 1 solved by preinjecting low dose Lidocaine 2 solved by preinjecting low dose dexamethasone The two patients with more than one side effect had symptoms of general skin allodynia.

**Conclusion:** Subcutaneous drug administration is widely used in our palliative in-hospice population. We administer 2/3 of drugs on off label subcutaneous prescription. Subcutaneous drug administration seems safe with good tolerability, Discomfort seems often related to needle irritations more than a specific drug reaction.
**Current Practice and Attitudes to Determining Ceilings of Treatment in an Acute Hospital Trust**

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**Background:** Treatment escalation plans are being introduced into many acute hospitals in the UK. This poster will detail baseline audits undertaken in one acute trust to guide implementation of a new UK wide treatment escalation plan due to launch in spring 2017.

**Aims:**
- To determine attitudes of all staff to treatment escalation planning
- To determine attitudes to education of all staff around treatment escalation planning
- To determine whether conversations and decisions about ceilings of treatment during an inpatient admission are communicated with community staff at the time of discharge

**Methods:** An electronic survey was circulated to all staff within one acute hospital trust. Consultants were also emailed individually to encourage response.

All discharge summaries were scrutinised for 50 consecutive discharges Jan-March 2016, who all died within 28 days of discharge.

**Results:** More senior staff had higher levels of confidence discussing ceilings of treatment with patients. They also had less desire for further education around this subject and hold a preference for e learning.

89% discharge summaries did not contain any details of ceilings of treatment, DNACPR or end-of-life care planning. More detailed scrutiny of these inpatient admissions is being undertaken and will be presented.

**Discussion:** Attitudes to the principle of treatment escalation planning are positive across all staff groups however, in practice these discussions and decisions are poorly documented at the time of discharge.
Promoting Quality Care for Prisoners at the End of Life, Using the Gold Standards Framework (GSF) Adapted for Prisons

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Aim: Prisons have a growing population of older prisoners, who are likely to end their lives in prison. Many of them may have life limiting illnesses which can result in crises and repeated admissions to hospital (with prisoners necessitating 2 staff 24 hour escorts). Enabling the Healthcare and prison staff to be more proactive, identifying the prisoner’s stage of decline as they near the end of life and to anticipate needs and care at each stage can have huge benefits, not only on the morale and confidence of the staff and the well-being of the prisoners, but also cost saving benefits.

Method: GSF is a systematic evidence based approach to optimising the care for people nearing the end of life delivered by generalist providers, in any setting. GSF Programmes in end-of-life care, includes training, tools, evaluations and support followed by a rigorous accreditation process. We report here the findings from first GSF Accredited prison. The evaluations included baseline and follow up after death analyses and key outcome ratios, as well as a portfolio of evidence.

Results: We report on the outcomes of the GSF Accreditation evaluations of a prison healthcare unit that cares for 15 inmates with severe long-term conditions. Improvements include more proactive care in line with preferences, improved outcomes for prisoners and increased confidence and understanding of staff.

Conclusion: The GSF training and accreditation process helps the organisations and the individual staff to better meet the needs of the individuals they care for, achieving quality of life and death in prisons. Rather than focusing on individual learning the focus is on organisational and systems change, which leads to sustainable improvements in end-of-life care within the organisation and improved collaboration across boundaries.

There appear to be significant benefits to all in establishing GSF in a prisons context to enable better quality life and death for prisoners.
Abstract number: P01-048
Abstract type: Poster Exhibition

Reducing Hospital Admissions of People with Dementia from Nursing Homes: The Role of Anticipatory Care Planning

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Background: Dementia is increasing in prevalence and it is recognised that nursing homes are where older people with Dementia die. Almost half of people over 70 years old with an unplanned hospital admission have Dementia. Admissions from nursing homes are common and it is recognised that hospitalisation can create adverse health outcomes.

Aim: The aim of this audit was to promote a reduction in hospital admissions of people with Dementia in nursing homes through anticipatory care planning.

Methods: A regional survey of a total sample of nursing homes designated to people with Dementia (n=118) took place in one region of the United Kingdom. Data were collected using a thirty-five item electronic survey tool piloted before use. The content of this tool was based on recognised regional GAIN guidelines on palliative and end-of-life care in nursing homes (www.rqia.org.uk) which reflect methods of anticipatory care planning evidenced in reducing hospital admissions at end of life.

Results: The survey generated almost a 40% response rate. Data were analysed using SPSS to obtain descriptive statistics. Key findings indicate that there are examples of good practice in anticipatory care planning to reduce hospital admissions of people with Dementia from nursing homes. Findings also indicate where service improvement is required in anticipating care needs of people with Dementia, which can reduce costly hospital admissions. Greater understanding of challenges and enablers to implementing anticipatory care planning has been achieved.

Conclusion: Examples of good practice and enablers to anticipatory care planning evidenced in reducing hospital admissions of people with Dementia from nursing homes have been highlighted. These findings could promote service improvement in anticipatory care planning within nursing homes which could reduce hospital admissions. As Dementia is recognised globally as a major public health issue findings could have international significance.
Utilisation of a Comfort Care Kit in a Home Hospice Setting

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**Background:** Home medication kits to manage anticipated symptoms in patients at the end of life may be useful in empowering caregivers and reducing patient distress. A previous study of a comfort care kit (CCK) comprising non-oral, non-parenteral standby medications for dying patients with low symptom burden within a home hospice service had shown feasibility of use.

**Aim:** To study the utilisation of a home medication kit for terminally-ill patients within a home hospice organisation three years after implementation, potentially identifying specific prescription patterns and evaluating the need to optimise its use.

**Methods:** Electronic medical records of imminently dying patients (on the Care of the Dying Pathway (CDP)) between January and April 2015 were retrospectively reviewed. The CCK prescription rate in eligible patients was evaluated and compared across five centres within the service.

**Results:** There were 166 patients on the CDP. Of 101 eligible patients, 22 (21.8%) were given the CCK, while 46 (45.5%) were given subcutaneous injections. 33 patients (32.7%) were prescribed neither of these; some in this group were prescribed other non-parenteral medications.

There were substantial differences in the CCK utilisation rates among satellite centres (ranging from 0% to 30.4%).

**Conclusion:** CCK prescription rates among actively dying patients in this cohort were relatively low, with considerable variation among satellite centres. This may be due to differing practice preferences, perception concerning lack of efficacy, or barriers that need further characterization.

Some dying patients were not given standby medications for common symptoms. This raises the question of whether families were sufficiently prepared for managing these symptoms at home.

Further work needs to be done, possibly using qualitative methods like focus group discussions, to elicit underlying reasons for low prescription rates. Findings will guide future iterations of the CCK to improve patient outcomes.
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Abstract type: Poster Exhibition

‘Gold Patients’ in End-of-Life Care – A Description of the Use of GSF across Boundaries of Care and the Development of GSF or Gold Patients

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Background: To meet the needs of the ageing population we need to think population-based End of life care. The Gold Standards Framework (GSF) Training Programme in end-of-life care, used in a variety of settings, is a systematic way to deliver the ‘right care, for the right person, in the right place at the right time’, extensively used across the UK. GSF aims to improve earlier recognition of patients in the last year of life, more patient centred care through more advance care planning discussions, care tailored to meet needs and preferences, and reduce avoidable hospital admissions. For some Cross Boundary care Sites, GSF can become a common vocabulary across different settings, aiming to improve cross boundary care.

Aim: To demonstrate change in end-of-life care in several settings across a wider area, through use of GSF Training Programme across different settings, for a wider population based approach.

Methods: A description of work in 8 areas, using GSF across different settings (hospitals, primary care, care homes etc) to improve cross boundary care , including use of the GSF Prognostic Indicator Guidance to identify patients early. Evaluation findings are described, with illustrative quantitative and qualitative measures. Some areas describe identified patients as ‘Gold patients’, with additional benefits such as the Gold Line, Gold cards and others.

Results: Increased use of GSF was enabled in different settings, with earlier identification, more offered ACP discussions, more dying where they choose described plus an exploration of the benefits of being ‘gold’ patients.

Discussion: Identifying patients early has many advantages and the benefits of being ‘Gold’ are appealing to many. Early results demonstrate that use of GSF as a vehicle to improve cross boundary end-of-life care supports whole area population based improvements in end-of-life care for a wider area, including social care, community and hospital care.
NECPAL CCMS-ICO© Program in Argentina: Early and Continuous Care for Advanced Cancer Patients with Palliative Needs

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In Latin America, less than 10% of people receive the PC they need. According to Gómez Batiste a significant change of approach on how health systems around the world attend most patients in end of life it is required. There exist methods for estimating the target population based only on mortality rates. We identified with an instrument based on prevalence rates, the NECPAL tool that, 1 in 3 patients with chronic diseases could die in the next year and had palliative care needs in Buenos Aires City.

Aim: To explore population assisted in the hospital, identifying patients with advanced cancer and palliative care needs in an early, comprehensive and continuous approach.

Method: It is a prospective study using the NECPAL tool as an indicative, not dichotomous, quali-quantitative multifactorial evaluation to be completed by the treating physician. All cancer patients assisted in the hospital during 2 years were included. It consists of 4 non-consecutive steps: 1) Identification and establishment of quality standards; 2) Baseline description; 3) patient identification and program Implementation; 4) quality evaluation.

Results: n 317, 66% female, median 77 years. Breast cancer 33.4%, GI 18.6%, lung cancer 10.7%. 71.3% patients with advanced chronic disease criteria and 57.7% with palliative needs (NECPAL +). 93% follow by Palliative Care team. Monitoring average 7.4 months. 135 deaths (73.7% NECPAL +). Survival: 32.2% died in the first month, 50% in the 4th month and 70% in the first year. Recommendations were written: 1 – NECPAL Program: early palliative care approach model for cancer patients integrating primary care 2 – Procedures for identification and assistance of cancer patients with palliative needs.

Conclusion: We have designed an innovative program, feasible, easy and cheap as a model for early and integrative palliative care approach for cancer patients in our country. We received the financial support from the National Cancer institute for research.
Antibiotic Use in Hospice Patients

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This study proposes to describe the prevalence and timing of antibiotic use in our hospice patients and the quality of MR documentation.

We reviewed the charts of all hospice patients that died within a one year period and had oral antibiotics prescribed in the last 30 days of life. We also determined if MR was documented on these patients. Descriptive statistics were used to describe the number of patients prescribed antibiotics, had documented MR after being prescribed antibiotics, and had antibiotics discontinued prior to death. An independent samples t-test was used to determine whether patients that had an active prescription for antibiotics at the time of death had a higher final Palliative Performance Scale (PPS) score than those not on antibiotics.

There were 824 patients who enrolled and died with hospice services during 2015. 135 unique patients were prescribed antibiotics during this period. At time of death, 64 (47.4%) patients had an MR documentation of continued antibiotic use. An additional 52 (38.5%) patients had antibiotics discontinued, but did not have an MR performed. Only 19 (14.1%) patients did not have antibiotic use addressed prior to death. The mean PPS score for patients prescribed antibiotics at the time of death was 23.9 compared to 16.6 for patients without (p=.002).

Our current project illustrated that antibiotics are frequently prescribed in the last days of life. In 116 cases (88.9%) hospice physicians and RN case managers appeared to be aware of their continued use. While all patients should have documentation of the rationale for prescribing antibiotics; for patients whose death is considered imminent such documentation must also relate to symptom control and quality of life. Our comparison of mean PPS scores suggests that providers may be appropriately considering a patient’s condition when deciding whether to continue antibiotics. Further studies regarding antibiotic use in hospice are needed.
Do we Recognize that our Patients Are Dying in the Palliative Care Unit and Do we Communicate about It? An Audit about Communication of Imminently Dying with Patients, their Family, in Team Meetings and with GP’s

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Background: In 2015 184 patients died in our 12-bedded palliative care unit (PCU). If we predict a patient will die, do we communicate that with the patient, his family, GP?

Aims: Collecting data on the communication about dying in a PCU in 2015.

Methods: Patients that died on the PCU in 2015 were included. Communication in the last 3 days of life was analysed in the patient files. Excel was used for storage and analysis of the data.

Results: Of the 184 patients, 119 patients were capable to communicate (65%). Dying was discussed with 23 of them (19%). 65 Patients (35%) were incapable; 36 were unconscious (55%), 10 (15%) confused and 19 (29%) had communication problems.

In 116 patients (63%) were asked their preferred place of death.

82 Patients (71%) wanted to die in a PCU, 27 (23%) at home, 1 not at home, 2 not at the nursing home, 1 at the nursing home, 1 indifferent, 1 unclear, 1 not in the acute hospital (total 6%).

In 64% of the patients who died, communication about the dying had taken place with family (117 patients). In 74% (136 patients) it was discussed in the multidisciplinary meeting.

After death the GP’s of 67 patients (36 %) were notified by telephone call. It was not noted if GP’s were being informed about the imminently dying of their patients.

Conclusion: The remainder of our patients are still capable of having discussions in the last 3 days of their life, but we do it only in 19% of cases. Communicating with family remains difficult (not in 36% of the cases). GP’s are not informed before and not often enough after death (36%). Of the 45% patients admitted in our ward we know that they wanted to die in our PCU.

With these results we will try to improve the multidisciplinary decision-making in labelling a patient as dying and this should prompt us to discuss this with the patient, his family and GP.
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Abstract type: Poster Exhibition

Care after Death

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Aim: To evaluate current hospice practice for care after death compared to national guidance published in 2008, in particular that bodies should be cooled within 4 hours of death.

Method: The care after death for all inpatients who died in a defined 6 week period was reviewed. The data was collected prospectively using a proforma. Times were noted for patient’s death, verification and notification of death as well as cooling after death. Since there was no onsite facility for cooling at the hospice, time collected by funeral directors was taken as the body cooling. The second 6 week survey of the audit incorporated an option of a different method for cooling (see below).

Results: There were 22 deaths within the first 6 week period. Median time to body being cooled was 6 hours 36 minutes – with only 27% (n=6) being cooled within the recommended 4 hour time period.

By way of intervention to ensure compliance with national guidance, the hospice purchased FlexMort™ cooling systems – a blanket attached to a mobile cooling device which is laid over the body and which starts the cooling process as soon as it is used.

In the second survey, time to cooling was redefined to include time when the FlexMort™ was applied. There were 20 deaths within that 6 week period. Of the 20 deaths, only 14 had data recorded regarding time to cooling. Of those 14 patients, 36% (n=5) were cooled within 4 hours of dying.

Conclusion: This result shows minor improvement from the first audit but sadly data accuracy was poor in the second survey and the numbers are too small to be significant. The timing of the second survey a few weeks after introduction of the FlexMort may have been affected by lack of clarity with new process; a further survey is underway.

The key lesson to share is to highlight the need to cool bodies within 4 hours after death and that devices are available that negate the need to have a mortuary or have rapid access from funeral directors.
The Monitoring and Management of Diabetes at the End of Life

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Background: Diabetes UK published national guidelines in 2013 for the monitoring and management of diabetes at the end of life. Comprising mostly diabetologists’ professional opinions, uptake of the recommendations within palliative medicine is anecdotally variable. Nevertheless, this guideline provides direction in the absence of evidence and considers patient’s priorities approaching end of life.

Aims: To investigate whether this guideline is used and adhered to regionally within palliative medicine.

To provide palliative medicine expert opinion which complements this guideline in order to aid its adoption within the specialty.

Methods: Two regional audits were carried out on the monitoring and management of patients with diabetes in the last hours to days of life. One collated professional opinion amongst palliative care professionals, the other was a six-month retrospective audit of practice.

Results: 37 mixed professionals from hospital, hospice and community responded to the professional opinion survey. 30% were not aware of national guidelines. 92% agreed with the use of insulin for symptomatic hyperglycaemia, but if asymptomatic 70% would not treat. All respondents would treat symptomatic hypoglycaemia, but only 50% if asymptomatic. Capillary blood glucose monitoring was the preferred method (70%) and discontinuation of routine monitoring was more common in type 2 diabetes.

83 case notes were audited. 17% had multiple episodes of hyperglycaemia, mostly treated with insulin. 44% of asymptomatic hypoglycaemia was untreated. 58% of cases did not have documentation about how their glucose should be monitored, and 10 patients had an advance care plan which made reference to their diabetes management.

Conclusions: There is practice variability regarding diabetes monitoring and management at the end of life. Further work should be done to educate and standardise practice in this clinical context, in line with shared expert opinions between the 2 specialties.
Analysis of the Activity of a Palliative Care Support Team during 2014

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The objective of this paper is to analyze on a high level how Don Benito-Villanueva Palliative Care Team (PCT) works, to study what are the main features of their patients, and to assess their performance by investigating the scope of such services, determining the mean time that patients with life-limiting illnesses is under treatment, and by identifying those disciplines/services within the Extremadura Health Care that require the PCT monitoring more often. In order to achieve the above mentioned objectives, a sample of two hundred and ninety (290) medical histories from patients with life-limiting illness was exhaustively reviewed and all the relevant parameters therein were arranged on an array. Subsequently, both a descriptive statistics analysis and a linear regression analysis were conducted. The results show that the greatest percentage of the patients are elder, that PCT provides treatment to 100% of its population and that the PCT action decreases the hospital stay, therefore improving the costs associated with it. Additionally, the results suggest that most of the patients, helped by PCT in the sample are transferred by oncology and internal medicine, that these teams pay attention not only to the symptoms evaluation, but also to the intensity of such symptoms, that opioid drugs most used by PCT are morphine and fentanyl, and that women, in the rural areas where this paper is developed, are still ranking the first position with regards to taking care of the studied patients. The quality of the care provided by PCT was revised by mean of the proposed key performance indicators from the Extremadura Regional Palliative Care Program, to detect which the strengths and weaknesses in the services provided by Don Benito-Villanueva Hospital PCT are, highlighting areas of potential optimization where the efforts could be allocated to continuously improve the quality of the provided services.
**Abstract number:** P01-057
**Abstract type:** Poster Exhibition

# Evaluation of Satisfaction of Primary Caregivers Regarding a Hospital Palliative Care Service


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**Background:** The assessment of the satisfaction of main caregivers and patients regarding in a hospital service can identify the deficient areas to develop strategies for improvement, since the patient’s needs determine the health care.

**Aim:** Determine the degree of satisfaction of the main caregivers of patients in palliative care on the care and attention received.

**Material and method:** Observational and descriptive study. The sample was taken from the primary caregivers of patients admitted to palliative care unit of a public hospital in Extremadura, from 01/02/2014 to 31/03/2014.

It was used opinion survey on the quality of hospital care (SERVQHOS), developed in Spain, in order to have a tool in the hospital sector, which allowed meet the perceived quality was used.

Data from the study have been validated and coded to be subsequently analyzed by statistical package SPSS19.

**Results:** Sample: 25 caregivers of palliative patients. 92% said he was satisfied or very satisfied. 8% dissatisfied. All results are in Tables 1 and 2.

**Conclusions:** The evaluated unit achieved a very positive assessment by caregivers in the period evaluated, but it would be necessary to continue studying data from all palliative care units of Extremadura, and compare them with previous studies. These data serve to identify areas for improvement and developing new strategies in caring for patients and their families.

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<tr>
<th>OVERALL LEVEL OF SATISFACTION WITH HEALTH CARE RECEIVED BY THE TEAM: DISSATISFIED:</th>
<th>8%</th>
<th>SATISFIED:</th>
<th>36%</th>
<th>VERY SATISFIED:</th>
<th>56%</th>
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<tr>
<td>WOULD YOU RECOMMEND THE PALLIATIVE CARE SERVICE OTHERS? HAVE DOUBTS:</td>
<td>16%</td>
<td>WITHOUT HESITATION:</td>
<td>84%</td>
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<td>HAVEN’T HAD TESTS OR PROCEDURES WITHOUT ASKING YOUR PERMISSION?</td>
<td>100%</td>
<td>NO</td>
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<td>TIME FOUND IN THE HOSPITAL LESS THAN EXPECTED:</td>
<td>24%</td>
<td>AS GOOD AS EXPECTED:</td>
<td>68%</td>
<td>MORE THAN EXPECTED:</td>
<td>8%</td>
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<td>DO YOU KNOW THE NAME OF PALLIATIVE CARE USUAL DOCTOR? YES:</td>
<td>100%</td>
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<td>DO YOU KNOW THE NAME OF PALLIATIVE CARE USUAL NURSE? NO: 28% YES: 72%</td>
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<td>HAVEN’T RECEIVED ENOUGH INFORMATION ABOUT THEIR CONDITION OR ILLNESS? NO: 28% YES: 72%</td>
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**Table 1. QUESTIONNAIRE SERVQHOS (1st part)**


1: Much worse than expected, 2: Worse than expected 3: As expected 4: Better than expected 5: Much better than expected.

**Table 2. QUESTIONNAIRE SERVQHOS (2nd part)**
Few End-of-Life Discussions with Patients in Hospital Wards

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Background: Communication about approaching death is important in end-of-life care. Hospitals are the second most common place of death in Sweden and during last month in life many patients are moved between different wards. Documentation about end-of-life conversations in medical records is therefore important and this quality indicator is monitored by the Swedish Register of Palliative Care (SRPC), a national quality register for end-of-life care.

Aims: To assess whether registered data about end-of-life communication reported to the SRPC matched the documentation in medical records at a university hospital.

Methods: Medical records from all deceased patients during a six-month period were examined at an internal medicine ward with a profile towards palliative care (A), and an acute medical ward (B). Data on end-of-life conversations between physician and patient, and between physician and next of kin were extracted and compared with data from each corresponding registration in the SRPC.

Results: Sixty-seven medical records (42 women, mean age 81 years, 18 patients with cancer) were examined. Communication about approaching death had been performed with the patient in 27% of the cases, and with next of kin in 78%. The corresponding figures from the SRPC were 16% and 69%, respectively. Congruence between medical records and data from the SRPC were shown in 40% of the cases regarding communication between physician and patient and in 69% of the cases regarding communication with next of kin. There were marked differences between the two wards, with a higher proportion of performed end-of-life conversations at unit A.

Conclusion: This study shows a lack of congruence between documentation of end-of-life communication with patients in medical records and register data in the SRPC. A minority of the patients received information about imminent death. Differences between the two units can probably be attributed to differences in care orientation.
Abstract number: P01-059  
Abstract type: Poster Exhibition

**Using Family’s Responses from a Questionnaire to Improve Clinical Practice in a Hospice**

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To evaluate and develop clinical practice at a hospice in Northern Sweden we continuously solicit information from families about their experiences and suggestions for improving the quality of care at the hospice. To collect this information, we have, based on literature reviews, created a questionnaire consisting of 21 statements addressing families’ experiences of the quality of care provided to the decedent and themselves by the hospice. In the questionnaire Families Experiences of Hospice Care (FEHC), the family members are asked to respond to the statements on an ordinal scale ranging from 1 (strongly disagree) to 5 (strongly agree). At the end of the questionnaire there are open-ended questions making it possible for the family to express their experiences in own words.

During year 2015, the questionnaire was, for the sixth time, administered to 50 family members, of these 37 responded, five did not and eight chose not to participate.

The result showed that a clear majority was very satisfied with all aspects of care covered by the 21 statements. A small number had opinions regarding improvements. Our conclusion is that the questionnaire is a very helpful tool when evaluating families’ experiences of care at a hospice. It facilitates the identification of areas in need of improvement and is an important help in our ongoing development of the good end-of-life care.

At the EAPC-conference in Madrid, we will offer an English-language version of the questionnaire to interested parties.

The study’s main source of funding has been The Foundation for Hospice care, Umeå, Sweden.
Audit in Action: Improved Medicines Management in an Inpatient Hospice Setting

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Introduction: A system of storing medicines in locked drawers in individual patient rooms was introduced to support timely administration of medications in a hospice setting. This represents a departure from the well documented practice of nurses dispensing from a central drug trolley. An initial audit was conducted to assess the contents and suitability of the medicines in the drawers and to identify possible risk issues. This audit identified a number of medicines management issues. To address these recommendations were made and implemented.

Aim: The aim of this study was to re-audit the contents and suitability of the medicines in the locked drawers on two occasions and to re-assess for potential risk issues within the current system.

Design and methods: A medicine drawer assessment form was designed. An audit of patient medicine drawers was conducted in February 2016. Re-audit was conducted in July 2016 and October 2016. The medicines in the drawer were assessed against the inpatient prescription chart.

Results: In February, a total of 33 drawers were assessed. At each re-audit 33% of the ward was assessed (4 drawers on each re-audit).

The findings were as follows:

- Drawer Contents (Feb, July, Oct)
  - % Medicines discontinued on prescription chart: 6%, 6%, 0%
  - % Medicines not prescribed on prescription chart: 3%, 0%, 0%
  - Regular Medicines (Feb, July, Oct)
  - % Present in drawer: 96%, 91%, 92.5%
  - % Patient’s Own Drugs in use: 3%, 3%, 3%
  - % Medicines unsuitable for use: 4%, 0%, 0%

Conclusion: On re-audit both the percentage of ‘medicines not prescribed on the prescription chart’ and of ‘medicines unsuitable for use’ fell to zero, indicating improved medicines management. Additionally, the re-audit did not identify any new risks associated with the current system.

It is recommended that clear procedures and documentation are developed to support this system with consideration of a second checking system and regular drawer checks.
**Abstract number:** P01-062  
**Abstract type:** Poster Exhibition  

**An Audit into Anticipatory Care Planning with Nursing Home Residents in South Manchester**

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**Background:** End of Life Care Strategy 2008 has highlighted the importance of advanced care planning (ACP) in promoting autonomy for end-of-life decisions by discussing about individuals’ preference and wishes regarding types of care that may be beneficial in the future.

**Objectives:** To evaluate the quality of advanced care planning in the nursing home patients.

**Targets:**  
- Assessment of resident’s capacity 95%  
- Family involvement 95%  
- Readmission plan 95%  
- Resuscitation discussion decisions 95%

**Methods:** This is a retrospective audit. We reviewed all our patients’ case notes in January 2016 and audited their advanced care plan between 1 January 2015 and 31 December 2015. We collected the data and processed it using Microsoft Excel.

**Results:** There were 229 residents included in this audit. 56.3% of them were female.

**Primary diagnosis:** Many residents had multiple diagnoses and interplay between these long term conditions. For the interest of this audit we focused on their primary diagnoses.

**Annual review of ACP:** 179 of 229 (78.2%) residents had an up-to-date advanced care plan.

**Documentation of advanced care plan:**  
- Assessment of resident’s capacity 67.1%  
- Family involvement 88.27%  
- Readmission plan 96.65%  
- Resuscitation discussion decisions 97.77%

**Conclusion:** Priority of ACP should be given to new residents who are at risk of rapid deterioration and recurrent hospital admissions. In order to ensure the quality of ACP, capacity assessment of patients should be performed and documented clearly. ACP proforma should be implemented to improve the quality of ACP.
A UK Service Evaluation Investigating the frequency at which Doses and Drugs Administered by CSCIs Are Changed; Investigating the Feasibility of 48-hour Continuous Subcutaneous Infusions

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Background: Continuous subcutaneous infusions (CSCIs) are an effective method of multiple drug administration in end-of-life care when the oral route is compromised. At present, currently available chemical and microbiological stability data limits the infusion time of a CSCI to a maximum of 24 hours.

The ability to deliver prescribed medication by a continuous subcutaneous infusion (CSCI) over 48 hours may have numerous benefits in both patient care and health service resource utilisation.

Aim: To gather broader data regarding both the most frequently prescribed CSCI drug combinations and the frequency at which CSCI prescriptions are altered.

Design: Hospital pharmacists or members of palliative care teams at 10 Acute NHS Trusts in the United Kingdom recorded the drug combination(s), doses, final volume, diluent and compatibility for CSCIs containing two or more drugs on a daily basis for a minimum of 2 days, to a maximum of 7 days.

Setting/participants: Anonymised CSCI prescription data were collected from an average of 50 patients at 10 Acute NHS Trusts in the United Kingdom.

Results and conclusion: Data collection is due for completion January 2017 and results will be presented.
End-of-Life Chemotherapy in an Acute-care Hospital in Spain

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Background: At the end of life, non-beneficial treatments should be avoided, being the goal of management symptom control over aggressive onco-specific treatments. Even so, terminally ill patients (P) are often over-treated with chemotherapy (CT), which can lead to an increased toxicity, hospitalization and decreased quality of life.

Methods: Describe management of terminally ill P in an acute-care hospital in Spain.

All solid cancer P who were in oncology tracking and died at our institution between January 2015 and June 2016 were included. Sex, type of cancer, age at death and date of last administration of CT were compiled from the electronic medical records.

Results: Among the 91 deceased cancer P (67% men), 37 (40%) didn’t receive CT at any time of the illness, being the major causes: functional status (FS) or comorbidity (35.1%), unexpected decease (27%), P rejection of treatment (13.5%), contraindication (10.8%) and others (13.6%). Median age was 73.1 years.

54 P were treated with CT, with a median age of 61 years and a CT median time administration before death of 87.8 days. P were treated in the previous 90 days, 60 days, 30 days and 15 days before death by 64.8%, 55.5 %, 40.7%, 22.2% and 7.4% respectively. Median age in the different groups was 62.1, 60.7, 59.5, 59.9 and 54 years respectively.

In the 15 days group, 7 P were receiving first line CT (58.3%) and 5 (41.7%) third line. 9 P (75%) were known by the palliative care team, 4 of them (44%) 15 days or less before death. FS was referred in 4 P (1 ECOG-2 and 3 ECOG-3), suggested in 5 P and not mentioned in 3 P.

Conclusion: A significant number of P were still treated within a month before death.

CT is not initiated in an important group of P due to their characteristics.

FS seems to be an important agent to decide whether to start a treatment. However it is not an item often revaluated in the course of illness, which may lead to prolong onco-specific treatments beyond the symptom control objectives.
Quality of Palliative Care Team (PCT) Assessed by Multiprofessional Hospital Staff

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Background: Palliative care is delivered by an interconsultant team at a Filantropic hospital with 466 beds since 2008. The team (PCT) consists of three doctors, one nurse and a psychologist.

Objective: To assess the quality of palliative care assistance in the opinion of the staff of the inpatient wards.

Method: The satisfaction survey was conducted through a questionnaire “Likert” scale and one open question, asking for suggestions. Data collection was done in February 2016, included staff of the inpatient units, intensive care, oncology, and pediatric ward, by convenience sample. Professionals were invited to respond the questionnaires voluntarily. Once filled, the formularies were sealed and placed in a locked urn anonymously.

Results: It was obtained 109 completed forms. 89% of respondents do not have formal training in palliative care; 70% responded that the PCT is “very helpful” in symptom management, 79% classified PCT “very helpful” in supporting families, 99% in end-of-life care. 90% of all respondents consider that the PCT “helps” to mediate conflicts, and 85% believe that the performance of the decreases the stress of the staff. It was pointed out by 58% of employees late referrals of patients to PCT. 32% pointed the need for better communication between PCT and the nursing staff.

Conclusions: From these results we concluded that the assistance provided by the palliative care team is satisfactory in the opinion of the hospital staff. And it is necessary to improve communication with nursing staff.
Abstract number: P01-066
Abstract withdrawn
At a Loss: An Audit of Bereavement Care in Palliative Care Services Shows Limited Training for Palliative Care Professionals

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Background: Grief is a normal emotional response associated with loss. For some, grief can be associated with significant anxiety and depression. Early identification of individuals who may develop complicated grief is important. The National Institute of Clinical Excellence (NICE) recommends 3 Components of bereavement care:

(1) universal,
(2) selective and
(3) indicative.

Most specialist palliative care services have some provision for Component 1 care.

Aims: To investigate levels of bereavement support provided as well as bereavement training offered within each service.

Methods: A survey was completed by bereavement or clinical leads in palliative care services within a regional palliative care network in North West England.

Results: 68 of 79 services responded. The regional audit highlighted a lack of training and supervision for those expected to provide Component 1 care. Of all services evaluated, 82% offered specific bereavement training to volunteers and 85% offered this training to specialist palliative care professionals involved in the bereavement service. In contrast only 19% offered specific bereavement training to other specialist palliative care clinical staff. 54% of all services offered annual training to their bereavement service volunteers and professionals. However, only 34% of services offered their specialist palliative care clinical staff training in bereavement within 3 years.

Conclusion: Specialist palliative care clinical staff are often ideally placed to initiate and provide Component 1 care. Whilst bereavement care services volunteers and professionals receive good training and support, other specialist palliative care clinical staff do not receive the same level of training. Services should focus on supporting more people to have knowledge of bereavement basics and Component 1 care.
**Abstract number:** P01-068  
**Abstract type:** Poster Exhibition

### Is Scotland Ready to Create its Own Day of the Dead?

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**Background and aims:** This work aimed to test whether, in Scotland, a national community-based festival of storytelling and remembrance is a culturally acceptable way of building individual and community resilience in dealing with loss. Social and personal support mechanisms are important in helping people to cope with bereavement, yet religious and/or community-based support networks are non-existent for many. People want to support others through bereavement, but often struggle to know how. Rituals of remembrance can build solidarity, yet many traditions relating to the expression of loss have faded. Improving experiences of bereavement is part of a public health approach to palliative care.

**Design, methods and approach taken:** A clear approach to developing the festival was established, drawing on authors’ previous work, relevant literature, and experiences of bereaved people and bereavement specialists. To Absent Friends, a people’s festival of storytelling and remembrance (TAF) was planned for 1–7 November 2014 and 2015. Carefully designed resources including website, film, leaflet and participation ideas were produced to encourage participation. These were promoted via the professional and personal networks of the authors and the media. Quantitative and qualitative data for evaluation of TAF 2015 was gathered via online survey of participants; structured questionnaire to event organisers; web and social media metrics; direct observation.

**Results:** In 2015 over 5000 people participated, from a broad variety of organisations and demographics. 1.75 million were exposed to the festival via the media. 98% of survey respondents reported taking part was a positive experience. Qualitative responses indicate that participation was of deep significance for many.

**Conclusion and lessons learned:** The festival is an acceptable approach and enthusiasm exists in Scotland to create a time of year when remembering dead loved ones is socially accepted and supported within mainstream culture.
Losing a Parent to Cancer as a Teenager – Reported Quality of Relationship with Siblings and Parents at Different Times in Life

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Background: Family cohesion seems to be of importance for children and teenagers’ wellbeing after losing a parent. Previous results showed that cancer-bereaved youth are at higher risk of reporting poor family cohesion after the loss of a parent when compared to their non-bereaved peers. That does however not give an insight into their relationship with individual members of the family.

Aim: To explore the reported quality of relationship with siblings and parents, during childhood, teenage years and in early adulthood in youths who lost a parent to cancer, compared to their non-bereaved peers.

Method: This nationwide population-based survey included 622 (participation rate: 73%) cancer-bereaved youths aged 19–26, who during teenage six to nine years earlier lost a parent to cancer as well as 330 (78%) non-bereaved peers. Associations were assessed using log-binomial regression.

Results: No statistically significant difference was found between the cancer-bereaved and non-bereaved youths in the reported quality of relationship with siblings. However, the bereaved youths were more likely to report a poor (no/little) relationship with their surviving mother, RR: 2.9 (1.9–4.6) or surviving father, RR: 1.6 (1.2–2.2) during teenage years as well as at the time of the survey. In both groups poor relationship with fathers was reported more often than with the mothers at all periods under investigation.

Conclusion: In cancer-bereaved youth, we could not document that the loss of a parent during teenage had an impact on the quality of sibling relationship when compared to their non-bereaved peers. We did however document an impaired relationship with the surviving parent both during teenage years and six to nine years later.
Perception of Loss and Grief in School Children

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Background: The way that children understand death and dying could be conditioned by their context. Parents, teachers and health professionals do not have enough resources to approach this question. In 1995 Tamm and Granqvist identified three categories, through drawings of children after asking them what the word death meant for them. Nevertheless, no previous research in Spain has been conducted to test the suitability of these categories.

Aims: The purpose of this study was to explore possible differences in children’s perceptions of death through their drawings and interviews.

Methods: A qualitative study was carried out. 99 children aged 9, 10 and 11 years drew a picture reflecting the meaning of the word death before being interviewed by the researcher. Drawings and interviews were analyzed and classified considering Tamm and Granqvist’s categories – Biological, Psychological and Metaphysical death.

Results: The three main categories were identified, but differences were found regarding the subcategories. Qualitative analysis showed the appearance of new aspects such as Well dying, that were included in subcategories map because of their prevalence in children’s depiction. Likewise, other subcategories where deleted or included in the previous ones. Younger children depicted more biological references that older, who expressed more psychological and metaphysical references. It seems that children prefer use feeling, imagery or religious references in older ages and violence or funerals and graveyards when they are younger.

Conclusion: The categories of Tamm and Granqvist seem useful to understand the concept of death in children, although new subcategories were identified in the current research. Knowledge of children’s perception of death could be a great tool to make school-integrated programs about death education that offer ways of understand bereavement without taboo and adapted for different ages.
The background for this pilot study was a request from relatives who wanted to have a memory of the voices of their loved ones to help them during their bereavement.

The aim was to explore the meaning of oral narratives in palliative care – both for relatives in the bereavement process, and for dying patients telling their stories.

This qualitative study was carried out at a Danish hospice from May 2015 to June 2016. 14 patients agreed to participate in the study and filled in a statement of consent.

Volunteers were trained in interviewing, recording and editing narratives. Patients approved the edited file of their narrative and were afterwards interviewed by a member of the project group. Relatives were contacted by phone 1–3 months after the death of the patient and interviewed about their experience with the recording. The study was supported financially by the Danish foundation TrygFonden.

We found that the bereaved were moved by the voice of their loved ones: “...I have pictures of her and that’s fine. But the voice. That gives a completely different dimension. Another kind of presence”. “There was something changed in her voice...She was so dignified...” “...The tone of her voice. She is cheerful and it’s very positive.”

Some of the patients doubted whether they were clever enough to formulate a narrative or had anything interesting to say. The volunteer helped them in this respect: “...she helped me believe that I was doing a good job”.

Data analysis will be completed in January 2017. Results already indicate that a recorded narrative can be meaningful for the bereaved, and that the recording process can help provide a sense of coherence and quality of life for patients.

This pilot study indicates the potential value of further studies and we assume the results would be of interest to other hospices, nursing homes, home carers, non-governmental organizations and health professionals working with terminally ill patients and their relatives.
Experience of a Bereavement Unit in Pediatric Palliative Care

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**Background and aim:** The loss of a child is a devastating experience for parents; it creates a wound of pain very difficult to heal. The main task is to be able to re-live having repositioned emotionally the loss itself. The hospital Bereavement Unit (BU) was created to accompany these parents in the process of elaboration of grief. The aim of this study is review the work done in a period of time and be aware of the most common topics treated during sessions in order to identify the needs of bereaved parents.

**Methods:** Descriptive, observational and retrospective study on the experience of BU attending parents of patients followed in the Pediatric Palliative Care Unit (PPCU) from September 2015 to May 2016.

**Results:** The BU has attended 37 people since its inception. The percentage of women was 59%. There have been 19 first-time visits (individual or in pairs), 25 follow-up visits, of which 92% have been with a partner and 8% individually. There are 2 groups of parents: cancer and non-cancer cause of children death. The topics more frequently treated in both groups are the relationship with other people, back to work, what to do with the objects of the child, the projects that are not carried out, guiltiness, sibling’s experience, the process of end-of-life and the difficulty for new attachments, among others.

**Conclusions:** The loss of a child is a risk factor to present a complicated grief in the future. The satisfaction that parents convey, the assistance to the groups and the link established among parents reinforces the necessity of being able to offer resources such as this to be able to accompany parents who lose a child. It seems that the cause of son death does not determine the topics. The opening of the unit is required, not only to the patients seen on PPCU, but the rest of the hospital and outside its doors. It would be appropriate for future research using of a tool that can assess, through indicators, the favorable development or not of parents within the groups of accompaniment.
Diversity and Intensity of Grief: A Primary Global French Study

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Background Aims: Each year, grief affects in France the relatives (family, friends, colleagues, etc.) of almost 600,000 deceased persons. The psychological effects of bereavement have been well studied and are now well known. However, the other effects (physical, family, social, economical, etc.) have never been studied as a whole, in their diversity and their interactions. For the very first time in France and in Europe, a global study has been conducted. It has been conducted by the CREDOC, a public entity specialized in such studies, and analyzed by a group of independent scientists and experts (sociologist, philosopher, psychologist, economist, etc.)

Method: Quantitative study (more than 3000 adult people) completed by a qualitative study (about 30 semi structured interviews). Most of the information collected is declarative and subjective.

Results and discussions: 1. The number of people who declare to be or have been bereaved is much more important than commonly admitted. 2. Certain topics have a decisive impact on bereavement: conditions and quality of end of life, cause and place of death, funeral and burial, post-funeral care, etc. 3. The effects of grief are complex and wide (in form, intensity, duration…) : illnesses, depressions, family problems, social isolation, suffering at work, etc. 4. Resources are many but more often private than public and not coordinated.

Conclusions and perspectives: The study demonstrates that bereavement is neither an accident nor a pathology. Prior to all, bereavement is depicted as a common social event that should receive specific social consideration and care.

This study also point out the lack of consideration for bereaved people from public services despite all the collective consequences.

This primary study should encourage others.

Note: Study financed by the CSNAF, a French syndicate of funeral manufacturers who didn’t interact in the scientific process nor in the conclusions.
Coping with Impending Death of Cancer Patients. The Opinions of Internal Medicine Residents

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Background: The practice of oncology terminal care includes withholding and withdrawing of care, when appropriate and the goals of care shift from curation to comfort and palliation. There are several difficulties and a diversity of opinions when dealing with the impending deaths of cancer patients. We decided to survey the attitudes and opinions of internal medicine residents in relation to the impending deaths of a Greek Anticancer Hospital.

Aims: Our aim is to show that the impending death of cancer patients affects the internal medicine residents during the provided quality of care and they experience grief when caring for patients at the End-of-Life (EoL).

Methods: A survey conducted through a Likert-scale questionnaire, divided into five composite measures of EoL skills at an oncology unit of a general anticancer hospital in Greece between the internal medicine residents of the department.

Results: Coping with the impending death of cancer patients can lead to feelings of failure of the internal medicine resident and a desire to distance oneself from patients to avoid personal harm. Research in this area of oncology and the way residents cope with the care of the terminally ill or dying patients, is not extensive. Yet, it has a great impact on the everyday life of the physician.

Conclusion: Dealing with the death of cancer patients is an emotionally difficult experience for doctors, particularly doctors-in-training, and can deeply affect their overall outlook on life and their practice of medicine. Communication skills can be taught and should be an important component of education within the field of oncology. There is a need for further training in skills around End-of-Life care. As this is a self-assessment survey, the specific measures of attitudes and opinions in impending death are limited, indicating a need for further research.

Keywords: Impending death, dying, grief, cancer patient death, physician grief
Abstract number: P01-076
Abstract type: Poster Exhibition

**Retrospective Analysis of the Timeliness of Completion of Paperwork and Communication to General Practice (GP) Following Death**

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**Aims:**
Primary aim: Assess compliance with national standards for completion of death certificates within 1 working day.
Secondary aim: Evaluate speed and form of communication of death to GP.

**Background:** It is understood that effective and prompt communication to GPs facilitates provision of bereavement support to relatives after a death. Delayed paperwork delays funeral arrangements and causes unnecessary distress to those bereaved. There is very little research on how timing of paperwork and communication to the GP impacts on bereavement. This audit forms the initial work to address these issues in greater depth.

**Methods:** Retrospective review of clinical notes in an acute cancer hospital between 1/12/15 and 31/3/16.

**Results:** 87 patients died during the audit period. Death certificates were completed within 1 working day for 91.9% (79/86) patients. 1 patient was referred for post mortem so was excluded here. GPs were informed of death via discharge summaries or telephone conversations. Overall it was documented that 78% (68/87) GPs were informed of the patient’s death. Summaries were completed within 1 working day of death for 60.9% (53/87), 2 or more working days for 17.2% (15/87). For 21.8% (19/87), the summary was not completed. 20% (17/87) deaths were communicated by phone.

**Conclusion:** Overall, death certification was completed in a timely fashion. Discharge summaries were completed promptly for most, but 21.8% were never completed. The discrepancy in communication with GPs highlights the need for interventions to ensure information is communicated promptly and effectively to facilitate ongoing bereavement support. This could be achieved with dedicated proformas, guidelines for staff, teaching sessions and the development of a standardised protocol for timely report to GP.
Bereavement over the Life Course

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**Background:** Bereavement has been defined as a normal adaptive reaction to the loss of a loved one and also as a stressful life event of the first magnitude that, sooner or later all humans have to face (Landa y García, 2005).

**Aim:** To review the most relevant literature in recent years, regarding the different types of loss and the variations in the bereavement process according to the stages of life: childhood, adolescence, adulthood and old age.

**Method:** Three types of search (initial, systematic and manual) were carried out in different databases (DISSERTATION ABSTRACTS, PROQUEST CENTRAL, PsycINFO, MEDLINE, PUBMED) with two inclusion criteria (last 10 years, items directly related to the object of study).

**Results:**

**CHILDHOOD/LOSS OF PARENT:**
Early childhood: perception of abandonment.
3–6 years: belief that the lost parent is “asleep”.
12 years: full understanding of “death”.

**ADOLESCENCE:**
**Loss of childhood**
Depersonalization: cessation of being the center of attention for parents, requirement of adult behavior, loss of childhood’s body and self-image.

**Loss of parent**
Early adolescence: crying as main response to loss.
+14 years: school failure, aggression, isolation.

**ADULTHOOD:**
**Loss of a child**
Affectation of communication in the couple, discussions indirectly related with the child’s death.

**Separation or divorce**
Fantasies about reconciliation, guilt, doubt, difficulties in trusting new relationships.

**OLD AGE/ LOSS OF ABILITY AND PARTNERS:**
Both types of loss entail dependence, reduction of social relationships and loneliness.

**Conclusion:** Given the wide range of reactions that can take place according to the life stage, the support in the bereavement process should be differentiated.


**Keywords:** Grief, lost, mourning on: childhood, adolescence, adulthood, old age.
Abstract number: P01-078
Abstract withdrawn
Abstract number: P01-079
Abstract type: Poster Exhibition

Characteristics of Derivatives Family Complicated Grief

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Background: Studies reports that only 10–20% of bereaved people have significant problems in the process of adaptation

AIMS: Describe the characteristics of the relatives referred to the Palliative Care Unit for psychotherapeutic intervention.

Method: Descriptive and prospective study. Relatives derivatives Palliative Care Units 49%; Primary care 36% and 15% other services. Complicated grief was assessed with complicated grief Inventory (ICG), DSM-IV and clinical judgment. It applies chi-square test (Pearson or Fisher) and t-Student. Data were analyzed using SPSS 9.

Results: 187 relatives of deceased cancer patients, 81% women are included. The mean age is 59 (SD = 15) years. 76% widowers. 71% had no psychiatric or psychological (78%) history, women more than men go to a psychiatrist p < 0.05

Significant differences between men and women p < 0.05 in depression (BDI) mean19 (SD = 8), complicated grief (ICG) mean 42 (SD = 11), general health (GHQ-28) in somatic symptoms (p = 0.006), depressive symptoms (p = 0.016) and overall general health (p = 0.008)

No significant > 0.05 differences in hopelessness (BHS) mean 10 (SD = 5), anxiety (BAI) mean19 (SD = 10), coping strategies (COPE), stress (ESEE) mean1228 (SD = 463 ) and social support (DUKE-UNK) mean40 (SD = 11).

Conclusions: Family members have a high stress level in the last 2 years. Women come with higher mean values in depression, somatic symptoms, general health and men in complicated grief Coping strategies most commonly used are seeking social support, religion, focus on emotions and let off steam (especially in women).
Abstract number: P01-080  
Abstract type: Poster Exhibition

**The Role of the Hospice of the Livorno Hospital in the Corneas Procurement**

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The cornea of an oncologic patient could be donated without any risk of neoplastic transmission, because the cornea doesn’t contain blood vessels, as the literature data confirm. The Hospice, where the 90% of the patient die of metastatic cancer, represents the adequate ward to promote the corneas donation.

At the beginning the general suitability of the donor and of the quality corneas tissue is evaluated. Next step is the preliminary screening of the absolute contraindications and the informative meeting with the family to obtain the signature on the memo about the matters of tissue donation. The tissue removal is allowed also in the presence of original in life statement of the donor. Right post mortem saline solution is administered sterile in the conjunctival sac and the eyes are closed. By the 4th hour of the death, the corpse is transferred to the morgue with all the official papers regarding the death and the donation consent. By the 5th hour of the death the cadaver has to be made available to the morgue personnel to withdrawal blood samples to the virological determinations. At the end the personnel will proceed with the corneal withdrawal.

In the donor procurement is important to inform the family about the possibility of donation from their beloved despite the neoplastic disease. It is also important to add the complete liberty of this choice. The patient can also take the decision when he/her can still choose independently and he/she is fully aware of his/her terminal condition.

Our data confirm the high activity of the Hospice: for the 2015 the 73% of the corneas collected at the Livorno Hospital came from the Hospice.

The Hospice is the ward in which the support relationship is taken very seriously and the informative meeting about the donation is integrated in this welfare path; the donation gesture represent a positive element at the end of a painful time for the family of the donor, and a component of hope in the course of the grief process.
Abstract number: P01-081
Abstract type: Poster Exhibition

Development of a Bereavement Information Pack for Families/Carers of Patients Looked after by a Hospice Home Care Team

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Aims of the work: To develop bereavement care in a Hospice Home Care setting.

Approach taken: Review of the bereavement literature highlighted the fact that there was a gap in the level of bereavement support provided by the local Hospice Home Care Team. An information pack was developed in response, based on the Public Health approach to bereavement. The ‘Public Health’ model addresses what bereaved people need i.e information about ‘normal grief’ and coping – this is evident in the information leaflet. By adding contact numbers of support agencies and national resources on information, it meets the needs of practical help as outlined in the model. The inclusion of a Citizens Advice Booklet in the pack addresses the aim of minimising additional stressors i.e. financial hardship and isolation (Keegan 2013). This bereavement pack fits the needs of people in line with the National Institute of Clinical Excellence (NICE) (2004). It is consistent with the standards developed by Health, Information and Quality Authority (HIQA) (2014), that bereavement support should be based on individual need.

Results: The information leaflet was piloted over a two week period. Six information leaflets were given to bereaved families/carers. Initial informal feedback on the leaflet content was positive. Respondents liked the bereavement support received from the Hospice Home Care team and did not have significant suggestions for improvement in the service. However, evaluation of the anonymised evaluation forms is ongoing and changes to the contents and presentation of the pack are being considered.

Conclusions: The bereavement information pack is now part of the bereavement policy of the Hospice Home Care team, so it is sustainable. By issuing the pack and getting feedback on it, nurses now have evidence of how the Hospice Home Care team gives bereavement support to families/carers of its patients. A follow up study could determine the extent to which bereavement support has improved for carers.
Bereavement Attention in Palliative Care (PC): Spain and Other European Countries

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Background: Palliative care includes attention to bereavement. Public health models support are recommended.

Aims: Compare bereavement attention to services in CP in Spain (SP) with other countries in Europe (EU) regarding public health models and framework NICE.

Method: Descriptive study. A survey was used to describe current support. Online questionnaire based on previous research comprises 54 questions divided into 6 sections: background information, activities, personnel, access, community links and funding. It was sent to 56 national associations in 32 countries. Comparisons between Spain and other European Countries are made using Fisher’s exact test or the test of Chi-Square. Statistical program SAS 9.3 (SAS Institute, Cary, NC USA).

Result: 56 (15%) answers from PC in Spain versus 314 (85%) EU answers. 41% (73%) offers a bereavement service in Spain versus 261 (83%) in the other countries p=0.092.Bereavement care in PC is carried out by different professionals p<0.05: Nurse EU 55% SP 27%; Psychologist EU 49% SP 65%; Social Worker EU 38% SP 22%; Spiritual Guide EU 38% SP 20%; Coordinator EU 24% SP 5%;CP Voluntary EU 20% SP 11%; Bereavement Volunteer EU22% SP2%. p>0.05: Doctor EU40% SP 33%; Mental health EU 6%SP 0%.The needs are managed in a multidisciplinary team in the EU and SP, p>0.05. Spain 61% were aware of the guidelines of services in their country.

Conclusions: More psychologists & fewer volunteers are involved in bereavement care in SP.
**Palliative Treatment of Dyspnea by Terminal Ill Patients with Transdermal Applied Buprenorphine: A Pilot Trial**

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**Background:** Dyspnea is a distressing symptom of many terminal ill patients that has to be treated. Opioid use against dyspnea is off-label-use and there is still great restraint for use, despite recent guideline recommendations.

**Aim:** We wanted to know, if our patients would benefit from transdermal (TD) applied buprenorphine (BUP) to reduce their basal dyspnea.

**Design:** We included all terminal ill patients with refractory dyspnea at our university hospital treated by the Center for Palliative Care, all of them were opioid naive. We used numeric analog scales (NAS) for dyspnea, the Medical-Research Council-dyspnea-scale (MRC) and following parameters: SpO\(_2\), breathing frequency (BF) and pulse frequency before and two days (48h to 72h) after starting the therapy with low dose TD BUP (up to 5\(\mu\)g/h). Treatment effectiveness and patient satisfaction were also enquired.

**Results:** Until now we could interview 15 patients (100% had MRC-Score 5). The basal dyspnea-level measured on a NAS decreased significantly (p< 0.05) from 6.45 to 3.91 (-2.5 points), the severity of breathlessness attacks (maximum dyspnea) went down as well. The mean BF could be reduced from 26.9/min to 19.6/min (-7.3/min) to a nearly physiological range. There was no decrease of the average SpO\(_2\) under treatment. The majority of our patients felt (rather) helped (72.8%), did not have any side effects (81.8%) and were satisfied (81.9%).

<table>
<thead>
<tr>
<th></th>
<th>mean</th>
<th>p</th>
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<tbody>
<tr>
<td>basal dyspnea</td>
<td>-2.545</td>
<td>.000</td>
</tr>
<tr>
<td>maximum dyspnea</td>
<td>-1.273</td>
<td>.031</td>
</tr>
<tr>
<td>breathing frequency</td>
<td>-7.273</td>
<td>.000</td>
</tr>
<tr>
<td>SpO(_2)</td>
<td>1.545</td>
<td>.075</td>
</tr>
</tbody>
</table>

**Conclusions:** Transdermal buprenorphine seems to be a safe and effective option to treat refractory basal dyspnea. Further investigations with higher number of patients are needed to confirm our preliminary results.
Considerations for Nurses in a Hospice for Unique Application of Respiratory Therapy in the Terminally Ill Oncological Patient with Dyspnea

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Background: For all health care professionals in palliative terminal care, dyspnea is one of the most difficult symptoms to treat. Given the high incidence and impact of dyspnea in oncology patients in the palliative terminal phase, early and appropriate intervention through breathing therapy by a multidisciplinary team is of great importance. Next to the pharmacological treatment it is important to know what the points of attention are for nurses who provide 24 hours of care in a hospice, in order facilitate the physiotherapist in performing respiratory therapy as good as possible.

Design and method: This is a qualitative explorative study in the form of individual interviews and focus groups with nurses, trained in palliative care and working in a hospice for more than five years. The participants are divided into six one to one interviews and two focus groups of six persons each. Both the interviews and the focus groups are fully transcribed. A topic list for the focus groups has been used based on the interviews.

Results: In total, fourteen nurses participated. The specific education, targeted advice and instructions, optimal cooperation, better reporting, time and good accessibility, were the things that the nurses indicated to facilitate the administration of breathing therapy by the physical therapist. The concerns of the participants were specifically in the area of targeted advice and instructions, good reporting, optimal accessibility and time for multidisciplinary cooperation. Further elaboration of these concerns is recommended by practical training and education programmes.

Discussion and conclusion: Nurses do have a role in respiratory therapy in therapy in the terminally ill oncological patient with dyspnea if they are well instructed by the physiotherapist. Good reporting is necessary for both nurses and physiotherapists. More research is recommended in measuring the impact of the achievements with regard to the attention points for the nurses.
Dyspnea in Patients Admitted for Heart Failure and Respiratory Disease

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Background: Dyspnea is a disabling symptom of heart failure (HF) and respiratory diseases (RD). Dyspnea quantification is essential to guide treatment, but specific rating scales are underused in the hospital setting, and the data regarding its impact on quality of life are scarce.

Aims: The objectives of this study are to estimate the degree of dyspnea at hospital admission, the maximum during hospitalization, and at discharge. Health-related quality of life and pain quantification were also assessed.

Methods: This is a registry in the hospital setting, aimed at patients admitted for HF and RD (chronic obstructive pulmonary disease/lung fibrosis). Dyspnea and pain were assessed using the verbal 0–10 numerical scale. Quality of life was determined by EuroQoL 5d.

Results: From April to September 2016 a total of 258 patients (157 men [60.6%]) were included. Mean age was 74.0±1.2 years, 190 had HF and 68 RD. Mean dyspnea at hospital admission by numerical scale was 7.5±0.2 points (7.3±0.2 in HF vs. 8.1±0.2 in RD, p=0.01). Dyspnea at hospital discharge was 2.4±0.2 points (2.0±0.2 in HF vs. 3.3±0.3 in RD, p=0.0005). Pain was more severe in HF patients at admission (4.1±0.3 vs. 2.8±0.5 in RD, p=0.01), but similar at discharge (1.4±0.2 vs. 1.1±0.3, respectively). Scores in five dimensions of EuroQoL 5d are summarized in Table 1.

At discharge 59 patients (23.1%) still presented severe dyspnea (≥5 points in numerical scale).

Conclusion: Patients admitted for HF and RD present a heavy degree of dyspnea at hospital admission that improves during hospitalization but remains severe in almost a quarter of cases. Pain is perceived less intense than dyspnea. Compared with RD, HF patients presented less dyspnea but worse quality of life.

<table>
<thead>
<tr>
<th></th>
<th>Total N=258</th>
<th>Heart Failure N=190</th>
<th>Respiratory Medicine N=68</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>146 (56.8)</td>
<td>118 (62.1)</td>
<td>28 (41.8)</td>
<td>0.004</td>
</tr>
<tr>
<td>Self-care</td>
<td>96 (37.4)</td>
<td>73 (38.4)</td>
<td>23 (34.3)</td>
<td>0.55</td>
</tr>
<tr>
<td>Usual activities</td>
<td>160 (62.3)</td>
<td>119 (62.6)</td>
<td>41 (61.2)</td>
<td>0.88</td>
</tr>
<tr>
<td>Pain/discomfort</td>
<td>105 (40.1)</td>
<td>82 (43.2)</td>
<td>23 (34.3)</td>
<td>0.25</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>114 (44.4)</td>
<td>86 (45.3)</td>
<td>28 (41.8)</td>
<td>0.62</td>
</tr>
<tr>
<td>Visual Analogic Scale</td>
<td>59.9±1.3</td>
<td>57.9±1.6</td>
<td>65.6±1.0</td>
<td>0.006</td>
</tr>
<tr>
<td>EuroQoL Index</td>
<td>0.64±0.1</td>
<td>0.6±0.1</td>
<td>0.7±0.1</td>
<td>0.02</td>
</tr>
</tbody>
</table>

[Impairments in quality of life by EuroQoL 5d.]
Changes in Communication Capacity of Terminally-Ill Cancer Patients with Refractory Dyspnea: A Multicenter Prospective Observation Study

Mori M.1, Morita T.1, Matsuda Y.2, Yamada H.3, Kaneishi K.4, Matsumoto Y.5, Matsuo N.6, Odagiri T.7, Aruga E.8, Kuchiba A.9, Yamaguchi T.10, Iwase S.11, J-FIND Study Group

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Background: Maintaining communication capacity is among the essential components of a good death. Parenteral morphine is widely used for refractory dyspnea of cancer patients very close to death, but little is known about how long and which patients maintain their communication capacity.

Aims: To clarify periods of maintained communication capacity and identify factors predicting shorter periods in terminally-ill cancer patients receiving parenteral morphine.

Methods: This was a multicenter prospective observational study. Inclusion criteria were metastatic/localy advanced cancer, ECOG performance status 3–4, a dyspnea intensity ≥2 on a Support Team Assessment Schedule, and receiving specialized palliative care. The primary endpoint was the period of maintained communication capacity measured using the Communication Capacity Scale after morphine administration. Patients were evaluated every 6 hours over 48 hours. Univariate/multivariate analyses were conducted to identify factors predicting shorter periods of maintained communication capacity (i.e., ≤48 hours).

Results: Of 167 patients, 70 (42%; 95% confidence interval (CI), 35–50%) lost their communication capacity at ≤48 hours, while 58% did not. In multivariate analysis, factors significantly correlated with shorter periods were ECOG performance status 4 (odds ratio (OR), 4.0; 95%CI, 1.4–11.4; p=0.0084); Palliative Prognostic score >11 (OR, 6.4; 95%CI, 1.2–33.5; p=0.029); SpO2 < 93% (OR, 2.3; 95%CI, 1.0–5.2; p=0.045), the absence of chronic obstructive pulmonary disease (OR, 0.27; 95%CI, 0.09–0.81; p=0.019), and the absence of respiratory infections (OR, 0.40; 0.19–0.98; p=0.028).

Conclusion: Recognition of the cumulative inability to communicate and its predictors may enable clinicians to help patients and families to say goodbye in their last days.
Feeling Drained = Feeling Better!
Audit of Hospice Pleural Aspiration

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**Background:** Hospice pleural aspiration has been undertaken for the last 25 years, following training by local chest physician. When the requirement for ultrasound (US) guided aspiration was introduced, a US machine was purchased and staff training undertaken. The British Thoracic Society issued guidance for pleural drainage in 2003 & standards were adapted for use in respect of pleural aspiration in hospice.

**Method:** Retrospective review of all pleural aspirations undertaken over a 3 year period drawn from electronic clinical record. Documentation of the procedure was audited against 20 standards identified.

**Results:** 36 procedures identified. 14 of 20 standards were 100% met; 2 met in 97% & 2 in 94%. Although pleural aspiration was always undertaken with a standard pleural aspiration kit with a small bore needle and 3 way tap, the documentation did not specifically say so. The consent form (1 missing) did not contain the list of common complications, which were outlined on the leaflet about the procedure given to each patient. The procedure sometimes took place out of hours where symptom control demanded it. Post procedure - analgesia was not always prescribed, as it was often done as a day case and patients brought their own & observations were not recorded as per protocol in the two failed procedures.

**Conclusions:** The template for procedure documentation has been adjusted to incorporate items which were not present; consent form & information leaflet rewritten to include same list of common complications; analgesia now routinely prescribed & offered, & use of patient’s own is documented; procedure adjusted to ensure that post procedure observations completed even when procedure failed; anticoagulant administration & blood results documentation improved; standard rewritten to ensure that out of hours procedures should continue to take place when required for symptom management, but undertaken by most experienced clinician.
The Prevalence and Management of Breathlessness at End of Life in Children with Cancer

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Background: Breathlessness is a common yet poorly managed symptom in children and young people (CYP) at end of life (EOL). It is a complex symptom that can be highly distressing. A range of pharmacological and non-pharmacological interventions are recommended, however this guidance is driven from research in adults with almost no studies in CYP. The aim of this study is to review the prevalence and treatment of breathlessness in CYP with cancer.

Method: A retrospective case note review was undertaken of patients under 18 years old who died between 2010–2015 whilst under the care of a specialist palliative care team in the UK. Patients who experienced breathlessness in the last two weeks of life were included.

Results: A total of 172 patients died within the inclusion period of which 39 (22.7%) experienced breathlessness at EOL. This included 23 boys and 16 girls with a mean age of 9.8 years (SD= 4.8, range 2–17). Breathlessness was most prevalent in patients with solid tumours (n=23, 59%) followed by liquid (n=11, 28.2%) then central nervous system (CNS) (n=5, 12.8%). Non-pharmacological interventions were rarely documented although positioning (n=7, 17.9%), fans (n=3, 7.7%), reassurance (n=2, 5.1%) and non-invasive ventilation (n=1, 2.6%) were reported. The most common pharmacological interventions were oxygen (n=28, 71.8%) and opioids (n=24, 61.5%). Less common medicines included nebulisers/inhalers (n=5, 12.8%) and dexamethasone (n=2, 5.1%). Midazolam was used to manage anxiety associated with breathlessness in 24 (61.5%) CYP.

Conclusion: Many CYP experience breathlessness at EOL and this is not limited to those with lung metastases as liquid and CNS cancers made up 41% of breathless patients. A range of interventions were used although oxygen and opioids were most frequently documented. Breathlessness is highly associated with anxiety and often requires medication to manage effectively. Prospective studies are recommended to assess treatment effectiveness.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>n</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Oxygen</td>
<td>28</td>
<td>71.8</td>
</tr>
<tr>
<td>Opioids</td>
<td>24</td>
<td>61.5</td>
</tr>
<tr>
<td>Nebulisers/inhalers</td>
<td>5</td>
<td>12.8</td>
</tr>
<tr>
<td>Fan</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>Dexamethasone</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Reassurance</td>
<td>2</td>
<td>5.1</td>
</tr>
<tr>
<td>Non-invasive ventilation</td>
<td>1</td>
<td>2.6</td>
</tr>
</tbody>
</table>

[Table 1]
Abstract number: P01-090
Abstract type: Poster Exhibition

Evaluation of Duration of Washout Period Following Fan Therapy for Breathlessness: a Methodological Pilot Study

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Background: Breathlessness is a common symptom in advanced cancer patients. There is emerging evidence that facial fans can reduce the sensation of breathlessness. Randomized crossover trials have shown some clinical benefits, but there is no empirical data to determine the optimal wash-out period.

Aims: To clarify the length of time for breathlessness to return to baseline after using a fan to the face.

Methods: This was a methodological pilot study and took place in a Palliative Care Unit of Japan. Data were collected from September 2015 to March 2016. Nine patients with advanced cancer were recruited; they had breathlessness at rest and rated its severity as at least 3 on a 0–10-point numerical rating scale. All participants received three types of interventions accordingly: no fan, fan-to-legs, and fan-to-face. Each participant used a fan for 5 minutes, and scored their breathlessness at 10-minute intervals for 60 minutes or until the score had returned to its baseline value, whichever was sooner.

Results: All patients completed the study. Of the 9 participants, 6 experienced benefit from using a fan to their faces. Breathlessness scores of only 2 of the participants (2/6) had returned to baseline by the end of the 60-minute assessment period after the exposure of fan-to-face therapy. In fan-to-legs and no fan settings, there was no change in scores.

Conclusions: This methodological pilot study provides important new information on the design of clinical trials of fan therapy on breathlessness relief. If using a crossover design to investigate the effect of fans on breathlessness, 1 hour is an insufficient wash-out period.

This study was funded by the Yasuda Medical Foundation.
Abstract number: P01-091
Abstract type: Poster Exhibition

Defining, Refining and Streamlining Heart Failure Treatment in Hospice Patients

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Introduction: The literature is replete with studies documenting the benefit of palliative care in end stage heart failure patients. Symptom management, in these cases, is a collaboration between the cardiologist and the palliative care clinician. This case highlights care of these patients once hospice enrolled, when the hospice clinician is solely responsible for optimizing cardiac performance while incorporating a comfort medication regimen.

Case description: PT is a 91 year old male diagnosed with Ischemic Cardiomyopathy and Biventricular Heart Failure. He enrolled in hospice services 09/05/2016 upon discharge from a local tertiary care hospital where he had been admitted four times in the past two months to treat dyspnea and anasarca. PT was transferred directly to an inpatient hospice facility believing this was his immediate end of life.

On admission to the hospice house PT exhibited dyspnea with conversation, and peripheral edema extending up to his thighs. He required continuous nasal cannula oxygen, 4 liters/minute; he was not hypotensive. In addition to PRN opioids and benzodiazepines to treat dyspnea and anxiety, a low dose anti-congestive medication regimen was initiated consisting only of oral daily Demadex, twice daily Coreg, and daily oral Digoxin. Administration of each medication was guided by vital sign parameters. Adding afterload reduction with an ACE/ARB medication was a daily consideration, but his blood pressure never permitted this next step.

On this simple medication regimen, PT (to his surprise) improved. His New York Heart Classification fell from IV to III, and his pedal edema dropped from 4+ to 2+. He was discharged home to the care of his son on 09/16/2016.

Conclusion: Applying a physiology-based approach to prescribing anti-congestive medications, while establishing a foundation of opioid and benzodiazepine dosing to remedy breathlessness and anxiety, best optimizes hospice patient’s symptom relief from end stage heart disease.
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Abstract type: Poster Exhibition

Prognostic Factors in Patients with Malignant Pleural Effusion: A Retrospective Study

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Background: Malignant Pleural Effusion (MPE) causes debilitating breathlessness in cancer patients which is often difficult to control using non-invasive procedures. Indwelling pleural catheters relieve symptoms, but remains an invasive intervention. However, predicting survival in patients with MPE is challenging, and whether to insert a pleural catheter or not remains a decision that should be taken after discussing risks and benefits with patient and family.

Aim: Identify prognostic indicators that help determine the overall survival in patients with advanced malignancy and malignant pleural effusion and to compare it with LENT prognostic system (Pleural fluid Lactate dehydrogenase, Eastern Cooperative Oncology Group (ECOG) performance score (PS), neutrophil-to-lymphocyte ratio and tumour type).

Methods: We conducted a retrospective study of 222 patients who had advanced cancer (stage 3 or 4) and pleural effusion treated by indwelling pleural catheters between January 2013 and December 2015 at King Hussein Cancer Center. Prognostic indicators such as cancer type, history of smoking, radiation exposure, comorbidities, and laboratory data, including albumin, calcium, white cell count and differential in serum and pleural fluids.

Results: Initial results showed that most common cancers with malignant pleural effusions are breast cancer (37.6%) and lung cancer (13.9%). In all cases, no major life threatening complications. 16.1% of catheters were removed due to other complications (infection or malfunction) LENT score was calculated in all patients. Patients with higher LENT scores found to have a decrease in survival rates.

Conclusions: To study prognostic indicators and correlate results with LENT prognostic system. Another prospective study will be enrolled in the near future to evaluate the role of indwelling pleural catheters in symptoms control and improve quality of life.
Intermittent Palliative Sedation for Decreasing Dyspnea, Anxiety and Extreme Tiredness in the Last Weeks of Life

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**Background:** Palliative sedation (PS) can be continuous (C) or intermittent (I). Guidelines indications for PS are refractory symptoms (RS) but the type of sedation has not been specified. With IPS, patients are sedated temporarily and then awakened after a predetermined time to assess if RS have improved.

**Aim:** Presentation of a case of IPS and discussion of its indications.

**Case presentation:** A 65-year-old man with pancreatic neoplasia with hepatic, pulmonary and bone metastasis was referred to our hospital. He had uncontrolled pain (8/10) with neuropathic component and iv morphine and paracetamol were given for pain control as well as gabapentin, ketamine, amitriptyline, dexamethasone and column RT. During hospitalization refractory (10/10) dysnea, intercostal retraction, tiredness and anxiety occurred. TC revealed bilateral pulmonary thromboembolism, intra alveolar hemorrhage, bilateral pneumonia and pulmonary metastasis.

The patient had intolerable suffering but wanted to stay with his wife the maximum time possible. An IPS limited to nighttime was proposed. IV haloperidol 5mg and midazolam 5mg were given to induce unconsciousness and then 0.1 mg/kg/h midazolam as a continuous infusion. Symptoms reduced to 6/10 upon awakening and less fatigue when talking, but there was a progressive worsening, so IPS was done 3 h during morning and afternoon. The patient died peacefully three weeks later.

**Discussion and conclusion:** Symptoms were controlled to tolerable stages by IPS, allowing contact with family till end of life, contributing to quality of life. IPS safety and reversibility of consciousness is considered. Literature regarding IPS is limited to few articles with incidental pain, dysnea, agitation, and general malaise as indications. IPS may stop vicious cycle of physical and psychological distress in terminal cancer patients. Patients in the dying stage who have refractory symptoms and want to preserve their awareness might be appropriate candidates for IPS.
Increased Carbon Monoxide as Possible Cause for Fatigue and Dyspnea in Cancer Patients – A Case Report

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Background: Moderate carbon monoxide poisoning in an area of 2–10% is known to cause symptoms like dyspnea and fatigue. In cancer cells, Heme Oxygenase-1 activity can be increased. Products of HO-1 are biliverdin and carbon monoxide. We report a cancer patient with increased carbon monoxide and bilirubin associated with dyspnea.

Case report: A 48 year old women with metastasized breast cancer was admitted to our palliative care unit with an infection and treated with antibiotics. She never smoked and was not exposed to carbon monoxide else. Despite good treatment response she still had profound dyspnea in activity and fatigue. Investigations included oxygen saturation, thorax x-ray, ultrasound, and blood samples including arterial blood gas. X-ray showed moderate atelectasis. Lung ultrasound showed pleural effusions < 500ml, but excluded alveolar interstitial syndrome, higher grade lung embolism or heart failure. Oxygen saturation levels were between 91 and 97. Arterial blood gas showed mildly decreased pO2 (8,05), but surprisingly a COHb of 4,8. In the following days two more venous blood gas showed 6,1% and 4,9%. In addition the patient had increased bilirubin despite normal liver imaging studies and normal liver enzymes. The patient was treated with blood transfusions and oxygen with positive effect on the symptoms.

Discussion: Increased carbon monoxide in palliative care patients as cause for dyspnea has not been presented before. The activity of Heme oxygenase I can be increased in several tumour lines which can lead to increased carbon monoxide and biliverdin/bilirubin. CO binds hemoglobin with high affinity, impairing delivery of oxygen to tissues. CO also binds to myoglobin, and mitochondrial cytochrome oxidase, impairing adenosine triphosphatase production. All these mechanisms can contribute to dyspnea and fatigue. Carbon monoxide levels in blood samples should be considered in differential diagnosis of dyspnea and fatigue in cancer patients.
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Cancer Patients Receiving Specialized Palliative Care: What is the Effect? A Systematic Review

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Background: Due to multiple of symptoms of physical, psychological, existential and social nature, patients with advanced cancer often have reduced quality of life (QoL), which need interventions with specialized palliative care (SPC). However an overview of the effect of SPC is needed.

Aims: To make an overview of the existing knowledge about SPC and its effect on QoL, physical and psychological symptoms, and survival among adult patients with cancer.

Methods: This systematic review used a search strategy based on PICO framework and words related to cancer, QoL, symptoms, mood, and palliation. The search was performed in Embase, PubMed and Cochrane until October 2016. The selected studies were analyzed according to methods, results, quality of evidence, and strength of recommendation.

Results: The number of abstracts retrieved was 1115, out of which six studies were selected for analysis; all of them were randomized controlled trials (RCTs). One study was found by hand search, and data was only published as an abstract. The RCTs differed in terms of aims, interventions, control groups and outcomes. Common to all was the primary aim to investigate the effect of SPC on QoL. Four studies found an improvement in QoL in the intervention group. Physical symptom intensity decreased in two studies, and two studies found an increase in mood beneficial for the intervention group; however, physical and psychological symptoms were secondary outcomes in these studies. Two studies found an improvement in survival. All the studies presented generalizability, but the level of evidence varied between studies.

Conclusion and discussion: Due to several methodological limitations, the evidence of the studies ranged from low to high. The effect of SPC is varying between the studies. It can be discussed whether the negative/neutral findings in some of the studies are due to the selection of patients, the intervention programs, the analytic strategy or to biases.
A National ‘One Day Survey’ of Patients Requiring Palliative Care in French Comprehensive Cancer Centers

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Background: Screening patients requiring follow-up by a palliative cares team (PCT) is a challenge. The French society for palliative care proposes ten questions (PALLIA-10 scale) addressing medical, psycho-social and ethical issues. Referral to a PCT is recommended if score>3/10.

Methods: PALLIA-10 was assessed through a national 1-day survey carried out in 18 French cancer centers in 2015. Survival data and palliative follow-up were updated 6 months later. Main objective was to determine the prevalence of patients with a score>3. Secondary objectives were to determine the prevalence of patients with a score>5, the mean score for patients already followed by a PCT, predictive factors for follow-up by a PCT and prognostic factors of overall survival.

Results: 840 patients were included (64y [18–92]; 53.3% women). Main tumors were digestive (18.2%) and breast (15.8%). 687 (81.8%) were in palliative setting. Among them, 479 (69.7%) had a PALLIA-10>3 and 230 (33.5%) >5. 216 (31.4%) were already followed-up by a PCT, including 186 (38.8%) with a score>3 and 110 (47.8%) with a score>5. Main reasons for palliative management were symptoms (74.5%), psychological (40.3%) and referrals support (35.6%). Six months later, 9.2% of curative patients and 65.9% of palliative ones were dead. Among these patients, 76.0% with a score>3 and 82.6% with score>5 were dead. 152 (32.3%) had a new palliative management initiated. Even after adjustments, PALLIA-10 score with a threshold of 3 is a predictive factor for management by a PCT (OR: 3.6; 95% CI 2.0–6.2) and a prognostic factor for death at 6 months (HR=1.726; 95%CI [1.332–2.237]).

Conclusion: PALLIA-10 is a good screening tool for palliative care needs. To date, as allocated resources for PCT are limited, a threshold of 3 is too sensitive. A threshold of 5 could allow medical staff to identify rapidly in-patients who need palliative care, while developing early palliative care for ambulatory patients.

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Autonomy and Information: Do Patients with Advanced Cancer Receive What They Want?

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Background: About two-thirds of all Dutch patients who die of cancer remain at home at the end of life. In the Netherlands, the GP and home care nurses are key professionals in palliative care.

Aim: To give insight into (a) which specific aspects of autonomy and information patients with advanced cancer find most important, and (b) whether the care they receive matches with these important aspects.

Methods: 86 GPs completed a written questionnaire about the care delivered to a total of 96 home-dwelling patients with advanced cancer. In addition, 74 of those 96 patients (most with advanced breast, lung or colon cancer) completed a questionnaire. Furthermore, 26 home care nurses involved in the care for these patients completed a questionnaire.

Results: The table shows the proportion of patients reporting specific aspects of autonomy and information as (not) important and as (not) received.

Conclusions: Almost all patients with advanced cancer indicated that they found all aspects of autonomy and information important. However, substantial proportions reported that they did not receive adequate information about risks and benefits and/or about the expected course of the disease. These aspects of respecting autonomy and providing information concern priorities for improvement of care by GPs and home care nurses.

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<table>
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<th>(Not) important and (not) received</th>
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<th>Important, not received</th>
<th>Not important</th>
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<tr>
<td>Being involved in decisions about care</td>
<td>97%</td>
<td>3%</td>
<td>0%</td>
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<tr>
<td>Receiving consistent information</td>
<td>94%</td>
<td>6%</td>
<td>0%</td>
</tr>
<tr>
<td>Professionals taking personal preferences in account</td>
<td>94%</td>
<td>4,5%</td>
<td>1,5%</td>
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<td>Being assigned a contact person</td>
<td>89%</td>
<td>9%</td>
<td>1,5%</td>
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<tr>
<td>Professionals explaining things in a way one can understand</td>
<td>91%</td>
<td>4,5%</td>
<td>4,5%</td>
</tr>
<tr>
<td>Being told about benefits and risks of treatment</td>
<td>80,5%</td>
<td>11,5%</td>
<td>8%</td>
</tr>
<tr>
<td>Reciving information about expected disease course</td>
<td>71%</td>
<td>20%</td>
<td>9%</td>
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Living Well with Advanced Cancer

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Background: Palliative Care is about living as well as possible, until the end of a person’s life. However, little is known about the process of living well with advanced cancer. A grounded theory that explains the process of living well with chronic disease has been developed, but it is unclear whether the theory is applicable to advanced disease.

Aims: The aims were twofold: to better understand the experience of living well with advanced cancer, and to advance theorizing about living well.

Methods: Secondary analysis of 22 in-depth interviews from a phenomenological study exploring the lived experience of patients having advanced cancer was conducted using constant comparison. The theory about living well with chronic illness was used as a tentative analytic framework, with the aim of theory development.

Results: The 5 phases of the theory of living well with chronic illness proved to be a useful beginning explanation for living well with advanced illness, but required the addition of new aspects related to awareness of dying and limited time that shaped the whole process. The process entailed five phases that were re-visited over time as things changed. 1. Struggle or fight against the illness and prognosis; 2. Accepting; 3. Living with advanced disease rather than against it, which meant learning how to ‘do life’ alongside illness; 4. Sharing the experience, which included choices about how to involve family and setting boundaries to diminish loved ones’ suffering; 5. Reconstructing life, which involved putting living in the foreground and illness/dying in the background.

Conclusion and discussion: The theory of living well with advanced illness elaborates and advances the theory focused on chronic illness, accounting for the influence of awareness of dying and limited time. The theory offers a detailed explanation of the process of living well in the context of palliative care and gives direction for interventions that maximizes quality of life and wellbeing.
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Abstract type: Poster Exhibition

Feasibility of Early Integration of Palliative Home Care into Oncological Treatment

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Background: Recent studies show that early integration of palliative care (PC) into the oncological treatment has beneficial effects on the patient’s quality of life and survival time. These studies were developed for oncology settings in different countries and for PC provided in a hospital setting. There is a need for research on early integration of PC in the home setting. For that reason, this study aims to develop an intervention for the early integration of palliative home care (PHC) into oncological treatment.

Methods: We constructed a phase 0–1 study according to the Medical Research Council (MRC) Framework. Phase 0 consisted of a literature review of existing integration models to identify key factors. In phase 1, we developed an intervention model for the early integration of PHC based on the results of phase 0. Because of the specificity of the existing models, we wanted to know to which extent the key factors were applicable to the Belgian care system. Therefore, we conducted six focus groups with PHC teams.

Results: Phase 0 resulted in the identification of five key factors: 1) palliative care needs instead of prognosis as a trigger for the early introduction of PHC, 2) general practitioner as coordinator, 3) regular visits by the PHC team, 4) systematic needs assessment, and 5) a communication tool to facilitate interdisciplinary communication.

Analyses of the focus groups show consensus on these factors, but it is unclear which patient groups should be included in the trial and which type of communication tool is appropriate.

Conclusion: Following the steps of the MRC Framework, we conducted an intervention model and discussed it with PHC teams in focus groups. Consensus is reached on the key factors, but further research is needed to concretize some of them. These findings are helpful to design a model applicable to the Belgian care system, which will be tested in phase 2 of the Framework.
Comprehending Patients’ Experiences of the Wish to Hasten Death: A Systematic Review and Meta-ethnography

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Background: In the context of advanced or life-threatening illness patients may express a wish to hasten death (WTHD). This WTHD is often understood as a request for euthanasia/assisted suicide. However, many studies highlight the verbalisation of a WTHD can express meanings that do not necessarily imply an authentic desire to die. In 2010 a systematic review and synthesis of qualitative studies was carried out. However, 7 new studies have since been carried out in countries with different legal and cultural frameworks. Updating knowledge about the WTHD and analysing these different contexts is necessary in order to deepen our understanding of the complex nature of the WTHD.

Aims: To conduct a systematic review and meta-ethnography of primary qualitative studies of patients with life-threatening illnesses’ experiences of the WTHD.

Methods: The search strategy used MeSH terms with free-text searches in Pubmed, Web of science, CINAHL and PsychInfo databases. Fourteen studies were included in the review giving a total sample of 155 participants. The studies were evaluated using the CASP guidelines. The qualitative synthesis followed the methodology described by Noblit and Hare. The meta-ethnography update followed the procedure suggested by France (adding to and revising the original).

Results: Five themes emerged from the analysis: suffering, which was an overarching theme across the other four; reasons for the WTHD; meanings attributed to the WTHD; functions of the WTHD and experience of timeline towards dying and death.

Conclusion and discussion: The WTHD therefore seems like a reactive phenomenon inseparable from physical, psycho-emotional, social or existential suffering, which impacted on the sense of self, dignity and meaning in life. The suffering was inseparable from expressions of the WTHD, without it, said WTHD cannot be understood. Knowing the factors behind the WTHD is necessary for care plans and interventions fit for patients’ needs.
Cancer Patients Dying in Hospitals Risk Poor End-of-Life Care Quality – A Population-based Study from the Swedish Register of Palliative Care

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Background: One quarter of all cancer deaths in Sweden takes place in a hospital.

Aims: To investigate if hospital cancer deaths are comparable to cancer deaths outside hospitals with respect to EOL care quality in Sweden.

Methods: Population-based, retrospective study of expected adult cancer deaths in 2011–2013 (N=41,729), based on the Swedish Register of Palliative Care covering >85% of all cancer deaths. Quality indicators were chosen to include aspects of autonomy, information, support, and the assessment and treatment of EOL symptoms in the last week of life. Hospital deaths (HDs) were compared to deaths occurring in specialized or general palliative care (PCDs) or nursing homes (NHD). Odds ratios (OR) with 95% confidence intervals were calculated using logistic regression, with specialized home PC as reference.

Results: For 63% of HDs the patient’s preferred place of death was unknown compared to 2 % of PCDs (p< 0.001). Compared to other places of death, HDs were less likely preceded by information from the physician to patients (OR 0.3; 0.28–0.33, p< 0.001) or families (OR 0.51; 0.46–0.57, p< 0.001). Pain (OR 0.32; 0.30–0.34; p< 0.001) or other symptoms (OR 0.31; 0.28–0.34, p< 0.001) were less likely to be systematically assessed for HDs. Prescriptions of injectable drugs as needed against anxiety (OR 0.27; 0.24–0.30, p< 0.001), nausea (OR 0.19; 0.17–0.21, p< 0.001), or death rattles (OR 0.29; 0.26–0.32, p < 0.001) were less common for HDs. Nursing homes and general home PC performed better than hospitals with respect to prescriptions, though less well than specialized PC. Bereavement support was offered to families in only 57% of cases after HDs compared to 97%, 94% and 87% and 72% in specialized home PC, specialized in-patient PC units, general home PC, and nursing homes (p< 0.001).

Conclusions: Cancer patients dying in hospitals risk poor end-of-life care quality in Sweden, in particular when compared to specialized palliative care.
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Abstract type: Poster Exhibition

Determinants of 6-month Mortality in Patients with Haematological Malignancies

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Background: Among others factors, the lack of a formal definition of advanced haematological malignancy (HM) is identified as an obstacle for Palliative Care (PC) consultation.

Aims: To identify 6-month mortality risk factors in patients (pts) with HMs after admission to a haematology (HMT) ward.

Methods: Retrospective multicentre study. Pts admitted to HMT ward from 31/12/2014 and forward, diagnosed with: Aggressive Lymphomas, Hodgkin Disease, Multiple Myeloma, Indolent Lymphoma, Acute Leukaemia or High-risk Myelodysplastic Syndromes, were included. It was collected from clinical records: demographic variables, HM type, disease current status, No. Chemo-lines used, previous bone marrow transplantation, previous /current thromboembolic disease, infection, renal failure, hepatic failure, electrolyte imbalance, nutritional state and coagulation disorder. Accordingly the HM incidence in each centre, it was estimated necessary a sample size of 275 pts, assuming 6-month death prevalence of 50%, with a CI95% confidence, precision of ± 10%, and 1% repositions. The study was approved by the Ethics Committee.

Results: The multivariate analysis identified the following risk factors: pts with acute leukaemia (AL) had a OR 2.91 (CI 1.2–7.04), P=.018; HM in progression/relapse OR 5.53 (CI 2.51–12.23), P< .001; Renal failure OR 3.59 (CI 1.89–6.62), P< .001; Hepatic failure OR 3.9(CI 2.07–7.36), P< .001.

Regarding the No. of Chemo-lines used there is a tendency with the 2on line: OR 2.13, P=.268. Analyzed pts with AL, only hepatic failure was significant for 6-months mortality [OR 3.86 (9CI1.16–12.81),P=.028]

Conclusion:

a) Independently of the HM type to be in progression/relapsed at admission, had renal or hepatic failure increases between 4–5.5 folds 6-month mortality risk.

b) Patients with AL has nearly 3 times more risk to die at 6 months, especially if hepatic failure is present.

c) Prospective studies are urgently needed to confirm or refuse our findings.
The Effect of Patient’s Attachment Orientations with the Health-care Professionals and their Demographic Characteristics to their Satisfaction of Care

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Background: Patients’ satisfaction with care is a crucial aspect in palliative care related to issues such as quality of life and death. Proximity to a health-care professional may serve an attachment function.

Aim: The aim of the current study was to assess the effect of patient’s attachment orientations with the health-care professionals and their demographic characteristics to their satisfaction of care.

Method: This is a cross-sectional study consisting of 100 cancer patients. Patients’ satisfaction was assessed using the Greek version of the Patient Satisfaction scale, while attachment orientations were evaluated using the Greek version of the Close Relationships scale.

Results: Univariate analyses found statistically significant positive correlations between patients’ satisfaction with “information/interaction” metastasis (p=.009), chemotherapy (p< .0005), and hormonotherapy (p=.005). Similarly between patients’ satisfaction with “availability of care” education-p=.0016, chemotherapy-p< .0005, and hormonotherapy-p=.025). Also statistically significant correlations were found between “information/interaction” and ca duration (p< .0005), and between satisfaction of “availability of care” with discomfort with closeness (p=.035), anxiety (p=.051), and avoidance (p=.007). Multiple regression analysis revealed that patients who didn’t undergo chemotherapy (p< .001) and surgery (p=.019), and had a long illness duration were satisfied with “information/interaction” (p< .001), while the higher the discomfort with closeness the lower the satisfaction with “information/interaction” (p=.060). Also, the higher the discomfort with closeness (p=.019) and avoidance (p=.049) the lower the satisfaction with “availability of care”, while patients with higher education were more satisfied with “availability of care” (p=.047).

Conclusions: These findings may help healthcare professionals to plan appropriate interventions to optimize patients’ satisfaction with care.
Abstract number: P01-105
Abstract type: Poster Exhibition

Referral of Pancreatic Cancer Patients to Palliative Care: A National Service Evaluation

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Background: There are 475 new cases of pancreatic cancer diagnosed in Ireland each year. Pancreatic cancer carries a 5 year survival of 6.8% and is the fifth most common cause of death from invasive cancer. Research shows that early referral to palliative care alongside standard oncological treatment improves quality of life, leads to less aggressive care at end of life and can lead to prolonged survival.

Aim: To evaluate the referral pathway of pancreatic cancer patients, discussed at the two Irish dedicated pancreatic cancer multidisciplinary team (MDT) meetings, to palliative care.

Method: A chart review was conducted of all patients with adenocarcinoma of the pancreas discussed at MDT in Cork in 2012. The information gathered was then combined with an existing database of pancreatic cancer patients discussed at MDT in Dublin in 2012 to create a national database (n=128).

Results: 72 (56.25%) of the patients are recorded as having contact with palliative care services. The mean time taken between first discussion at MDT and contact with palliative care was 175.6 days. In those that died the mean time between contact with palliative care and date of death was 125.9 days.

Conclusions: This study shows that many patients discussed at MDT are not referred to palliative care services. For those patients that are referred the majority are referred a number of months after diagnosis. Literature shows that patients with pancreatic cancer could benefit in a number of ways from early referral to palliative care. A review of current referral practices is indicated.
How Do Cancer Patients in Early Palliative Care Experience a Structured Advance Care Planning Intervention? A Qualitative Study

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Background: Advance Care Planning (ACP) can improve a patient’s quality of life, lessen distress, and increase compliance with patients’ wishes. The SENS framework provides a pragmatic structure for ACP conversations focusing on Symptoms, End-of-life decisions, Network, and Support for next of kin. However, patients’ experiences as well as perceived benefits or unexpected effects of such a conversation remain unknown.

Aims: As part of a clinical trial testing the effects of the ACP conversation based on SENS, this qualitative study aimed to identify patients’ experiences with the intervention, and how the SENS domains met their needs.

Methods: Patients with advanced cancer not amenable to curative treatment (n=16) participated in one-on-one semi-structured interviews. Qualitative content analysis according to Mayring was performed on verbatim interview transcriptions.

Results: Analysis revealed that the SENS domains cover topics relevant to patients’ daily life. SENS facilitated discussion about complex and not yet raised issues such as housing situation when becoming weaker or organizing social network support. Some patients felt empowered by the intervention and were influenced in their decision to write an advanced directive or to organize support for their family. None of the topics were perceived as unnecessary, and no patient felt distressed by the intervention. Certain patients reflected critically on earlier conversations with their specialist and felt that a more sensitive communication about their illness prognosis would have fitted better to their needs.

Discussion and conclusion: Patients appeared to benefit from the structured ACP according to SENS, feeling more self-assured and knowing where to turn for support. Additional research is necessary to identify how the intervention influences the communication within the family as well as the specialist-patient conversation, and whether the SENS framework may be relevant to non-cancer patients.
Frequency and Intensity Assessment of the Wish to Hasten Death in Patients with Advanced Cancer

**Abstract number:** P01-107  
**Abstract type:** Poster Exhibition

**Frequency and Intensity Assessment of the Wish to Hasten Death in Patients with Advanced Cancer**

**Porta-Sales J.**

**Crespo I.**

**Monforte-Royo C.**

**Guerrero-Torrelles M.**

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**Background:** The wish to hasten death (WTHD) usually fluctuates over time. The Desire for Death Rating Scale (DDRS) can be used in clinical practice for the assessment of the WTHD. However, it does not evaluate the intensity and frequency (F&I) of this wish. Evaluating the F&I of the WTHD would offer the clinician a better understanding of the WTHD, providing more options to help patients (pts).

**Aims:** To describe the F&I of the WTHD reported by advanced cancer pts using a clinical tool designed for this purpose, and to examine its correlation with the DDRS.

**Methods:** A descriptive cross-sectional study was carried-out enrolling 65 advanced cancer pts, 22 from the outpatients palliative care clinic, and 43 from the oncology ward. All pts were evaluated with both the DDRS and the new tool about F&I of WTHD (FIW). Standard descriptive statistical analysis and Spearman correlation coefficient between DDRS and FIW were used.

**Results:** Using the DDRS, 8 pts (12%) reported WTHD, while using FIW, WTHD was reported by 11 pts (17%) of which, 6 stated that it was something they had only thought without progressing to any action. In contrast, 4 pts had shared their WTHD thoughts with others, and only 1 recognised suicidal ideation and planning. Six pts reported occasional thoughts of WTHD, and 3 reported daily or almost daily WTHD thoughts. The correlation between FIW and DDRS was 0.627 (P< 0.0001).

**Conclusion:**

a) Frequency of WTHD in our population is similar to that previously described but in the majority of cases it is mild and infrequent on a daily basis.

b) The FIW adds new and valuable information for clinical practice to assess the WTHD and allows us to differentiate between F&I. Moreover, FIW has a good correlation with the DDRS, supporting its use in assessing the WTHD.

**Funding:** Instituto de Salud Carlos III and the European Regional Development Fund (FEDER) project PI14/00263; AECC-Catalunya contra el Càncer – Barcelona 2014; RecerCaixa 2015.
Does Early Palliative Care Improve Quality of Life for Patients with Incurable Gastro-intestinal Cancers? A Randomized Study

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Background: There are a growing body of evidence demonstrating the benefits of palliative care (PC) and how the introduction of PC shortly after the diagnosis of a metastatic cancer increases a patient’s quality of life (QoL). An early integration of PC alongside tumor specific palliative treatment may also facilitate discussions with the patient concerning end-of-life (EOL) care preferences.

Aim: The aim is to study how early PC affects QoL in patients with incurable gastro-intestinal (G-I) cancer, as well as QoL in nearest relative. Patients’s survival, given tumour specific treatment and hospitalization are among the secondary endpoints.

Method: Patients recently diagnosed with incurable noncolorectal G-I cancer referred to a tertiary oncological clinic for first line chemotherapy (CT) together with patients with colorectal cancer receiving second line CT are invited to participate. The patients, irrespective of diagnosis, are randomized 1:1 to receive early PC integrated with oncological treatment (active arm) or oncological treatment alone. Nearest relative is followed until 1 year after patients death.

Results: The study was initiated in January 2015, with a planned inclusion of 108 patients. In August 2016, 41 patients are enrolled, with 21 patients randomised to the active arm. Median age is 73 (45–84) years. Diagnosis are: pancreatic cancer (n=31), colorectal cancer (n=4), gastric cancer (n=3) esophageal cancer (n=2) cholangiocarcinoma (n=1). 24 of the 41 patients have died, with a median of 152 (31–404) days from randomization to death.

Discussion: The study is feasible although accrual is slow. One reason can be a hesitance from informing doctors (oncologist), due to lack of time or a reluctance to discuss the trajectory of the incurable disease as commencing palliative CT. Close cooperation between oncologists and PCU is important to enable the discussion of EOL care planning with patients with a short expected survival entering palliative CT.
Abstract number: P01-109  
Abstract type: Poster Exhibition

**Proactive Assessment of Wish to Hasten Death: What Do Patients Think?**

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**Background:** The wish to hasten death (WTHD) is somewhat frequent in patients (pts) with advanced cancer. Nevertheless, the health professionals usually avoid asking about the WTHD for fear of doing harm to the pts, even in specialist palliative care settings. Therefore, pts are not often given the opportunity to discuss such feelings in advance.

**Aims:** To know the advanced cancer patients’ opinion on the proactive assessment of the WTHD.

**Methods:** A descriptive cross-sectional study was carried out enrolling 107 advanced cancer pts, 48 (45%) from the palliative outpatients clinic, 56 (52%) from the oncology ward and 3 (3%) from palliative care unit of a comprehensive cancer institute in Barcelona. All pts were assessed with an *ad hoc* clinical tool. Standard descriptive statistical analysis was done.

**Results:** The great majority of pts (97%) did not feel that talking about the WTHD was inappropriate or annoying. Moreover, 97 (91%) pts found that asking about the WTHD was quite to extremely important and necessary, meanwhile only 10 (9%) pts felt that talking about the WTHD was of non-important or of little relevance. Even, 73 (90%) pts who “never” experienced the WTHD, reported that it would be “quite” to “extremely” necessary or important to talk about it.

**Conclusion:** We could conclude that the great majority of pts in our sample consider appropriate and necessary to talk about the WTHD, even if they had never experienced it. This supports the proactive assessment of WTHD by the health care professionals in clinical practice.

**Funding:** Instituto de Salud Carlos III and the European Regional Development Fund (FEDER) project PI14/00263; AECC-Catalunya contra el Càncer – Barcelona 2014; RecerCaixa 2015.
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Abstract type: Poster Exhibition

**Advanced Cancer (AC) Patients’ Perception of Timeliness of Referral to Outpatient Supportive Care: A Prospective Survey**


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Studies have shown that early integration of supportive/palliative care (SPC) is associated with better outcomes. Early SPC best occurs in the outpatient (OP) setting, but very few OP programs exist. The attitudes and beliefs of healthcare providers and patient caregivers regarding palliative care referral and utilization have been assessed, and most report referrals occur late in the disease trajectory. The patients’ perspectives regarding OP SPC services have not been well studied.

Our aim was to determine AC patients’ perceptions of the timeliness of their referral to an OP SPC clinic.

This was a prospective survey of AC patients who were referred to the University of Texas M.D. Anderson OP Supportive Care Center. Patients then completed a telephone survey within 4 to 35 days of their initial consultation visit.

207/253 (81.8%) AC patients were enrolled; 7 did not answer all questions. 144/200 (72%) reported that their referral was just in time while 21%(42/200) thought it was late or much too late. 76/193 (39.4%) and 103/193 (53.4%) felt referral to SPC should have occurred at the time of cancer diagnosis for themselves and for other cancer patients, respectively. Less than 8% felt that referrals either for themselves or for other cancer patients should occur when there are no further treatment options available, 15/200 (7.5%) and 14/200 (7.3%) respectively. Those who perceived their referral to be late preferred referrals to occur earlier in the disease trajectory as compared to those who perceived their referrals to be early, p=.003. Of those who perceived their referrals to be late, the vast majority of them felt their referral to be useful (85.7%) whereas those who received perceived their referrals to be early reported their referrals to be less useful (64.3%), p=.0002.

Most AC patients who were referred to OP Supportive Care for the first time felt that the referral was timely and useful and that referral should occur at the time of diagnosis.
The Patients’ Experience of Cancer Associated Venous Thromboembolism: an Impact on Quality of Life: A Systematic Review

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Abstract type: Poster Exhibition

Background: Venous thromboembolism (VTE) affects about one in six people with cancer and is associated with important clinical and economic consequences, including delayed anticancer treatment, hospitalization, anticoagulation use, bleeding complications, recurrent VTE and decreased survival.

Aim: To summarize the published literature about patients’ experience of living with cancer and VTE, and the impact on their life quality.

Method: A systematic literature review was conducted. Databases (Medline, EMBASE, CINHAL, Cochrane, and PsychINFO) were searched to Oct 2016 by two independent reviewers for qualitative or quality of life observational studies. A web-based search was performed of relevant journals and bibliographies. Strict selection criteria were applied and disagreements resolved by a third reviewer. Eligible studies were retrieved, data extracted and quality assessed. Thematic synthesis of the qualitative studies was conducted.

Results: 1398 articles were retrieved, 6 of which were included (4 qualitative, 1 mixed-method and 1 quantitative) with 593 participants (259 women, mean age 54, age range 19–89y) adults with cancer-associated VTE. Thematic analysis of the included studies revealed four major themes and associated subthemes describing patients’ experience of living with VTE: Gap in knowledge; Effects of VTE; Effects of Anticoagulation; Coping strategies. VTE can be an unexpected, traumatic and life challenging event in people already struggling with cancer, its treatment being an additional burden. Symptoms are often misattributed and patients inadequately supported.

Conclusion: The review highlights opportunities to improve the quality of care of cancer patients with VTE. Patients should be educated about signs and symptoms of VTE as part of routine care and encouraged to seek help early and supported. Clinicians need to be alert to symptoms and signs which may mimic those of the underlying cancer.
A Good Death According to Palliative Cancer Patients

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Background: Previous studies of what constitutes a good death have indicated that a good death cannot easily be defined in general terms. There are some recurrent themes of what constitute a good death, such as pain and symptom management. However, the concept is complex. Research has for example indicated differences between the experiences of what patients and healthcare staff perceive as a good death. There is a knowledge gap regarding the Nordic context and what severely ill patients in these countries consider a good death.

Aim: To study dying patients’ perception of a good death.

Methods: 66 adult patients with cancer in the palliative phase were recruited from oncological outpatient clinic, palliative home care and hospice in Sweden (30–90 years old; 44% men; 42% had ≤3 months from interview to death). Participants were interviewed and transcripts were analysed using qualitative content analysis.

Results: The patients generally viewed death as a process rather than an event. A good death was associated with living with the prospect of imminent death, preparing for death and dying comfortably, e.g. dying quickly, with minimised suffering, with social relations intact and with independence. Some were comforted by their belief that death is predetermined. Others felt uneasy as considering death an end to existence. Past experiences of the death of others affected participants’ views of a good death.

Conclusions: To comply with the WHO definition of palliative care, healthcare needs to adopt a more individualised view on dying patients. Staff in palliative care should consider asking their patients to describe what they consider to be a good death to identify goals for care. Exploring patients’ personal experience of death and dying could help dealing with their fears as death approaches. Good communication with patients and their families, as well as between healthcare staff, is necessary for establishing the conditions for patients to experience a good death.
Goal: The aim of this study was to describe clinical profile of hospitalized patients on a palliative care unit of a Cancer Hospital in Brazil.

Design: A retrospective observational study was performed to describe demographic characteristics, cancer site diagnosis, cause of hospitalization, length of stay and clinical outcomes on a palliative care service from April to September 2016. It comprises inpatient care (12 from the 407 beds), clinical consultation and ambulatory care inside hospital and also hospice service outside the city. For this study data from patients hospitalized in-between the period mentioned were considered and descriptive analysis was performed on Microsoft Excel Software.

Results: Over a 6-month period 345 inpatients were followed. 53% male, with mean age of 64-year-old. Most frequent solid tumors sites were lungs (14%), colon (14%) and head and neck (10%), stomach/esophagus (8%), prostate (6.7%) and breast (5.8%). Hematological tumors were 9%. Decompensated symptoms – mainly pain (35%), delirium (19%) and dyspnea (18%) – and infections were the leading causes of hospitalizations. According to Karnofsky Prognostic Scale (KPS), 56% of the patients ranged from 10 to 30, 40% from 40 to 60 and 4% from 70 to 100. Emergency department (59%), subspecialties inpatient units from hospital (37.2%), ambulatory service (3%) and ICU (0.8%) were first references for all patients followed. From those, 74.5% were already followed by palliative care team. Mean hospitalization length was 6.5 days. From the 345 followed patients, 53% died in hospital, 31% were discharged with ambulatory follow-up and 15% were referred to hospice.

Conclusion: Hospital still seems to be the main site were most of terminal patients spend last days of life, being infections and uncontrolled symptoms the leading causes of hospitalizations. Most patients had an admission KPS lower than 40, which, aligned to previous considerations, may alerts us to a late referral for palliative care.
Abstract number: P01-114
Abstract type: Poster Exhibition

**Physical and Psychosocial Determinants of Quality of Life in Cancer Patients Attending Outpatient Pain Clinic**

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**Introduction:** With increase in number of cancer survivors, improving every domain of Quality of Life (QOL) needs consideration. In a busy clinic, where most clinicians focus on the treatment of disease, it is quite likely that like psychosocial factors affecting QOL are neglected.

**Objective:** To identify physical and psychosocial factors which influence QOL among cancer patients visiting pain clinic outpatient department (OPD)

**Methods:** Observational study including cancer patients >18 years of age, who were attending pain clinic OPD for the first time and who willing provided informed consent. Data was collected from 175 patients for demographics, psychosocial factors, and disease, pain and distressing physical symptoms like headache, lack of appetite, insomnia, fever etc. QOL was evaluated with the Hindi version of World Health Organisation-Quality of Life instrument (i.e. WHOQOL-BREF). Statistical analyses were done using STATA version14 to identify the association between the physical and psychosocial variables, and four domains of QOL i.e. physical, psychological, social and environmental. P-value < 0.05 was considered significant.

**Results:** The patients included had mean age 47.9 years and 50.29% males. Married patients reported better with overall health [$\chi^2(2)=11.84$, $p=0.002$] and QOL [$\chi^2(2)=9.91$, $p=0.007$]. Educational status was significantly correlated with all domains and overall health and QOL ($p<0.05$). Improved environmental domain of QOL was depicted with employment status ($p=0.021$) and provision of any benefit schemes for reimbursement ($p=0.001$). As the number of physical symptoms increased, patients’ QOL decreased ($p<0.005$). They reported better QOL with six to eight hours of sleep as compared to short/long sleep hours ($p<0.05$).

**Discussion/conclusion:** In order to provide holistic patient care, it is important to consider the influence of psychosocial factors like marital status, educational status, occupation, benefit schemes in cancer patients.
Analysis of Factors Associated with Hiccups Based on a Spontaneous Reporting Database in Japan

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Hiccups are occasionally experienced by most people. Although hiccups are not life-threatening, they can lead to a decline in the quality of life. Several studies have reported that hiccups can occur as a side effect of certain medications during chemotherapy. Furthermore, male dominance in hiccups has been reported. However, there have been minimal reports on the factors that influence hiccups. This study aimed to investigate the influence of medicine and patient characteristics on hiccups using a large-scale spontaneous reporting database; specifically, the Japanese Adverse Drug Event Report Database (JADER). Cases with adverse effects associated with medications were extracted from the JADER, and a Fisher’s exact test was performed to assess the presence or absence of hiccups for each medication. Additionally, we conducted a multiple logistic regression analysis using the medication and patient characteristic variables exhibiting significance. Furthermore, we examined the role of dexamethasone in inducing hiccups. The main diseases of the patients with hiccups were lung and colon cancers. Medications associated with hiccups included dexamethasone, levofolinate, fluorouracil, oxaliplatin, carboplatin, and irinotecan. Patient characteristics associated with hiccups included the male gender and greater height. The combination of anti-cancer agents and dexamethasone use was found for more than 95% of patients in the dexamethasone-use group. Hiccups also occurred in the anti-cancer agent-use group who did not use dexamethasone. This study suggests that a higher risk for hiccups can be predicted by patient characteristics. We confirmed that dexamethasone was the drug that influenced the induction of hiccups to the greatest extent. However, the impact of anti-cancer agents on the induction of hiccups should not be overlooked.
The Role of Family Physicians in Palliative Care of Patients with Advanced Cancer

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Background: Family Physicians (FPs) are important providers of palliative care in the outpatient setting and at home. The purpose of this research was to examine perspectives of patients with advanced cancer regarding their FP’s involvement in their palliative care.

Methods: Patients with advanced cancer seen in the Oncology Palliative Care Clinic at an urban teaching cancer hospital were invited to complete a survey. Eligible patients were English-speaking, over 18 years of age, had at least one prior visit to the clinic, passed a cognitive screen, and had seen a FP in the last 5 years. The survey included questions concerning involvement of patients’ family physicians in their care. A chart review was conducted to gather demographic and clinical characteristics.

Results: To date, 68 participants completed the survey. Of these, 42 (62%) were female; 37 (54%) were married/common law, 36 (53%) had a university education, 63 (93%) had received cancer treatment, and 25 (55%) were currently receiving treatment. Sixty-six patients (97%) stated they currently had a FP, 44 (65%) had seen their FP in the last 6 months; 18 (26%) had seen their FP for palliative care (defined as pain/symptom control, helping with Advance Care Directives, and/or emotional care related to cancer) in the last 6 months, and 33 (49%) had never seen their FP for palliative care. Six (9%) stated they knew their FP provided home visits, 39 (58%) stated the FP did not, and 22 (33%) did not know. Sixteen (24%) stated their FP provided 24/7 access to telephone advice, 30 (44%) stated the FP did not, and 22 (32%) did not know. Fifty-six (82%) stated that they wanted their FP to continue being part of their ongoing care.

Conclusion: Although patients were overall engaged with their FPs and considered them important in their ongoing care, many had not seen their FP for reasons related to palliative care and only a minority thought their FP provided 24/7 access to telephone advice or did home visits.
Abstract number: P01-117
Abstract type: Poster Exhibition

Malignant Bowel Obstruction in Adult Cancer Patients: A Single-centre Retrospective Study

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Background: Malignant bowel obstruction (MBO) is a frequent complication in advanced cancer patients, mainly among patients with abdominal and pelvic malignancies.

Aim: To characterise cancer patients admitted to an oncology unit with MBO and to determine predictors of worst prognosis.

Methodology: Retrospective analysis of adult cancer patients admitted to an oncology unit with MBO, between 1 Jan 2013 and 31 Mar 2015. Demographic and clinical features were collected. Primary outcome was resolution of the MBO and secondary outcome was readmission due to MBO.

Results: We identified 49 patients, 63 episodes of MBO. The median age was 64 (27–84) and 69% (n=34) were women. The most frequent primary tumor was gynecological (43%, n=21), followed by gastrointestinal (39%, n=19). Obstruction was complete in 21 episodes (33%) and abdominal bloating and pain, nausea and vomiting were the most common symptoms. All patients had plain abdominal x-ray and 94% performed an abdominal CT, which documented carcinomatosis in 85% and the site of obstruction in 21%. Anaemia was observed in 54%, ascites in 21% and acute kidney injury (AKI) in 17%. NGT was used in 53 episodes (86%), octreotide in 6 (10%) and TPN in 4 (6%). Surgical approach and chemotherapy were performed in 3 (5%) and 5 (8%) episodes, respectively. 74% of the patients restored normal bowel function (including 2 pts submitted to surgery). From these, 33% were readmitted with MBO. 41% of patients died in hospital. The median days of hospitalization was 6 days (1–133). In the multivariate analysis only AKI is associated with unresolved MBO (OR 8.51; p=0.04). Readmission was associated with the presence of palpable mass (OR 38.14; p=0.04).

Conclusion: Patients admitted in this unit with MBO have comparable characteristics to those who participate in studies suggesting benefit of dexamethasone in symptom control in MBO. AKI was associated with unresolved MBO. Palpable mass is proposed as a predictor of recurrence.
Abstract number: P01-118
Abstract type: Poster Exhibition

What Features of Oncologic Patients at Admission in a Universitary Hospital PCU Can Help us to Predict Survival?

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Background: The possibility to determine survival in patients with advanced cancer is important for clinic, organizing and ethical purposes.

Aims: To analyze factors of quick and easy access for any professional that may be related to the survival estimation in patients at admission in a Acute Palliative Care Unit (PCU).

Methods, design, data collection and analysis: We conducted a prospective study including all cancer patients admitted in the PCU between January 2012 and April 2015. We collected demographic variables, source of admission, tumor types, number of metastatic locations, time lapse from initial diagnosis to referral to palliative care (TTD), ESAS, Global Distress Score, ECOG and Charlson’s Comorbidity Index. Descriptive statistics were made and Cox regression analysis in order to explore the relationship among available factors at admission and survival time. OR and IC 95% were calculated.

Results: Out of the 1294 admissions, 959 patients met the inclusion criteria. Mean age was 70.1±14.5 years. Males: 57%. Main sources of admission were: 41% emergency room, 39% other hospital departments, and 20% home-based palliative care services. Average stay was 10.4 ±8.4 days. 48% died during first admission. Average TTD was 12 months (Range IQ 2–34). Average time between referral to PC resources and death was 41 days. Symptomatic charge at admission was moderate-severe (ESAS Global Distress Score > 30) in 72% of patients (average 38% (DS 12.9)) The ECOG performance status were as follows: 2 (9%), 3 (50%) and 4 (41%). 83% of patients had a high score in the Charlson index (average of 7). The chart summarizes the univariate analysis of factors that were related to survival.

Conclusion: The most important factors related to survival were source of admission, a short TTD, the need for a hospital admission short after derivation to PC resources, hematologic neoplasms and tumors with many metastatic locations, severity of symptoms, and performance status of the patients.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Survival Time (days) (IC 95%)</th>
<th>OR (IC 95%)</th>
<th>p</th>
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<tr>
<td>Admission: Home-based palliative care services</td>
<td>33 (23.06–42.93)</td>
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<td>-</td>
</tr>
<tr>
<td>Emergency</td>
<td>19 (14.04–23.95)</td>
<td>1.45 (1.22–1.74)</td>
<td>&lt;0.001</td>
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<td>Department of Oncology</td>
<td>14 (10.26–17.74)</td>
<td>1.69 (1.38–2.07)</td>
<td>&lt;0.001</td>
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<td>TTD (months)</td>
<td>0.99 (0.99–1.00)</td>
<td>0.012</td>
<td></td>
</tr>
<tr>
<td>Time lapse: referral to PC to be admitted in PCU (days)</td>
<td>0.99 (0.99–0.99)</td>
<td>&lt;0.001</td>
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</tr>
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<tr>
<td>Lung cancer</td>
<td>18 (11.14–24.85)</td>
<td>1.54 (1.06–2.25)</td>
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<td>Gastrointestinal cancer</td>
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<td>1.55 (1.07–2.27)</td>
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<td>Hematologic cancer</td>
<td>16 (7.77–24.23)</td>
<td>1.71 (1.10–2.66)</td>
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[Table 1]
Measuring Symptom Burden and Emotional Component in Hospitalized Patients with Hematological Malignancies

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**Background:** Patients with hematologic malignancies have prolonged hospitalizations and treatments often associated with severe adverse effects. These symptoms require a specific control, thus optimizing the overall condition of the patient, their functional and nutritional status, adherence to therapy and tolerance to adverse effects. In addition, it prevents the development of psychiatric comorbidities such as mood disorders, which are often underdiagnosed. There are several tools that can objectify these features, one of the most validated at the Edmonton Symptom Assessment System (ESAS). In addition, among the instruments that allow a diagnosis of psychiatric comorbidity specifically mood disorders is the Patient Health Questionnaire - 9 (PHQ-9).

**Aims:** This study aims to assess symptom burden and the presence of depressive comorbidity in hospitalized patients with hematologic malignancies by applying the ESAS and PHQ-9.

**Methods:** We apply both instruments (ESAS and PHQ-9) to all patients with hematological malignancies hospitalized in the Department of Medicine at the Hospital del Salvador in Santiago de Chile during the month of May 2016. A descriptive analysis of the data obtained was performed.

**Results:** Consent of 50 hospitalized patients was obtained. Average age of 52.76 years (range 24–81 years), 53.84% female. The main pathologies were Non-Hodgkins Lymphoma and Multiple Myeloma. The prevalence of symptoms was: pain (84.6%), depression (84.6%), anxiety (84.6%), somnolence (83.3%), impaired sleep quality (76.9%). The average symptoms per patient was 5. With regard to mood disorders 15.3% met diagnostic criteria for Major Depressive Syndrome 15.3% for Other Depressive Syndromes 23.0%.

**Conclusion:** The presence of severe symptoms and mood disorders are very prevalent in this population. A therapeutic approach directed towards both situations could improve the overall condition of this patient group.
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Time Series Analysis of QOL of the Cancer Patients: The Correlation between Daily Living Symptoms and Symptom Distress

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Background: In palliative care, it is very important to monitor patient QOL so that it is reflected in a positive way during daily care. However, studies have shown how much the activities of daily living and symptom distress affect QOL and that estimated the mutual relations are rare, while patients' condition changes every day.

Aims: To study the correlation between daily living symptoms (DLS) and symptom distress (SD) over time, which affects general QOL changes.

Methods: We conducted an epidemiological investigation of clinical data from Kawasaki Municipal Ida Hospital collected using objective evaluations from October 1998 to April 2014. We investigated 584 patients with terminal cancer that had survived more than 30 days after hospitalization in palliative care (13% gastric/esophagus cancer, 37% lung cancer, 10% pancreas cancer, 3% bladder cancer, 5% liver cancer, 8% colon cancer, 9% prostate cancer, 12% breast cancer, 5% malignant brain tumor and pharyngeal cancer). The chronological change of both SD and DLS factors are analyzed. DLS factors included intake, conversations, ambulation and psychological and/or neurological symptoms. On the other hand, SD factors related to pain, fatigue, respiratory symptoms, abdominal symptoms, psychotic and/or neurological symptoms. Their mutual causation was analyzed.

Results: The correlation of DLS (RC=0.68–0.75) with QOL was stronger than that of SD (RC=-0.1–0.19) with QOL. Associations among DLS factors were also studied. There was a tendency that intake (RC=0.71–0.85) was strongest in correlation with QOL and chronological order in DLS. Exceptionally, in the case of malignant brain tumor and pharyngeal cancer, leisure (RC=0.73–0.74) and ambulation (RC=0.70–0.76) were stronger.

Conclusion: For terminally ill patients, maintaining daily life activities is more important than symptom management. Symptom management may not always improve QOL, as evidenced by the chronology.
Abstract number: P01-122
Abstract type: Poster Exhibition

Revie ⊕: The Influence of a Life Review Intervention that Includes a Patient-centered Positive Approach toward Enhancing the Personal Dignity of Patients with Advanced Cancer: A Mixed Method Investigation

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Background: Existential concerns must be addressed to promote dignity of patients with advanced cancer. A number of interventions have been developed, however, none have so far focused on a positive approach. We developed a patient-centered intervention Revie ⊕ , focusing on personal development and aiming to promote existential needs in advanced cancer patients.

Aims: The main aim of the study was to evaluate the feasibility of Revie ⊕ and to assess potential changes in sense of dignity, posttraumatic growth, and satisfaction with life for patients with advanced cancer within a university hospital.

Methods: A mixed method study was performed including a single group pre and post-intervention, using Patient Dignity Inventory (PDI), Post-Traumatic Growth Inventory (PTGI) and Satisfaction with Life scale (SWLS). The qualitative part informed about participants’ experiences. Questionnaires, diaries and a focus group explored nurses’ acceptability.

Results: 41 participants benefit from the intervention (recruitment: 12 months). Most are satisfied (97.8 %), considered helpful and recommend the intervention. Six themes emerge from patient’s verbatim: good idea, flood of emotions, individual process, personal gain, leave a trace and change of the relationship. Two items of PDI scale changed significantly: no longer feeling like who I was (p=0.004) and not feeling supported by health care providers (p=0.017). We found no significant difference between before and after measurements for PTGI and SWLS. Nurses (n=8) considered the intervention supportive. The focus group brings out four themes: appropriating Revie ⊕ , testifying the life history, living timeless and authentic moments, moving on with the patient.

Conclusion: This preliminary study informed about the recruitment process, intervention delivery and outcomes. Globally the intervention Revie ⊕ was considered acceptable and seems to be a way of enhancing the end-of-life experience for patients with advanced cancer.
Is it Feasible to Care for Leukemic Patients at Home at the End of Life?

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Background: Hemato-oncological (HO) patients are referred to mobile hospice care less frequently than patients with solid tumors. Leukemias are perceived as very dramatic, causing unbearable symptoms. Dependency on transfusions and on hospital-based therapies are obstacles as well.

Aims: Our retrospective study focuses on the description of a patient group and management in mobile hospice care. We were interested in indicators of insufficiency of care such as transports to in-patient facilities or unavailability of transfusions.

Methods: We have analyzed all cases of patients with HO malignancies in two mobile hospices in the city of Prague, Czech republic in the period of 70 months (2011–2016).

Results: We have identified 33 pts of median age of 69 years, 19 men and 14 women, with an average performance status of 35% (Karnofsky) at admission to hospice care which lasted for (median) 16 days. There were 15 pts with acute leukemia, 8 pts had multiple myeloma, 9 patients with non-Hodgkin lymphoma, 1 patient had myelofibrosis. 8 pts received erythrocyte transfusion and 5 pts received thrombocytes. 5 pts were referred to another facility and did not die in mobile hospice care – one surprisingly reached remission of AML and successfully underwent allogeneic transplantation, one improved considerably. 3 pts were sent to in-patient hospice.

Conclusions: 28/33 pts remained at home until they died and there were two cases in which hospice team sent patients back for life-prolonging treatment. There were no acute hospitalizations. 8/33 and 5/33 pts received erythrocyte and thrombocyte transfusions respectively as a marker of cooperation of hematology centers with hospices. We dare to interpret these results as an argument for more use of mobile hospices for HO patients. In spite of the limitations of the retrospective analysis, small numbers and no sophisticated quality of care evaluations, it seems that dying at home is feasible for motivated leukemic patients.
Analysis of the Timing and Route of Referral of Cancer Patients to a Hometown Hospital for End-of-Life Care: A Single Center Experience

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Aim: We evaluated the timing and route of referral of cancer patients (pts) to a hometown hospital for End-of-Life care (EoLC) and analyzed the provision of hospice and palliative care in this patient population.

Methods: We performed a retrospective review of cancer pts who received palliative chemotherapy in other hospitals, but were referred to a hometown hospital to receive EoLC, and who subsequently died in the hometown hospital.

Results: From March 1, 2013, to March 31, 2015, sixty pts were included in this study. The mean age of the pts was 67 years and 58.3% were male. Of the pts included, 96.7% received palliative chemotherapy in other hospitals located in the Seoul metropolitan area. The median overall survival after the referral was 40 days, and 30% of the pts died within a month. For first visit for EoLC, 56.3% and 43.3% of the pts were referred to outpatient (OPD) and emergency departments (ED) of the hometown hospital, respectively. And the pts referred to the ED showed significantly shorter survival than the pts referred to the OPD. And The hospice palliative care system (HPCS) of Korea was utilized by 45% of the pts. The median time from the transfer to the hometown hospital to enrollment in HPCS was 26 days, and the median time from HPCS enrollment to death was 19 days. The most common reason pts opted not to participate in HPCS was the refusal of pts or family member (84.6%).

Conclusion: The duration from referral to death in pts transferred to the hometown hospital for EoLC was still short. Although frequently visiting the ED is a marker of poor quality of life in terminal cancer pts, the ED was the route of referral for EoLC in many pts. Though the pts were referred to receive EoLC, many pts or a member of their family refused HPCS. As well, even among the pts who utilized HPCS, their decision to participate in HPCS was prolonged. Therefore, these results show that more education and explanation for HPCS are neccessary for pts in Korea.
Experience of a Palliative Care Unit

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Objectives:
1. To describe the demographic and clinical characteristics of patients with advanced cancer disease hospitalized in the CPU unit of Hospital Puerta del Mar.
2. To analyze the clinical activity of the Unit in relation to the fate of patients, their origin, monitoring, place of death, survival to hospital admission and entry into Palliative Care Program.

Material and methods:
Design: Descriptive observational study.
Scope: Patients admitted in the CPU unit of Puerta del Mar Hospital between January and July 2014.


Collection and analysis of data: Introduction of variables in data collection sheet. Creating database in Excel and subsequent analysis in SPSS.

Results: 113 patients were included. Predominantly male (59%), the average age is 70 years old. The gastrointestinal tumor site was the most frequent (24%), followed by lung (16%). The pain was the most prevalent symptom in the initial assessment (31%), followed by dyspnea (20%). The main cause of admission was infection (27%), followed by disease progression (26%), and failure of symptom control (18%). Most come from the area of oncology (42%) and emergency (41%). 74% died in the hospital. The average stay in palliative care program was 54 days.

Conclusions: The clinical profile of our hospitalized patients is similar to that described by other units. The average stay in the program is short, confirming the initial suspicion that patients are referred to the CPU in very advanced stage of the disease. Most of our patients die in the hospital.
Is More Dynamic Palliative Care by Rehabilitation Intervention Patient-first One?

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Background: There’re many problems with advanced cancer patients with bone metastases from orthopedic point of view, such as bone pain, pathological fracture and muscle weakness especially to be cancer cachexia. Push-up is a prerequisite for basic movements in patients with traumatic paraplegia. However, this movement must be avoided in advanced cancer patients with bone metastases, because of the risk of severe bone pain and pathologic fracture, and the muscle weakness due to cancer cachexia as well as disuse syndrome. The purpose of this presentation was to show a method for transferring paraplegic patients from bed to wheelchair for example considering the characteristics unique to patients with advanced cancer and to present its usefulness.

Methods: We reviewed cancer then considered paraplegia compared with traumatic and malignancy. We pointed out a method that enables the safe transfer from bed to wheelchair of paraplegic patients with advanced cancer with spinal bone metastases. Our method was applied to 25 advanced cancer patients with paraplegia, and the activities of daily living, success/failure of transfer, possibility of overnight stay outside the hospital, and possibility of discharge were investigated. And the method improved quality of life of the patients.

Results: In our transfer method entailed no problems such as pain or pathological fracture. The Barthel Index scores were significantly increased. In all, over 60% of the subjects could be successfully transferred 60% successfully stayed overnight outside the hospital, and 50% could be discharged.

Conclusion: Our findings suggested one of tactics that even if advanced cancer patients cannot resume walking in the upright position due to paraplegia with malignancy, the use of our method of transfer described herein enables them to be transferred with sitting position from some place to other.
Fentanyl Pectin Nasal Spray versus Oral Formulation of Fentanyl for the Management of Spontaneous-type and Incident-type Breakthrough Cancer Pain: An Observational Study

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Fentanyl products have shown superiority over oral opioids for the management of breakthrough cancer pain (BTcP). A number of oral or nasal formulations are currently available, as a fentanyl buccal tablet Effentora (FBT), a fentanyl Ethypharm, Vellofent (FE) and an intranasal fentanyl pectin nasal spray, Pecfent (FPNS). The aim of this study was to compare the efficacy and the level of patient’s satisfaction of FPNS and oral formulations of fentanyl (FBT, FE), for control of incident or the spontaneous BTcP.

Methods. Cancer patients with pain receiving =/>60 mg of OM equivalents/day and presenting with < 4 episodes of BTcP/day were included. Pain intensity was measured before, 15, and 30 days after study drugs. Functionality and satisfaction assessments included change from baseline to the end of the treatment period in the Edmonton Symptom Assessment System (ESAS), and Patient’s Global Impression of Change (PGIC).

Results. From July 2015 to April 2016, 60 cancer pts were recruited to the study. Median background intensity was 3.0 (mild) throughout the study. 30 patients reported incident-type BTcP and were treated with FNPS; 30 patients spontaneous-type BTcP with FBT or FE. The median of the time to peak intensity for the whole group was < 20 minutes in 55% patients, and in 75% for patients with incident-type pain; the median for patients with spontaneous-type pain was >20 minutes in 80% of 27 patients.

The median of the duration of untreated episodes for the spontaneous-type pain group was >30 minutes in 63% of patients. After the treatment period, mean global ESAS score improved from 40.1 at baseline to 34.6 after treatment in patients with spontaneous BTcP; from 34.2 to 28.9 in incident pain. After the treatment period, 85.7% of patients with incident-type pain and 79% with spontaneous-type pain reported improvement in overall PGIC.

Conclusions. This therapeutic management of BTcP may improve overall functional status and satisfaction in the management of BTcP.
Abstract number: P01-129
Abstract type: Poster Exhibition

Hypercalcaemia of Malignancy: An Analysis of the Medical Management of Palliative Cancer Patients in Community, Hospice and Hospital Settings

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Background: Hypercalcaemia of malignancy (HCM) is a common and significant cause of morbidity and mortality. Treatment includes clinically assisted hydration and bisphosphonates. Denosumab has been used in some centres. Clinical management of hypercalcaemia varies across settings and many recommendations are based on expert opinion.

Aims: In a Regional Clinical Network we aimed to:
1. Evaluate management of HCM in community, hospice and hospital.
2. Develop new standards and guidelines.

Methods:
1. Systematic literature review.
2. Six-month retrospective case note analysis of the management of HCM in community, hospice and hospital.

Results: The literature review identified 32 articles to inform development of the regional standards and guidelines. Data for 79 patients was recorded from hospital (n=53, 67%), hospice (n=25, 32%) and community (n=1, 1%) settings. Patients reported high symptom burden: fatigue (n=41, 52%), weakness (n=38, 48%), drowsiness (n=32, 41%) & constipation (n=26, 37%). Intravenous fluids were administered in 72 (91%) patients; 0.9% saline was most used (n=67, 85%) within 24-hours of diagnosis (n=64, 81%). Bisphosphonates were used in 55 (70%): zoledronic acid (n=28, 35%) & pamidronate (n=24, 30%) most common. Two (3%) received denosumab and one (1%) calcitonin.Thirty-four (43%) had a previous episode of HCM, 20 (25%) in the previous 4 weeks. Twelve (60%) of those treated for HCM in the previous 4 weeks achieved normocalcaemia following bisphosphonates. Calcium monitoring plans not documented in 33 (43%) cases. Healthcare professionals considered treatment inappropriate in the dying (n=51/66, 77%) and 8 (12%) had used denosumab previously for HCM.

Conclusion: This analysis provides data about HCM management in a variety of settings and has informed development of standards and guidelines. Further study is needed to determine the role of denosumab in management of HCM.
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The Use of Technology in Cancer Palliative Care in the Dying Process

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The search for a “good death” seeks to preserve the patient’s requests, therefore, taken the difficult and unexpected clinical decisions should be considered about the need to use high-tech classified disease as “terminal”.

Objective: To quantify and analyze the scientific production, the technology applied in cancer palliative care in the dying process.

Methodology: A reference is made to an integrative review, the main question: – Does the technology is applied in the practice of oncology palliative care in the dying process? Therefore, we performed a search of scientific works published in 2012 to 2016, in the databases LILACS, MEDLINE, PUBMED and CINAHL through official descriptors: technology, death, palliative care and oncology were also used descriptors in English: technology, death, palliative care and oncology.

Results: The literature search yielded 104 publications (5 LILACS 71 MEDLINE, CINAHL 28) and, after thorough analysis, two productions were selected, and MEDLINE. The findings in scientific publications showed that there is a lack of publications regarding the applicability of the technology related to the cancer palliative care for the dying process. Qualitative analysis identified that the use of technology during the dying process in oncology has generated an improvement in the quality of survival.

Conclusion: The update and reflection on how to take advantage of the technology is required in cancer dying process to the relief of suffering and generate a co-relation to a “good death”.
Patient Reported Outcomes (BPI) as a Predictor of ER Visits, Admissions and Survival in Patients with Prostate Cancer

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Background: The prevalence of pain is 70–80% of patients with advanced cancer. Uncontrolled pain may require additional healthcare resource utilization (emergency room (ER) visit or a hospital admission) for pain management.

Aim: Evaluate for correlation between pain reported in clinic (mild, moderate or severe) and ER visits, unplanned admissions, and survival among prostate cancer patients seen at a tertiary cancer center.

Methods: Among 1534 cancer pain patients seen by pain/palliative care specialists at our center, 112 were prostate cancer patients who completed iPad surveys of patient reported outcomes including the Brief Pain Inventory (BPI) among other scales.

Results:

Pain and ER visits: We found 85 instances of patients requiring ER visits for acute symptom management after being seen by a pain/palliative care specialist in clinic. We found no difference in mean or median days from the clinic visit to ER visit, though the overall incidence of ER visits was the highest for the severe pain category (49%), followed by moderate and mild pain (40% and 33% respectively).

Pain and Unplanned Admissions: The percentage of prostate cancer patients with unplanned admissions was highest in the severe pain category, followed by moderate and mild (50%, 40 and 35%). Conversely, number of days to an unplanned admission was the lowest in severe pain (21 days), followed by moderate and severe pain (42 and 34 days).

Pain and Survival: 47 patients (42%) of 112 prostate cancer patients died within 1 year. Although the difference was not statistically significant there was a strong trend towards severe pain correlating with shorter survival being 82 days in severe pain category and 129 and 140 days in mild and moderate pain categories.

Conclusions: Inadequate pain control, in addition to decreasing quality of life and increasing suffering may increases cost of care by causing visits to an ER, unplanned admissions and may impact mortality.
Evolutive Changes in Complexity Factors in Advanced Palliative Care at Home

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Background: Complex palliative care situations should be referred to specialized settings. Assessment of complexity factors should be done along admission to advanced palliative care setting, to decide whether patients remain controlled by specialized services or sent back to their previous professionals. IDC-Pal is a tool designed to assess complexity factors according to clinical, psychoemotional, social or spiritual needs.

Aim: To describe evolutive changes in complexity along admission to advanced palliative home care in a cancer center.

Method: Descriptive, prospective, longitudinal study, developed in a hospital-at-home service in a cancer center along three months. Complexity was assessed at 0, 15, 30 and 60 days of admission with IDC-Pal tool. No funding was received.

Results: We obtained a sample of 63 patients, 35 male and 28 female. Mean age was 69.69 (SD: 12.13). PPS median score was 60 %. 2 patients showed no criterion for complexity when admitted. Only 1 other patient decreased its level of complexity while the other 62 patients remained at the same level or increased its complexity. Nevertheless, some of the complexity factors were solved.

10 patients died along the 60 days of observation. 43 patients were rated as “high complexity” at admission. Clinical and psychoemotional items where the most frequent causes of complexity.

Discussion/conclusions: Patients referred to advanced palliative care setting usually remain controlled by these professionals, as their situations tend to worsen. More research is needed to assess complexity and referral criteria to advanced palliative care settings.
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The Complications at the Patients with End Colostomy in the Republic of Moldova

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Introduction: Colorectal cancer (CRC), also known as bowel cancer, is the development of cancer from the colon or rectum (parts of the large intestine). From 2005 in the Republic of Moldova colorectal cancer is on the first place, from the total numbers of malignancy, according to statistical data. Hospice Angelus is the only provider of the stoma bags for ostomy patients in the Republic of Moldova. Simultaneously there are about 900 patients in care.

Aim: To evaluate and assess the complications at the patients with colostomy in Hospice Angelus care.

Methods: Nine hundred patients with end colostomy were studied. The complications were divided in two groups: early and late complications. In group of early complications were included: discomfort, pain, irritation, bleeding, and prolapse. In the late complications group were included: stenosis, retraction, perforation with fistula formation. To evaluate the quality of life of these patients the questionnaire „A Quality of Life Questionnaire For People with Ostomy“ was applied.

Results: According to questionnaire all the patients had psychological problems. 130 (14.44%) of patients had no complications. 770 (85.55%) of patients had discomfort during the activity, 250 (27.77%) of patients had moderate pain, 640 (71.11%) of patients had irritation, 88 (9.77%) of patients had a bleeding, 60 (6.66%) of patients had a prolapse, 20 (2.22%) of patients had a stenosis, 420 (46.66%) of patients had a retraction, and 12 (1.33%) of patients a fistula had developed.

Conclusion: The prevalence of psychosocial problems, discomfort during the activity, moderate pain, irritation, retraction needs special attention and is a new direction in education of a new concept in stoma care.
Nutritional Status of Cancer Patients in the Terminal Stage – A Reality to Be Taken into Account

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Introduction: Malnutrition in cancer patients is frequent and multifactorial and is associated with the decreased of quality of life. In patients receiving palliative care, nutritional intervention plays a important key role in improving symptomatic control. The application of scale Patient-Generated Subjective Global Assessment (PG-SGA) stratifies patients according to need for nutritional intervention.

Objectives: To evaluate the impact of nutritional intervention in oncological patients in palliative phase applying the PG-SGA scale.

Methods: A retrospective study conducted in a Hospital of Palliative Care in the period of July to September 2015. We evaluated all oncological patients in palliative phase and applied to PG-SGA before and after nutritional intervention. Evaluated demographic characteristics, nutritional status pre and post intervention.

Results: We studied 22 patients, 65% female. The median age was 77 years (Minino 55, maximum 87). We applied PG-SGA to all oncological patients: 40% were in the state A (well nourished or anabolic), 35% in state B (moderate malnutrition or risk) and 25% in state C (severe malnutrition). The patients in state C were subjected to personalized nutrition monitoring, adjusting food plan. The symptoms it is noted 80% with anorexia, 20% with nausea or vomiting, 40% with asthenia, 10% of those with performance status 4. In all of these patients there has been an improvement in symptoms of anorexia and asthenia and the reevaluation of these 10% passed to state A and 15% to state B. In 45% of patients found to improve the IMC.

Conclusion: With this study we conclude that patients at risk for malnutrition should receive nutritional support from a professional because that will reflect positive results in clinical evaluation and on quality of life.
Palliative Patients in Accident and Emergency Department (A&E)

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Introduction: The increasing longevity and the incidence of chronic diseases since the second half of the twentieth century resulted in the frequent referral to A&E departments of patients with palliative care needs, although there are other well defined units and services to receive them. A&E professionals are designed to act fast to save lives and dealing with patients like these is therefore challenging, not only on managing symptom control but also in discussing critical decisions with families and loved ones.

Methods: Demographic and clinical characterization of patients admitted to an emergency department who were hospitalized in a palliative care service between January 2014 and December 2015.

Results: 169 patients were admitted directly to the Continuing and Palliative Care UNIT. The median age was 77 years. 64.4% had oncological disease (n = 109). The main urgent (acute) reasons for admission were prostration (n = 20), dyspnea (n = 19), pain (n = 13) and the degree of dependence was serious or complete in 29% of cases. The average length of hospitalization of these patients was 16 days and there was an intra-hospital mortality of 55%.

Discussion: Oncologic patients present to the A&E department for many reasons, and they are a challenge. They present specific characteristics that require an adequate approach along the disease course. On this final stage, the majority requires a fast A&E admission and a quick referral to the CPCU, where they will be offered the more adequate treatment with benefits to the overall survival, quality of life and comfort, avoiding recurrent visits to A&E.
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Analysis of Cancer Survivals Receiving Palliative Care

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Background: It is well documented that early integration of palliative care with standard oncologic care in patients with metastatic disease resulted in survival that prolonged by approximately 12 months or more, actually this survivorship might extended up to 3 to 4 years, with clinically meaningful improvements in quality of life and mood for the patients with metastatic disease.

Aims:
1. To document the characteristics of patients surviving after diagnosis with metastatic disease or locally advanced disease.
2. To determine the average time lapse between referral to PC and return to active treatment.

Methods: A descriptive retrospective study.

Results: The total number of patients included was 107. The demographic data are age, sex of the patient, the diagnosis of the disease. Major organs of metastasis were identified: bone, liver, brain, lung. The history of illness, effect of active treatment on metastasis, and the tolerance to the treatment. Males was 18%, while females were about 82%, and the ages ranged from 1 to 70 years old, from (19–60) years old as adults (and this is the majority), who return again to the active treatment and tolerated the treatment well.

The breast is the major site; 62%, others are thyroid, prostate, ovary, all of those were only 38%.

Brain metastasis 6%, liver metastasis about 30% with bad prognosis, since the bone and lung metastasis has medium incidence 44% and 40% of each respectively.

Conclusion:
1. Most common type of cancer treatable with good prognosis is breast cancer, even there is metastasis on lung (which has poor prognosis).
2. Patients with Ca breast survived better than other diagnoses.
Falling in Love with Life in the Light of the Disease: Preliminary Results on the Experience of Living with Advanced-stage Cancer

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Background: Each day more people are living with advanced-stage cancer. What do we really know as health professionals about living with this disease?

Aim: To understand the experience of living with advanced cancer.

Method: A phenomenological hermeneutic study following van Manen in three settings: two oncology departments and a palliative care unit. Study was conducted in three settings Twenty-two patients with advanced cancer purposively selected took part in the in-depth interviews. A thematic analysis was conducted, following the steps developed by van Manen. Ethical approval was granted.

Results: The following findings make up the theme “Cancer makes life visible”, which is one of the themes of the experience of living with advanced-stage cancer.

Life is wonderful and makes me incredibly happy to be alive: From the consciousness of the nearness of death the person feels life is scarce and valuable. The person re-discovers life, as if so far she had not been truly aware of its value. Life details become extraordinarily valued and the person is happy to be alive.

The person brims with wishes to continue living: The person chooses to focus on living, despite being aware of the nearness of death. Even when suffering is so intense that the person poses if life is worthy, is able to find reasons to continue living.

Enjoying everyday details of life makes me fortunate: The disease eliminates the routines of daily life, and shows simple things which really represent the essence of life. Now the person values details that he/she did not value before.

Conclusions: People living with advanced-stage cancer are enchanted by life while being aware of the nearness of death. These findings can be applied in clinical practice, making health professionals to be aware of the need to focus on what helps the patient to live.
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Palliative Care in Lung Cancer: From the Challenges to the Home Care

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Background: Lung cancer is currently one of the most common malignant neoplasms worldwide. Distress symptoms related to the primary disease or in combination with disease progression have challenges faced by the patients, family, and the health care team.

Aims: Demonstrate the benefits of an integrated palliative care approach for lung cancer patients at the time of diagnosis and also the benefits of care these patients at home.

Methods: Integrative review on the ISI Web of Knowledge, PubMed, CINAHL and Academic Search Complete. The keywords were “Lung Cancer”, “Palliative Care”, “Approaches” and “Therapies”. The inclusion criteria were articles in the English published until 2015 with full-text and references available and peer-reviewed. The research and documentation were carried out in accordance with the Prisma 2009 Referencia guidelines.

Results: 164 articles were found, of which 33 were selected to full analysis. Most of the lung cancer patients suffer from multiple distressing symptoms with high levels of intensity and are simultaneously influenced by disease progression and the undertaken therapies. Palliative interventions have an integrative philosophy that has demonstrated to be an effective relief of the patients suffering. Moreover, palliative develops interventions that control the symptoms related to the disease and integrates the different dimensions of people and their problems in the evaluation of their health status and therapeutic intervention to respond favorably to the patients and family’s needs because many cancer patients prefer a conservative or supportive treatment.

Conclusion/discussion: The provision of specialized palliative care at home allows the respect of the patients’ preferences and providing humane care throughout the course of the disease, particularly at the end-of-life.
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The Prognosis in Palliative Care II (PiPS2): Preliminary Recruitment Data

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Background: More accurate methods of prognostication are likely to lead to improvements in the quality of care of patients approaching the ends of their lives. The Prognosis in Palliative care Scales (PiPS) are prognostic models of survival. The scores are calculated using simple clinical data, observations (+/- a blood test). The models predict whether a patient is likely to live for ‘days’, ‘weeks’ or ‘months’ and have been shown to perform as well as, or better than Clinician Estimates of Survival (CES).

Aims:

a) To validate the PiPS models in a new cohort of patients and
b) to evaluate the accuracy of other prognostic tools (see below).

Methods: This is a multi-centre, prospective, observational cohort study, aiming to recruit 1,361 patients via 55 palliative care services (i.e., hospices, hospital support teams and community services) across England and Wales over two years. Eligible patients have advanced, incurable cancer, no longer receive curative treatment and have recently been referred to the palliative care services. Patients with or without capacity are included in the study.

The primary outcome is the accuracy of PiPS predictions and the difference in accuracy between these predictions and the CES. The secondary outcomes include the accuracy of predictions by the Palliative Prognostic Score; Palliative Prognostic Index; Palliative Performance Scale; and the Felius Prognostic Nomogram compared with actual patient survival and CES.

Results: In the initial 2 months of recruitment, 199 patients were screened across 7 recruiting sites. Of those, 107 were approached to participate in the study and 60 were recruited (48 patients with and 12 patients without capacity). Updated recruitment figures and a breakdown of the reasons for ineligibility, inability to approach patients and refusal to consent will be presented.

Conclusion: This study demonstrates the feasibility of recruiting large numbers of participants to a prospective palliative care study.
In France, all cancer patients have access to supportive care, involving different professions. It is proposed by the oncology unit, depending on patients’ need. Palliative care consult provides evaluation if required.

The aim of this study was to evaluate integration of early palliative care in management of cancer patients.

Patients with advanced gastric, pancreatic cancer or cholangiocarcinoma diagnosed between June and September of 2015 were seen less than 4 weeks after cancer announcement, and every 4 weeks until September 2016. Consults evaluated symptoms, alimentation, anxiety, social situation, and perception prognosis.

Twenty patients with advanced cancers were diagnosed and 15 were followed. Thirteen were seen every 29 days: 1 patient died after first consult and 1 was lost of sight. Ten patients died in a mean of 6 months after first consult, and 4 of them in palliative care unit. Twelve patients were already followed by a specific comfort caregiver. Seventy-nine consults were made, and 54 led to adaptations (pain treatment, other treatment, social supports and palliative home care). On the 41 planned consults that were missed, 33 were for chemotherapy pause, 6 for planning dysfunction, and 2 for patient’s refusal.

On visual analogic scale, symptoms tended to lower from first to last consult: pain decreased from 3.9 to 3.6, anxiety from 3.1 to 2.4, anorexia from 4.3 to 3.4.

On the 12 and 10 patients at first and last consult that answered questions about their perceptions, respectively 6 and 4 patients thought that treatment was for cure, 8 and 7 that treatment was to get rid of cancer, and 8 and 9 that treatment was to live longer.

It is possible to propose at same time supportive and palliative care, without increasing anxiety, and with benefits in global management. Early palliative care proposed personalized palliative care in the appropriate place. Patient’s beliefs seemed to remain stable. Prospective randomized study might be conducted in France.
A Survey of Symptom Prevalence in an Inpatient Population within a Cancer Centre in Pakistan Using an Urdu Version of POS (Palliative Care Outcome Score)

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Introduction: Late presentation of cancer is commonplace in Pakistan with an emphasis on antitumour treatments. Symptoms such as pain have been largely ignored although symptoms are the main concern of patient and families.

Aim: To describe the symptoms of a sample of inpatients in a regional cancer centre using the Urdu (national language of Pakistan) version of the Palliative outcome scale (POS), a validated tool with several domains including scores for pain, psychological distress and mood.

Methods: A proforma incorporating demographic data, cancer stage and POS was handed out and collected by ward staff. Completed proforma were stored confidentially. The data was anonymised and entered on Excel and analysed.

Results: All 33 patients approached had metastatic cancer and a DNACPR (do not attempt cardio-pulmonary resuscitation). 31 patients completed the questionnaire (20 females and 10 male) age range 30–69. Of these 20 had pain (8 severe to overwhelming) 21 reported high levels of anxiety, 29 high levels of family anxiety whilst 18 reported feeling depressed. 20 had pain and 18 moderate to severe symptoms other than pain and 20 reduced self-worth. 25 had wasted ½ or more of a day on appointments etc. 22 had practical problems being addressed. Only 3 completed the questionnaire themselves the rest had staff (5) or family (23) help.

Discussion: This is the first symptom survey of cancer inpatients from Pakistan using an Urdu version of POS. The results demonstrate a high symptom burden with majority of patients reporting uncontrolled pain and other symptoms such as High levels of patient and family anxiety, low mood and self-worth. All merit further enquiry to define need and develop effective interventions. Although significant amount of time was spent in waiting for appointments etc the vast majority felt the problems were being addressed. The main limitation is the small number and short period. This will be addressed by ongoing data collection with additional fields.
Designing End-of-Life Conversations from an Ecological Perspective: Understanding Concordance in Hospice Admission Conversations

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Although the decision to enroll in hospice is affected by many factors, little research has examined the role of the hospice admission conversation in end-of-life decision-making – the conversation that happens when a patient is referred to hospice but has not yet decided. Furthermore, little research has examined the multiple expectations that enter these interactions in need of finding a degree of concordance that can enhance how people relate to one another, before making decisions.

**Aim 1:** Enhance clinician understanding of patient and caregiver expectations and needs around hospice admission conversations.

**Aim 2:** Identify communicative strategies to facilitate concordance that incorporates patient and caregiver perspectives.

Data was collected using ethnographic observations and in-depth interviews with hospice nurses, patients and caregivers (n=30). Data was transcribed, coded and analysed using critical discourse analysis.

Hospice admission conversations are ecological sites of struggle around concordance. **Patients struggle** to shift from talking about treatment options to values and preferences at a time when they are extremely ill and fatigued. **Caregivers struggle** to understand what it means to choose comfort over curative care at a time when they are deeply involved in the care of their loved one. **Hospice nurses struggle** with their own comfort talking about dying with patients and caregivers who are not used to talking and hearing things in this way. **Hospice organizations struggle** to keep their doors open (enroll patients) while meeting patients and caregivers where they are.

Where there is struggle, concordance is risk. Our response to difference is the catalyst for discovering intersections between participants’ preferences, concerns and circumstances that conversation concordance. Integrating these perspectives in a way that facilitates concordance is a logical next step to improve communication and high-quality care at the end of life.
Reframing Advance Directives: Approaching Advance Care Planning from Patients’ Perspectives

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Background: Advance Directives (AD) play a role in supporting and articulating patient wishes within the broader process of Advance Care Planning (ACP). The relationship between ADs and ACP, however, is complex, frequently misunderstood and evolving. This paper examines patients’ perspectives on ADs using data from 32 group medical visits with 118 older adults (ages 65 and older) conducted in a primary care setting. ADs have rarely been engaged from a patient centered perspective. Examining how patients and families engage with these tools in the ACP process can transform such conversations and enhance clinical effectiveness.

Aims: Our objective is to enhance clinician understandings of patient expectations and perspectives on the usefulness and purposes of ADs to facilitate high-quality ACP conversations with patients and prepare patients and surrogates for future medical decision-making.

Methods: Data collected from this study includes transcripts from 32 group discussions about ACP, perspectives and progress on working with advance directives, including how to engage as individual patients in the process. Using a team-based approach, transcripts of the group visits were coded and analyzed qualitatively using content analysis.

Results: Three analytical themes emerged from the transcribed group discussion:
1) ADs function as an organizing concept for patients to speak openly about a complex process;
2) interacting with ADs underscores the need for preparatory conversations to ensure forms accurately reflect patient wishes and values, and
3) patients view ADs as a tool for future medical decision-making and not an end goal.

Conclusions and discussion: Patient perspectives on ADs highlight how they mediate patient expression of desires during ACP. Future work will focus on developing and disseminating real-world means of assisting patients with their ACP process, including on-going education regarding the role of AD forms.
Missed Opportunities to Introduce Non-acute Care Pathways for Hospitalized Elderly Patients with Palliative Care Needs

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Background: Most chronically ill older people want to die at home but many still seek hospital services in their last year of life.

Aims: To typify elderly patients who may benefit from earlier transition to palliative care rather than long hospitalization in acute care.


Results: Of the 1,143 hospitalized elderly in the cohort, 48% were managed by four specialties: Geriatrics, Cardiology, Respiratory and Neurology. Only 5 patients (0.44%) had advance care directives. Ten percent died within six months of admission, 60% during the acute hospital stay, 9% later in palliative care services, 2% in hospices, and the remainder presumably at home. One in 10 of in-hospital deaths occurred within a week of admission, and overall median time to death was 41 days. The following indicators could have signaled time for transition to palliative care: relative to the survivors, the deceased were significantly more likely to: be older than 80 years (mean 82.5 vs 79.6 years, p=0.0003); be residents of nursing homes or in supported accommodation (20% vs. 6% of survivors, p< 0.0001); suffer from at least two chronic illnesses (28% vs. 14%, p< 0.0001); have been admitted to hospital at least once in the previous year (73% vs. 57%, p=0.0012); have a do-not-resuscitate order (18% vs.3%, p< 0.0001); and have hospital length of stay longer than a week (mean LOS 9.6 vs. 6.1 days, p=0.0163).

Conclusion and discussion: Communication of imminent death is complex and difficult, particularly in busy emergency departments. However, being alert to the presence of indicators for imminent death could result in earlier referrals to palliative care and less patient and family suffering. Further research is needed to quantify the need for palliative care services and clarify the reasons for their under-utilization in the Australian context.

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Advance Care Planning for People with Intellectual Disabilities, Focus on DNAR Decision-Making

Background: Although we know that the process of end-of-life decisions is more important than the decisions themselves, not much is known about advance care planning (ACP) for people with intellectual disabilities (IDs). Within ACP, patients and their relatives often focus on Do-Not-Attempt-Resuscitation (DNAR) decision-making. The aim of this study was to clarify the problems and pitfalls of non-emergency DNAR decision-making (ACP) for people with IDs, from the perspective of ID physicians.

Methods: This qualitative study was based on semi-structured individual interviews, focus group interviews and an expert meeting, all recorded digitally and transcribed verbatim. Forty ID physicians and trainees were interviewed about problems, pitfalls and dilemmas of DNAR decision-making for people with IDs in the Netherlands. Data were analysed using Grounded Theory procedures.

Results: The core category identified was “Patient-related considerations when issuing DNAR orders”. Within this category medical considerations were the main contributory factor for the ID physicians. Evaluation of quality of life was left to the relatives and was sometimes a cause of conflicts between physicians and relatives. The category of “The decision maker role” was as important as “The decision procedure in an organisational context”. The procedure of issuing a non-emergency DNAR order was important for the ID physicians.

Conclusion: A theory was developed in which was clarified that DNAR decision-making for people with IDs is complex and causes uncertainties. This theory gives good grounds for a method for advance care planning and a training for physicians to deal with uncertainties regarding DNAR decision-making.
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How Is Palliative Terminology Used in Discussing Treatment Options for Patients with Advanced Lung Cancer?

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Aims: To identify information and decision support needs of patients with advanced lung cancer, facilitating discussion of the risks and benefits of treatment options.

Background: Despite evidence that early palliative intervention can improve quality of life and lead to less aggressive care and longer survival, patients with advanced lung cancer often receive systemic anti-cancer therapy. Although guidelines recommend patients are fully informed in making treatment decisions, patients commonly misunderstand disease extent, prognosis, and treatment aims.

Methods: Non-participant observation of 12 MDT meetings and 15 patient-clinician consultations explored how treatment pathways are determined. Interviews with patients and clinicians explored perceptions of treatment options and involvement in decision-making. The OPTION tool was used to assess extent of participation in decision-making. Patient-clinician consultations were analysed using narrative techniques. Analysis findings will inform development of an intervention to facilitate discussion about treatment options for advanced lung cancer.

Results: Communication of palliative chemotherapy as a treatment option in advanced lung cancer varied. Oncologists were concerned with how patients perceived and understood palliative terms. The rationale for recommending chemotherapy with palliative intent was implicit rather than explicit in most situations. Oncologists used palliative terms more openly in discussions around the context of symptom control, particularly intractable pain, and the coordination of end-of-life care. There is ambivalence around the role of the oncologist in offering hope, and the use of palliative terminology.

Conclusions: There is a need for clarity and consensus around the use of palliative terms in consultations between oncologists and patients with advanced lung cancer to decide treatment options. The relationship between palliative terminology and offering hope warrants further exploration.
Patient/Family Education in Palliative Home Care – Between Empowerment and Protection

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Background: End-of-life care at home has been described as complex and challenging for the patients and family caregivers. Several researchers conducted qualitative and quantitative studies to either describe or demonstrate the evident output of psychoeducational groups to prepare the family caregivers for their caregiver tasks. Studies show that the family caregivers prefer individual counselling in their homes. There is a research gap especially on patient and family education that is offered to patients and their caregivers in their homes by the palliative home care teams.

Aims: The aim of the study was to explore the core concepts of the educational interventions offered by palliative home care teams. The goal of the study was to identify the main subjects covered by the health professionals and their use of communicative and relational strategies.

Methods: The data collection was conducted with an ethnographical design. The doctoral student observed the home visits of 6 teams (each one for 2 weeks) and developed field notes of the communicational interaction between the nurses (n=24)/physicians (n=9) and their patients (n=44) and family caregivers. Additional data was collected through a focus group with representatives of these teams. For the data analysis the steps of the Grounded Theory Methodology had been used.

Results: As core concept emerged the “uncertainty” of the patients and the family caregivers. They feel unexperienced, unprepared and therefor powerless. They seek for guidance or reassurance. The palliative care teams as well feel uncertain and respond with rather directive or technical advice and tend to avoid emotional labor. They have an affinity towards protection and comfort care instead of activating the self-management resources of patients and caregivers.

Conclusion: It needs to be further discussed whether the educational approach of palliative home care teams should be more caring and comforting or empowering and engaging.
Don’t Shoot the Messenger: Examining Prognostic Conversations in Palliative Care

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Background: The study of prognostic understanding is imperative as the trend toward individualized medicine continues. However, without guidelines for discussing prognosis, palliative care physicians face challenges presenting prognostic information in a way that optimizes patient understanding, adjustment, and decision-making.

Aims: The study draws on the experiences of experts in palliative care in order to examine the conceptualization and communication of prognosis. We investigate the mechanisms that contribute to patient understanding and uptake of prognostic information.

Methods: 15 oncology, psycho-oncology, and palliative care professionals with specific expertise in doctor-patient communication participated in semi-structured interviews which focused on identifying the breadth of factors underlying prognostic understanding, as well as methods to identify and quantify this understanding. Three independent raters utilized a Thematic Content Analysis framework for data reduction, to identify core themes that reflect unique aspects of prognostic understanding.

Results: Interviews yielded two types of information. Physicians offered ‘best practice’ techniques, including methods for determining a patient’s preferences for and understanding of prognostic information, suggested frequency of conversations, use of survival statistics, and inclusion of family members. Experts discussed the roles of culture, optimism, and hope when addressing prognostic understanding, and grappled with when to intervene when confronted with resistance.

Conclusion and discussion: Despite challenges faced by providers, results emphasize the need for physicians to join with patients to ensure that prognostic information is well understood. Results highlight the salience of health information preferences, the role of optimism, and cultural belief systems and strategies to provide comprehensive prognostic information, compassionately and with respect for each individual patient.
A Narrative of Dying: A Mixed Method Study of Language Used to Describe Dying in an Acute Care Hospital

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Aim: To characterize and understand the language used to describe the deterioration and death of patients in an acute academic tertiary care centre and to identify whether palliative care (PC) involvement was associated with clearer descriptions of this process.

Methods: A chart review of 150 patients who died on an inpatient internal medicine unit was conducted. Patient demographics; cause of death; involvement of PC, social work and spiritual care were extracted. A content analysis was done of the language used to diagnose, and describe patient deterioration and death within the chart.

Results: Of the 150 deaths, the median age was 79.5 (range22–101), 58% were male, and 69% spoke English. A total of 45% of deaths were from cancer, and 66% occurred with prior PC team involvement. Clinicians documented the dying process and imminent death in several manners; some identified the current state or process, the future state (i.e. prognosis) or used the care provided to the patient to imply patient status. There was no documentation of the dying process in 18 (12%) of charts. Clinicians used specific labels; ‘dying’ (24.7%), or ‘end of life’ (15.3%), as well as less specific language; ‘unwell’ or ‘doing poorly’ (6.0%). Prognosis was also used; specific predictions such as ‘hours to days’ (7.3%) to less clear ‘poor prognosis’ (26.0%). At times the dying process was described by the care they were receiving; palliative care (49.3%) or comfort care (28.7%). PC involvement was associated with more frequent use of specific language; ‘palliative care’, ‘comfort care’, prognosis of hours to days, and identify patients that were at ‘end of life’.

Conclusion: Death and dying in hospital is not adequately documented and is often described using unclear and vague language. PC involvement is associated with more frequent and clearer prognoses of death. Education strategies may help improve interprofessional communication through better documentation practices of death and dying.
Introduction of Early Integration of Palliative Care in Oncology Care: Is it a Challenge?

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Introduction: Evidence suggests that early integration of palliative care (PC) in standard care improves patients’ quality of life. In practice, referral to PC still occurs late in the disease trajectory. An important barrier to such early integration is the misconception of patients that PC is only provided at the end of life. Consequently, clinicians are hesitant of early integration of PC: they fear it will upset patients and will decrease hope. We wanted to know how often and for which reasons oncologists did not introduce early integration of PC and examined why patients declined possible early integration of PC.

Methods: Systematic registration of (1) oncologists’ reasons for not introducing a randomized controlled trial of early integration of PC to eligible patients with advanced cancer with a one year survival estimate and (2) reasons of non-participation by patients during the informed consent process.

Results: During the inclusion period (April 2013–March 2016), 359 patients were found to be eligible. The trial was introduced to 276 (77%) of those patients and in total 186 (67%) patients were included. The oncologists’ reasons for not introducing the trial were unspecified for 51 (14%) patients. For 32 patients (9%) the oncologists deemed that the patient could not handle an early introduction of PC. Ninety patients (33%) declined participation, most frequent reasons for non-participation were: not interested (n=62; 69%) and perceiving the term “palliative care” as threatening (n=14; 16%).

Conclusion: Oncologists were able to introduce early integration of PC to two third of eligible patients and deemed that 9% of patients would not be able to handle such an early introduction. Thirty percent of patients refused participation, one third because they specifically perceived the term ‘palliative care’ as threatening. This shows that PC is still not entirely understood by patients. Efforts are needed to further clarify the meaning of PC to cancer patients.
Perception of Curability in a Cohort of Advanced Cancer Patients Receiving Palliative Care

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Introduction: Advanced cancer patients (ACP) referred to palliative care (PC) need to know their diagnosis to make decisions. The literature reports that a third of patients referred to PC believe that their cancer is curable. Little is known about what patient characteristics are associated with patient perception of curability.

Aims: To report the proportion of ACP referred to PC who believe that their cancer is curable and to identify characteristics associated with this finding.

Methods: Data was obtained from a multisite observational study. ACP were assessed by the PC team at an academic hospital in Santiago, Chile were enrolled in this study. Baseline demographics, perception of curability and time from diagnosis were assessed.

Results: 100 patients with a mean age of 50 years old were included. 48% were female and 45% of patients had a Karnofsky performance status (KPS) ≥80. 39% of patients believed their cancer was curable. The univariate analysis showed an association between believing that cancer is curable with lower educational level (Cancer is curable: < 8 years of education (y) =11; 8–12y=22; >12y=6 v/s cancer not curable: < 8y=8; 8–12y=31; >12y=22; p=.036) and with shorter log time from diagnosis (5.0 v/s 5.9; p=.014). There was no association with KPS ≥80 (41% v/s 51%; p=.313).

In the multivariate analysis, perception of curability was independently associated with educational level (baseline < 8 years of education: OR=.09, for 8–12 years, p=.011; OR=.04, for >12 years, p=.002), log time from diagnosis (OR=.06 per point increase, p=.008) and KPS ≥80 (OR=3.91, p=.025).

Conclusions: 39% of ACP referred to PC believed that their cancer was curable. These patients had a lower educational level, a better KPS and a shorter time from diagnosis. Further studies are needed to improve communication of diagnosis before referral to PC.
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What’s the Story? Examining the Narratives of Clinicians, Patients and Carers Negotiating Treatment Options in Advanced Lung Cancer

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Aims: To identify the information patients need when considering treatment options for lung cancer, and develop a decision support intervention facilitating comprehensive discussion of treatment options.

Background: There is concern around presentation, discussion and understanding of treatment options to patients with advanced lung cancer, who risk undergoing systemic anti-cancer therapy where early palliative care intervention could enhance quality of life and survival. Understanding of diagnosis, prognosis and treatment aims is necessary for patients to be fully informed.

Methods: Multi-phase study with non-participant observation of 12 MDT meetings and 15 patient-clinician consultations exploring how treatment pathways are determined. Interviews with patients and clinicians explored perceptions of treatment options and involvement in decision-making. The OPTION tool assessed extent of participation in decision-making. Patient-clinician consultations and follow-up interviews were analysed using narrative techniques.

Results: Patients prioritised quality of life, treatment practicalities and availability of options. Carers prioritised symptoms, patient function in everyday life, and patients’ ability to tolerate and comply with treatment. Prognosis discussions varied from direct enquiry by the oncologist to, more commonly, patients or carers initiating discussions. There were challenges for patients around diagnosis implications, the wish to make the best choice for them personally and the speed necessary to process information.

Conclusions: Clinicians, patients and carers bring prior agendas, information and expectations to the decision-making consultation for treatment options in advanced lung cancer. Clinician require skill in negotiating where these agendas differ. Key points influencing decisions are prognosis, the patient in everyday life and the role of the oncologist in offering hope. Communication and interpretation of palliative terminology is complex.
The Effects of End-of-Life Discussions on Patients’ Good Death and Quality of Care

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Background: End-of-life (EOL) discussions are important for providing appropriate care to patients with advanced cancer at the end of their life. To explore the relationship between EOL discussions and the patient’s quality of death and the quality of care which they received at the end of life, from bereaved families’ perspective.

Methods: This was a nationwide questionnaire survey of bereaved families of deceased cancer patients who died at 75 sites (20 inpatient palliative care teams in acute hospitals, 33 palliative care units/inpatient hospices, and 22 outpatient clinics that provide home palliative care service) in Japan. 13,711 bereaved family members of cancer patients who died before January 2014 in each of the participating institutions were potential participants. We evaluated the prevalence and details of EOL discussions which were defined as “a discussion with physicians about the preferred place of death or resuscitation”. We also evaluated the quality of death (Good Death Inventory: GDI) and the quality of care (Care Evaluation Scale: CES).

Results: 9123 questionnaires returned (response rate 67%). Of those, 80.6% had EOL discussions. After propensity score weighted adjustment, EOL discussions were associated with better quality of death (The GDI score, 47.2 ± 8.5 vs. 46.1 ± 9.4; P < 0.001) and better quality of EOL care (the CES score, 84.1 ± 11.4 vs. 78.9 ± 14.3; P < 0.001). Moreover, significant differences were found on the trend test between those without EOL discussions and those initiating EOL discussions < 1, 1–3, and >3 months before the patient’s death in terms of mean scores of the GDI and the CES (P_trend < 0.001 and P_trend < 0.001 in weighted analysis, respectively).

Conclusions: EOL discussions may contribute to achieve good death and receive quality care at the end of life. EOL discussions should be initiated with advanced cancer patients when physicians expect a patient’s prognosis is limited to several months.
Attitude of Family Members of Elderly Patients with Progressive Incurable Chronic Diseases to Communication with Doctors during Treatment of these Patients in Critical and Intensive Care Units

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Background: Family members (FM) of the elderly patients with progressive incurable chronic diseases (EPWPICD) often have to make “surrogate” decisions instead of patients, especially during those treatment in critical and intensive care units (CICU). Thus, the communication of the FM with CICU physicians becomes important.

Aim: Study the opinions of FM of EPWPICD on the communication with CICU physicians.

Materials and methods: 27 FM of the 75–82 year-old 20 EPWPICD receiving treatment in the CICU in period 02/2014–02/2015 were selected by the method of “available selection”. The FM filled in questionnaires covering various aspects of communication with physicians including patients’ prognosis, death pathways, treatment plans and religion. FM ranked their responses from “0” to “10” (“0” represented “never” and “10”-“always”). The collected data were re-coded into three categories: 0–3 = “Never/Rarely/Unsatisfactorily”, 4–7 = “More or Less” and 8–10 = “Often/Always/Satisfactorily”. Descriptive statistical analysis was conducted to assess the variable distributions.

Results: Only 25.9% of FM assessed the communication positively; 51.8% of FM considered that doctors “don’t” or “more or less” discuss with them the possible worsening of the patient’s conditions; 63% assessed their communication with the doctors as insufficient; 14.8% had received a satisfactory explanation as to how the patient’s death may occur. 55.5% of the patient’s FM, considered that the physicians experienced difficulties while speaking about the death of the patient.

Half of the patient’s FM mentioned that the doctor had never/rarely talked about life-related issues pertaining to the patient’s spiritual and religious needs.

Discussion/conclusion: The study proves that the satisfaction of FM of the EPWPICD is not determined only by the results of treatment, received in CICU but by adequate communication, which shows the personal respect of the physicians to the patient and the family.
Improvement of Palliative Care Management at our Palliative Care Unit by Implementing a “Family Consultation Concept” to All In-house Adult Cancer Patients

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Background: Appropriate palliative care requires good communication skills enabling the professional to obtain important information with empathy. The “Family Consultation Concept” (FCC) covers physical, psychological, social and spiritual aspects of the patient and reveals the resources of the family. This enables professionals to reassure the patient optimal palliative care and future planning.

Aims: Improve palliative care by implementing the concept in the wards daily routines. Secure high percentage of patients invited to FCC and increase percentages of families receiving FCC. Secure all staff trained in the concept. All adult cancer patients admitted > 7 days and relatives invited to participate in FCC.

Method: Consultations always involved the patient, one or more members of family, a nurse and a doctor. Course of disease was summarized and palliative symptoms explained. The staff should, with respect for family integrity and autonomy, be aware of any needs or worries, the family might express. The development and implementation of the FCC was carried out by using PDSA (plan, do, study and act). A guideline of all important issues was made as well as a written invitation to participate. Staff was trained. We extended our patient-board with a special column in order to register dates of invitation and consultation for each patient. The board was “pictured” once a week as a sample of progress and maintenance.

Results: Implementation was carried out from May-October 2016. 75 patients were admitted > 7 days. The rate of patients invited to FCC increased from average 63 % before to 93 % during that period. The next 6 months we plan to maintain the high rate and study what impact, the FCC has on the families in terms of meaningfulness and security.

Conclusion: Using PDSA, we found that few initiatives (training, guide, written invitation, board, weekly samples) increased focus on the FCC – thereby improving the advanced care planning of our patients.
Medical Coordination in the Nurse Home Improves the Treatment of Residents and Contentment of the Staff

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Background: In crisis situations, comprehensive palliative care in care homes is frequently hindered by the absence of a doctor.

Aim: To improve advanced care planning in care homes by the establishment of medical coordination.

Methods: Medical coordination facilities were established in three care homes housing a total of 266 residents. The effect was compared with three care homes without medical coordination. Formative evaluation: In two focus groups, at the start and around the end of the twelve-month period the involved persons in the test and reference care homes as well as practicing doctors and health experts exchanged their views on the subject. 16 experts provided detailed information about specific aspects of the model project in the course of qualitative interviews. Furthermore, in a summative evaluation the following aspects were investigated: emergency plans, the registration of presumed will, emergency doctors’ missions, the number of ambulance services, and the provision of emergency medication. Statistics: Mann-Whitney U-test, Box-Ljung.

Results: Representatives of the test care homes reported their positive views concerning the model project: the expansion of consciousness and the introduction of structures for palliative work in homes for the aged, optimized coordination between nurses and doctors, the systematic documentation of helpful emergency plans, stores of on-demand medication in care homes, uninterrupted care, improvement of quality, and reduction of costs. The time curves for the five care-home-related parameters revealed significantly positive changes compared to reference care homes: 74%:48% and 61%:39%.

Conclusion: Medical coordination in the care home improves the quality of care for the residents. The economic evaluation shows that undignified ambulance services and unnecessary emergency doctors’ missions can be considerably reduced by medical coordination.
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Discussing Place of Death: Experiences of Specialist Palliative Care Professionals

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Background: Patients at end of life from a European context view dying in a preferred place of death as a priority. Endeavouring to meet this priority is a key focus of specialist palliative care and is increasingly utilised to measure the quality of palliative care services. In Ireland, forty eight percent of all deaths occur in acute hospitals. Little is known about how palliative care professionals undertake sensitive discussions about patients preferred place of death.

Aim: To describe the experiences of hospital specialist palliative care professionals discussing place of death with patients and families.

Method: A qualitative descriptive design was used. A sample of five doctors and six nurses working in specialist palliative care within the Irish acute hospital setting were the participants. Face to face semi-structured interviews were conducted using a devised interview schedule.

Findings: Four major themes emerged from the data. These were antecedents to end of life discussions, the dynamic nature of discussions, where to die and developing competence. The findings show that these discussions do not occur in isolation. Rather they are a culmination of many conversations over time that ultimately leads to a preference being arrived at. The quality of the care received appears to be more important than the location of that care. The value of team work was evident throughout these discussions.

Conclusion: Place of death discussions are planned, are not formulaic but are tailored to fit the individual. Much preparation in getting to know the patient and family occurs beforehand. These dynamic discussions are such that they often transcend words and thus rely on the power of what is not said. The value of team support is crucial to their success and the environment of specialist palliative care teams within this setting appears to be conducive to gaining support and expertise in this area.

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The Nurse-patient Relationship Saves the Person with Advanced and Terminal Cancer from Inner Loneliness

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Background: The nurse-patient relationship is a key element when caring for Persons with Advanced and Terminal Cancer (PATC). However, how to build up and develop an authentic relationship it is a challenge for nurses. The results derived from a research guided by van Manen’s Hermeneutic-Phenomenological Method (HPM) may contribute to the practices and experiences of nurses improving the relationships with PATC.

Aims: To study the relationship between oncology nurses and PATC in order to grasp and understand the essential elements of the relationship between oncology nurses and PATC.

Methods: van Manen’s HPM. 21 PATC hospitalized in the oncology ward of Clínica Universidad de Navarra were phenomenologically interviewed from June of 2012 to December of 2014 in order to gather their lived experiences. They were asked to describe their relationship with oncology nurses. The principal social sciences, philosophical and philological methods were applied with the purpose of grasp and describe the essence of the relationship between oncology nurses and PATC.

Results: Oncology nurses play a decisive role in the illness global experience of PATC. When the loved ones of PATC do not like or are unable to tackle with them difficult issues as their last wishes or death, patients are forced to live without venting their emotions and find themselves feeling with inner loneliness. However, when a caring atmosphere of trust is set up between nurses and PATC, nurses are capable to address the intimate and sensitive issues that patients need to express. In this way, nurses give the power to PATC to open their heart to tell their private matters and inner worries making them feel with inner wellbeing.

Conclusions: A relationship steeped in trust makes possible for PATC to express and share their most intimate and profound existential concerns. When nurses and PATC maintain an authentic relationship, PATC are saved from the loneliness to which sometimes they are forced to live.
Confronting the Forthcoming Death: A Classic Grounded Theory

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**Background:** Entering palliative care is in many ways a sad and overwhelming experience. Several researchers state that more attention needs to be given towards how patients perceive their own situation in palliative care since it is of importance to comprehensively understand how these patients cope with their situation.

**Aim:** The aim of this study was therefore to develop a classic grounded theory of patients receiving palliative care, exploring their main concerns and how they cope with such concerns.

**Method:** A classic grounded theory approach was used on data obtained from interviews and biographical books. The interviews were informal open-ended conversations where patients were encouraged to speak openly about their situation when living with an incurable disease. Through different stages of coding and theoretical sampling the theory emerged as an abstraction of the actions and meanings of patients receiving palliative care.

**Results:** “Confronting the forthcoming death” emerged as the pattern of behavior through which patients deal with their main concern: living in uncertainty of a death foretold. The theory involves four strategies; *Seeking concrete knowledge*, *Shielding off*, *Seeing things through*, and *Embracing life*. Holding on to hope and Suffering are also ever present.

**Conclusion:** The theory shows that there is no easy way straight ahead; patients strive to confront the situation as well as they can, both wanting and not wanting to know what lies ahead. For health professionals, knowledge about how patients use different strategies, which can be used in tandem or succession, or shifted back and forth between over time, to confront their imminent deaths, can create an awareness of how to encounter patients in this uncertainty.
Exploring How Disease Context Uniquely Influences Attitudes, Approaches and Processes of Advance Care Planning Engagement for Patients and Healthcare Providers

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Background: Individuals with capacity can consent to or decline medical interventions; however, many seriously ill people and those nearing death are no longer capable of making or communicating decisions. Advance Care Planning (ACP) is “the development and expression of wishes for the goals of medical treatment and the continuation or discontinuation of such treatment and care”. Little work has been done to explore how disease contexts may uniquely influence the attitudes, approaches and processes of ACP engagement for patients and healthcare providers.

Purpose: In this multi-perspective study we compared perceptions, from three disease contexts that have a recognized need for ACP. We aimed to understand how disease context may influence interpretation and uptake of that healthcare system’s ACP policy and procedure with the purpose of generating strategies to better target rates and quality of ACP engagement.

Method: We applied a qualitative interpretive descriptive (ID) design to prospectively characterize the approach, process and assess the barriers and facilitators to uptake of ACP from the perspectives of two stakeholder groups: patients and health care providers (HCP), within three different disease contexts in the out-patient clinical setting. Data was collected using semi-structured one-on-one interviews with patients and HCP.

Results: In the descriptive part of analysis, two key findings emerged: lack of shared understanding and a lack of consistent process related to ACP. We further found that ACP understanding and process was variably driven by:

1) disease burden,
2) possibility of medical intervention,
3) the nature of the physician-patient relationship and
4) the perceived function of ACP conversations.

Conclusion: Despite the implementation of a provincial ACP policy, there is little that is standard about the ACP process. Also there appears to be a very practical tension between standardization and routine in quality and safety of patient care.
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Essential Communication: Audit of Hospital Deaths Looking for Communication to Support Families

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Background: “Recognising that someone is dying & having open & honest conversations is crucial to patient & family experience.” (One chance to get it Right 2014). If there is no documentation of the conversation, then it cannot be assumed that an appropriate conversation took place. Where a patient & family were seen by the Transform Team (TT) or Specialist Palliative Care Services (SPCS), conversations were well documented, but was this the case where the TT or SPCS were not involved?

Method: A retrospective review of electronic TT/SPCS/hospital notes for 100 consecutive hospital deaths was undertaken. The standard was a supportive family conversation ensuring understanding that death might be imminent.

Results: 37% of those who died in hospital were seen by TT or SPCS & conversations about the fact the patient was likely to be dying and what to expect were documented. 63% had not had involvement from TT or SPCS. From these a further 51% were found to have documented conversations (therefore 88% in total). 12% had no conversation documented – there was sudden event as cause of death & no opportunity for a conversation in 7%; there were no family members or family member had dementia in 2%. 3% families apparently received no supportive conversation – dying was not recognised in 2%; & 1% had no documented conversation.

Conclusion: Dying appears to be recognized in the vast majority of people who do not suffer an unexpected sudden event. Where the patient is recognised as likely to be dying, there is a documented conversation with families unless there is a good reason (no family able to have conversation). Efforts need to be made to recognise those likely to be dying who are currently not recognised, if this is possible, so that appropriate conversations can be organized and because this conversation is so important to the wellbeing of the bereaved, there should be no instances where a conversation does not take place and there is no documentation to explain why not.
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End-of-Life Care Decisions Using Korean Advance Directives among Cancer Patient-Caregiver Dyads

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Background: The Korean advance directives (K-AD) consists of a value statement, treatment directives, preferences for cardiopulmonary resuscitation (CPR), artificial ventilation, tube feeding, and hospice care, and a proxy appointment. K-AD can facilitate a patient’s decision-making for end-of-life (EOL) care. This study aims to examine the extent to which patient-caregiver dyads would use K-AD and agree on decisions for EOL care.

Methods: 81 cancer patients were invited to participate. The final sample consisted of 44 patient-caregiver dyads who completed survey questionnaires, including K-AD. To examine the content of the K-AD value statements content analysis was conducted. The Cohen’s kappa coefficient was estimated to determine the degree of patient-caregiver dyadic agreement of K-AD.

Results: Spouse (70.5%) and adult children of the patient (20.4%) were primary caregivers with perceived bonding rated as fair (31.8%) or good (65.9%). Rejection of K-AD was mainly because of difficulty in deciding EOL care (50%). Comfort in dying was the most common theme of the value statement for patients (73.8%) and caregivers (66.7%). For treatment directives, dyads advocated for hospice care (66.7%) and reduced support for aggressive treatments of CPR or artificial ventilation. CPR (k = .43, p = .004) and artificial ventilation (k = .28, p = .046) showed significantly mild to moderate concordance among the dyads. Sixteen out of the 21 dyads identified their spouses as a proxy, with others designating their adult children.

Conclusion: The degree of patient-caregiver concordance surrounding K-AD value statements, treatment directives, and proxy appointments seemed applicable with mild-to-moderate concordances. The findings of the study are exploratory but suggest the need for ongoing EOL discussion where patient-caregiver dyads are encouraged to participate in the decision-making for EOL care.
Resuscitation Options and Preferences: Communication during Patient-physician Encounters

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Background: In Switzerland, discussions regarding cardiopulmonary resuscitation (CPR) options are practiced routinely for hospital admissions of geriatric and seriously ill patients. The information provided by the physician influences the patient’s decision. Yet, existing recommendations do not give sufficient information on how to communicate with patients about potential CPR.

Aims: We aim to explore the process and content of CPR discussions and investigate the difficulties that physicians face when leading them. The results will be used to develop a professional training module for improving CPR-related communicating.

Methods: We study CPR discussions that occur during the patient-physician encounter on admission to a geriatric rehabilitation facility of a Swiss university. We use a mixed-methods approach combining ethnographic observations, audio-recordings of the encounters, and semi-structured interviews. The transcripts of the recordings are analyzed through thematic and conversational analysis (qualitatively) and content analysis (quantitatively).

Results: Initial results show that most physicians fail to provide accurate details about CPR (chances of success, risks, long-term consequences) and to explore patients’ expectations regarding the quality of life. Though most physicians have a pre-formed medical opinion before approaching the patient, they rarely voice it and try to persuade the patient or negotiate a decisions conforming to their own opinion.

Conclusion: Appropriate communication is a core component of patient-centered healthcare, particularly when it comes to introducing sensitive matters and dealing with vulnerable populations such as hospitalized geriatric patients. Early advance care planning, initiated well before hospitalizations, may ease hospital discussions about CPR preferences.
Description of Behaviour Styles to Improve Communication with Patients with Advanced Chronic Conditions (PACC), Patients with Chronic Conditions (PCC) and their Families. Study of the Spanish Population

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Background: Communication skills are important for a successful end-of-life (EOL) interview in palliative care. Recognizing different behaviour styles can help convey information better. People with different behaviour styles may be receptive to different modes of presenting information. The four behaviour styles receive information effectively in different ways.

Aims: Describe the different behaviour styles of patients and their families using the DISC system (Dominance, Influence, Steadiness/submission, and Conscientiousness/compliance).

Methods: During an interview, patients and families were asked to list their behaviour style using the DISC system. We displayed a table with four behaviour styles and their characteristics. We asked the interviewee to identify with one or two of them, and of those, with which they identified most. Utility and appropriateness of the interview were asked. A standard descriptive analysis was carried out by SPSS 21.0.

Results: 23 patients and 19 family members were interviewed. 11 men and 31 women. Average age was 72.02 ± 14.96. PACC(13%); PCC(87%). The prevalent behaviour styles were: D (16.7%) I (42.9%) S (21.4%) C (19%). The prevalent mixed performance styles were: DI/ID (19%); IS/SI (35.7%); SC/CS (26.2%); CD/DC (19%). The prevalent behaviour styles in patients were D (17.4%); I (43.5%); S (17.4%); C (21.7%). The prevalent behaviour styles in families were: D (15.8%); I (42.1%); S (26.3%); C (15.8%). The interview was extremely useful 38.1%, very useful 52.4%, extremely appropriate 42.9% and very appropriate 50%.

Conclusion: The behaviour styles most prevalent in our Spanish population were influence behaviour followed by and the Influence/Steadiness mixed behaviour style. Recognizing different behaviour styles can help convey information about EOL care better.
**Art-therapy: Stimulation of Residual Capacities in Patients with Dementia**

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**Introduction:** Patients with dementia (Alzheimers disease or other forms of dementia) sometimes attend group sessions of art-therapy. Beyond obvious pleasure, could art-therapy be capable of connecting the person in all its human vitality and enabling stimulation of certain residual capacities in patients with dementia?

**Method:** An exploratory study carried out by an art-therapist/cellist working weekly for 4 years with patients resident in a long-stay hospital unit. The study concerns 70 sessions; 42 resident;, average age 88 years; 86% dementia, 5% bedridden, 15% aphasic, 25% wandering, 15% psychotic. Concerts were conceived combining the cello, percussion, bells, poetry and dance, aimed at generating psycho-emotional states (listening to lively music from a targeted repertoire), stimulating memory capacities (songs and words, tallied grid of reassimilated words), restoring confidence and self-esteem (musical and poetry improvisation, grid of individual involvement) enlivening motor capacities (playing instruments, choreography, grid of movements developed), expressive capacities (recital, bodily expression, collection of works created) and relational capacities (group dynamics, grid of relational capacities). An observation form was used to assess the patients, featuring items targeting the therapeutic strategy adapted to each patient.

**Results:** The impact of music is clearly evident revealing the possibility of stimulating residual capacities whether they be cognitive, motor or relational, improvements in self esteem and sociability, minimising behavioural or thymic disorders, relief of pain and anxiety as well as regaining a taste for living.

**Conclusion:** This experience has produced encouraging results nonetheless limited by the length of sessions. The study shows the extent to which the calming, energising and unifying properties of art can contribute to stimulating residual capacities in patients with dementia participating in an activity in a group dynamic.
Health Care Professionals’ Experiences with Conducting Advance Care Planning Conversations in Oncology: An International Focus Group Study

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Background: In oncology, both Health Care Professionals (HCPs) and patients experience Advance Care Planning (ACP) conversations as difficult and the rate remains low. Currently, a facilitated ACP Respecting Choices (RC) program is tested in a Phase III multi-center cluster-randomised clinical trial (ACTION study) in 6 European countries. Lung and colorectal cancer patients are invited to take part with, if they wish, a relative to have one or two conversations with a trained HCP (facilitator) to consider their goals, wishes and preferences for future care and treatment. Little is known about the facilitators’ experiences delivering the ACP RC intervention.

Aim: To understand how facilitators experience implementing and delivering the ACP RC conversations.

Method: Seven facilitator focus groups, involving 28 respondents from all participating countries, were recorded, transcribed, anonymized, translated into English and uploaded to NVivo 11 for comparative thematic analysis. Transcripts were open coded and categorized by the international research team. Results were validated by representatives of all participating countries.

Result: Several key themes were identified. Most facilitators welcomed the opportunity to be involved in the ACTION study as a means of learning new skills in an important area of practice. They found discussing ACP with a script to be challenging, and to conflict with their usual mode of communication with patients. Facilitators stressed the need for communicative skills during the discussion to attune to patients’ situated agendas and emotional needs. Facilitators felt that a key benefit of the RC intervention was that it provided an open discussion between the patient and their relatives.

Conclusion: Facilitators experienced benefits of the ACP RC conversations and felt it a privilege to be a facilitator. However, they emphasized the challenges involved in responding sensitively to their perception of the patients’ needs and emotional distress.
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Communication in Palliative Care: A Review of Recent Literature

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**Background:** Communication is an important element in palliative care. The quality of communication with patients, family, and team members is indeed found by medical specialists to be fundamental to the quality of care for the dying.

**Aims:** To know the most important aspects of communication at the end of life as well as the techniques of communication skills and establish the importance of communication prognosis.

**Methods:** We performed a literature review of communication at the end of life using Medline as search. In the search criteria, the following keywords were included: “communication” “palliative care” “bad news” and “humans”. Inclusion criteria were: articles which strictly speak in palliative care and studies about communication non-focused on a single country. Exclusion criteria were: articles not available full text, articles that are not written in English and old articles (since 2004 – inclusive – onwards).

**Results:** We obtained 53 items. The great majority of articles (56%) were original articles. 28% literature reviews, 7% opinion articles and 9% other types of items. According to the subject, we got articles that spoke of techniques communication skills, prognostic information, decision-making, communication in different services, non-oncological diseases and advance care planning, mainly.

**Conclusions:** The need for communication at the end of life has a growing base of evidence. The main recommendations for effective communication can be summarized in six steps, according to the protocol “SPIKES”. It has demonstrated the importance of advance care planning and the main role in communication hope to give bad news. It is essential to carry out effective communication with patients and families. The training of health professionals should include the development of communication skills that help manage the most appropriate way of handling these patients.
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**Serious Illness Care Programme UK: Assessing the ‘Face Validity’ and Acceptability of a Serious Illness Conversation Guide**

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**Background:** The Serious Illness Care Programme (the programme), developed in the US by Ariadne Labs, is a ‘systems wide’ complex intervention to support communication and individualised care planning, between clinicians & patients with serious illness. In collaboration with Ariadne Labs the programme has been developed for use within the UK, with pilot implementation funded by NHS England. Within the programme, clinicians are trained to use a Serious Illness Conversation Guide (the guide) to structure conversations with patients/families; prior to implementation the appropriateness of the guide for the UK context was assessed.

**Aims:** Establish ‘face validity’ & acceptability of the guide within the UK

Develop Serious Illness Conversation Guide UK

**Methods:**

Nominal Group

Participants: 3 expert groups: 5 Oncologists, 5 Communication Skills experts, 4 Palliative Care specialists

**Objectives:** Review guide; reach consensus; comment on applicability within UK

Cognitive Interviews; ‘think aloud’ technique

Participants: 6 patient/public representatives

**Objective:** Understand how respondents perceive & interpret prompts in the guide; assess format, context, language.

**Results:**

Nominal Group

Consensus: guide provides support for clinicians to initiate difficult conversations. Minimal amendments suggested.

Cognitive Interviews

- Overall concept valued; promotes ‘partnership’ approach to care planning;
- ‘Formality’ of some words/phrases a concern: goals, priorities and wishes, abilities, critical;
- Education and training key; guide must enable flexibility;
- Remove “we’re in this together”.

**Conclusion:** Participants felt the guide would aid communication between clinicians and patients, and the approach was valued by all. Small amendments identified; revised guide for the UK developed.

NHS England has funded a National pilot of the UK programme at three NHS sites; research to investigate acceptability & feasibility of implementation is being undertaken at one North West cancer centre.
Surfing through World Palliative Care Day: Spain’s Impact

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Background: Currently, Internet has become an essential tool, providing information that travels around the world in seconds. When something happens, we can see its online repercussion, giving us an idea about how many people could be reached.

Last 8th of October, social media and digital press were full of news related to palliative care, because it was the World Hospice and Palliative Care Day. In a country with insufficient pediatric palliative care attention, how much do we talk about this day? How do we care about this health problem? Can we measure it?

Aims: Reflect on the effect of this day in Spain, in order to improve strategies for a better impact next time.

Methods: Analysis of the most important spanish hashtags in Twitter, and news from the most read online newspapers in relation with palliative care the 8th of October.

Results:

<table>
<thead>
<tr>
<th>Hashtag /Number of tweets /People who tweeted it / Potential Reach</th>
</tr>
</thead>
<tbody>
<tr>
<td>#morirsindolor /1438 /776 /1.133.165</td>
</tr>
<tr>
<td>#paliativosvisibles /1084 /725 /1.155.433</td>
</tr>
<tr>
<td>#cuidadospaliativos /835 /817 /1.770.529</td>
</tr>
<tr>
<td>#diamundialcuidadospaliativos /68 /57 / 74585</td>
</tr>
<tr>
<td>#paliativospediatricos /8 /6 /2054</td>
</tr>
<tr>
<td>#cuidadospaliativospediatricos /3 / 3 /1329</td>
</tr>
</tbody>
</table>

From the 15 most read online newspaper in Spain, 6 of them wrote about palliative care. In 4/6, pediatric palliative care is included (El mundo, El Confidencial, Europapress, Ideal)

Conclusions: If we want to succeed in the expansion of palliative care through Twitter, people who have more followers needs to be implicated due to their influence.

The most popular hashtags were in relation with characteristics or demands from palliative care (“die without pain”, “palliative visible”) but not with the world palliative care day itself.

Although our work it’s increasingly present in social media and newspapers, we need to focus on pediatric palliative care, which doesn’t have the attention, dedication and resources that they deserve.
Perceptions of Success Rates of Cardiopulmonary Resuscitation: The Next Generation

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Background: Cardiopulmonary resuscitation (CPR) discussions can often be emotional and challenging situations for both patients and healthcare professionals. Our previous survey of the adult population revealed unrealistic perceptions of success rates of CPR.

Aim: To investigate whether our future adult population also share these misperceptions.

Methods: A survey was conducted by two work experience students at two separate secondary schools in Nottingham – The Becket School and Nottingham High School. Participants were from both sexes and aged between 16 and 18 years old. The survey involved a questionnaire asking individuals to decide on the likelihood of success of CPR following cardiac arrest in three separate theoretical case scenarios. Case 1 was of a previously fit and healthy 25 year old, case 2 was a 60 year old lady in a hospice with widespread cancer who had exhausted all therapeutic options, and case 3 was of an 80 year old living in a nursing home who consequently developed a severe pneumonia.

Results: In total 174 surveys were completed, of which encouragingly 78% of teenagers believed that the 25 year old had at least a 70% chance of survival following CPR. However the vast majority of the teenagers surveyed (72%) also believed that the end-stage cancer patient had at least a 30% chance of survival following CPR. More reassuringly, only 21% believed that the elderly patient in case 3 had a 30% chance of survival following CPR. Worryingly, nearly 5% of those surveyed believed that all three patients had the same chance of survival following CPR.

Conclusion: This survey highlights that the teenage population have significant misperceptions about the success rates of CPR in terminally ill cancer patients. It emphasises the need for these misperceptions to be addressed so that patients and their families can have more informed discussions, and also make more informed decisions in regards to CPR.
Towards Implementation of Advance Care Planning in Hospital: Did Anyone Think about Involving the Hospital Professional?

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In Belgium, Advance Care Planning (ACP) isn’t well implemented in hospital practice. One of the premises for successful implementation is involving the adopters in the implementation process. In hospital, important adopters of ACP are physicians, nurses, social workers and psychologists. First, this study wants to understand what about ACP is of value to these hospital professionals. Second, this study aims to get an insight in the barriers and facilitators to have ACP conversations. Twenty-four interviews were taken from the four hospital populations and analyzed with Content Analysis based on Grounded Theory. Three independent external auditors surveilled the analysis. Results show that hospital professionals value especially the process component in ACP. Professionals feel that the make-up of ACP in hospital is not guaranteeing ACP communication for all patients. Perceived barriers are related to the structure of care, the co-operation hierarchy between disciplines, the spontaneous nature of ACP and upon personal convictions.
Abstract number: P01-175  
Abstract type: Poster Exhibition

**When Do Palliative Patients Die during the Day, during the Week, during the Year?**


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**Introduction:** In the communication with palliative caregivers ask terminal patients and their family frequently when patients pass away preferably. Mostly they have a gut feeling that more patients die in the night, more in the weekends than during the working days and more in wintertime than summertime. Although data are available everywhere, this is not much analyzed, data are scarce in literature and so a scientific answer to these questions is lacking.

**Material and methods:** All the patients that died in the palliative care unit in the University hospital of Leuven between 1-9-1999 and 31-12-2016 were registered in a database. An analysis is made when they died during the day, during the week and how dead was spread over the year.

**Results:** Clinical data of nearly 3000 palliative patients that passed in the palliative care unit in the University hospital of Leuven (Belgium) between 1-9-1999 and 31-12-2016 were collected by this research group in a comprehensive data base.

It is important to mention that 98% of the patients died naturally without postponing or hastening death. Two percent of the patients got palliative sedation in a terminal phase of the disease for refractory symptoms and 0.2% got euthanasia in a terminal phase according to the criteria of the Belgian euthanasia law after repeated request of the conscious patient.

Every hour during a day died 4±1% of the patients, every day died 14±1% of the patients and every month died 8±1% of the patients.

**Conclusion:** The widely spread idea that there specific moments (night, weekend, winter) that patients preferably pass away is a misconception. Patients in a palliative care unit die spontaneously at random equally every hour of the day, every day of the week and every month of the year.
Communication Tools for Palliative Care Teams: The Comfort Project

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Communication is an important aspect of relationship building both between medical teams and patients. It is known that Palliative care team members need to communicate well within their teams, with other medical specialties and with their patients and families so they can provide excellent care. The Comfort Communication Project, supported by Archstone Foundation has been designed with achieving that in mind. Set up as 7 modules, using the COMFORT™ communication curriculum developed by Dr Elaine Wittenberg and Dr Betty Ferrell, enables members of a palliative care team learn communication concepts important for patient-centered communication, explore variety of communication tools used in team-based care.

Modules are set up as follows:
C-communication — learning the patient’s story
O-orientation and options
M-mindful communication
F-family caregivers
O-openings
R-relating: building trust with patients and families
T-team communications

The poster will highlight these 7 modules and provide clinicians with skills they can start incorporating in their teams and organizations to ensure effective communication in Palliative Care. The Poster will also allow for me, as an attendee of the Comfort Curriculum to speak to how our team uses this parts of this model at City of Hope to function with excellence in Palliative Care.

This Poster would be a great standalone session or can be taught in conjunction with the CARES tool that has also been submitted for your conference.
Factors Promoting and Limiting End-of-Life Discussion at Hematologic Malignancies’ Relapse According to French and Belgian Hematologists: A Qualitative Study

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Background: Hematological patients have half as much access to palliative care than their counterparts with solid malignancies. Having an early end of life discussion with the patients is linked to better palliative care for oncologic patient.

Ends: The main end of the study is to understand what makes an end-of-life discussion easy or difficult at the time of relapse of an aggressive hematologic malignancy, according to onco-hematologists. The side issue is to explore their consequences on integration of palliative care in hematology.

Methods: This study presents ten semi-structured, in-depth interviews of French speaking hematologists. Verbatim transcribed from the interviews were thematically analysed according to the grounded theory model.

Results: At the time of relapse, the possibility of an end-of-life discussion is subordinated to the fear of loss of therapeutic alliance. Hematologists have a lot of difficulty opening up to the patients’ subjectivity and to take one stand facing his progress in a therapeutic context. The anticipation of pejorative prognosis is not exploited in a doubt-full situation. Persistent hope silences threat of death.

Conclusion: This study shows the difficulties for clinicians of opening an early discussion, in palliative care of an aggressive hematologic malignancy, about the end-of-life patients’ wishes. These difficulties play a part in the difficulty of integrating the early palliative care in hematology model.
Abstract number: P01-178
Abstract type: Poster Exhibition

Hospice and Designers on Doctor-patient Communication

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The Hungarian Hospice Foundation (HHF) launched a doctor-patient communication program in August, 2014. Due to the psycho-oncology service the experts of the foundation provide, they have a wide and deep knowledge about the problems which cancer patients and their care-givers face in healthcare communication (how to gain all the necessary information, how to get being accepted and understood, how to get the best quality service, etc.). On the other hand the foundation – in everyday cooperation with state healthcare providers – is aware of the communication problems of doctors and nurses as well (keeping the balance between truth and hope in serious health status at the same time, finding the proper level of the communication, avoiding burning-out, etc.). HHF and Moholy-Nagy University of Arts and Design Budapest (MOME) evaluated a 3-term program for the MA students of the Design Institute of MOME. There was a two week communication program in the curriculum of each term. During the first week HHF and MOME organised lectures, talks and workshops on the communication and psycho-oncological aspects of the doctor-patient encounters, focusing on both of the curable and terminal period of cancer. During the second week students prepared a lot of creative products: the name and the logo of the program, posters and other creative art works, which can be used in social education. In the second and third terms students of medical universities from Budapest and Marosvasarhely (Romania) joined the program, making it interdisciplinary.
**Talking about Wishes and Priorities at the End of Life Using Cards as a Conversation Tool**

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**Background:** Palliative care is an active and holistic care that aims to take patients’ needs, values and priorities as its starting point. If healthcare professionals do not know the patient’s individual preferences, the care given may be influenced by what professionals know is most commonly preferred, rather than based on the patient’s own wishes. Previous research show that health care professionals may find it difficult to talk about these issues and we also need to know more about patients’ preferences. Another question is whether any tools could be conducive for such conversation.

**Aims:** To explore how patients receiving palliative care experience discussing wishes and priorities by using cards with preprinted statements.

**Methods:** The statements were developed from several national and international sources and commonly used instruments within palliative care. Ten patients receiving specialized palliative care were asked to choose the ten most important statements from a deck of 46 cards, including statements such as “to be free from pain” or “to sleep well”. The participants were also encouraged to comment the statements on the cards and how they experienced talking about end-of-life wishes and priorities.

**Results:** None of the patients considered the statements on the cards as offensive. They appreciated the conversation about wishes and priorities and the cards were considered helpful in facilitating such a conversation. However, patients expected their current wishes and priorities to change during the palliative trajectory.

**Conclusions:** Cards as a tool to facilitate a conversation about wishes and priorities at the end-of-life can be used by healthcare professionals to systematically offer such conversations during a patient’s palliative trajectory. The cards however, can also be used by the individual to clarify own wishes and priorities and as a conversation tool within the family.
Abstract number: P01-180
Abstract type: Poster Exhibition

Supporting QoL versus ‘Having Nothing More to Do’. Staff’s Perceptions of Palliative Care

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Background: The WHO definition of palliative care is frequently used all over the world. Yet health care professionals perceive palliative care in various ways, something which can affect the quality of care.

Aim: To explore health care professionals’ perceptions of palliative care.

Methods: Eleven inter-professional focus group interviews with six to eight participants working in hospitals, nursing homes and private homes were carried out between 2014 and 2016. Data were analysed by latent content analysis.

Results: Palliative care was linked both to end-of-life care and care of chronic diseases in different phases. New and longer treatment options have made the transition into palliative care to be even more ambiguous. Thus, the need for breakpoint talks was clearly emphasized, but not always satisfactory handled by physicians. Lack of communication and documentation jeopardized the team work and the relationship with patients and relatives. Palliative care was perceived as supporting QoL for patients and relatives rather than ‘having nothing more to do’. Using a holistic approach was important to offer e.g. symptom relief, care continuity, flexibility, safety and support. Important resources in caregiving were contact nurses and palliative advisory teams. However, with a lack of time and staff there was a need for strong priorities which influenced care quality, and sometimes patients care was compromised. The care organisation was not designed for palliative care of several patients at the same time. Further, professionals related to fear when they had to switch between curative and palliative care at the same unit.

Conclusion: The result indicates the importance of a joint awareness of the transition from curative to palliative care both in the team and for the patient and relatives. When this decision is documented, further conversations are facilitated to improve necessary conditions to deliver palliative care of high quality.
Abstract number: P01-181  
Abstract type: Poster Exhibition

The Attitudes and Beliefs of Ecuadorian Oncologists in Quito to Breaking Bad News

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The aim of this study was to investigate the attitudes and beliefs of Ecuadorian oncologists in Quito to breaking bad news. A literature search found no previous publications from Ecuador on this subject and for this reason a qualitative investigation was chosen. Nine oncologists working in Quito took part in semi-structured interviews and the data was analysed using thematic content analysis.

The major themes that emerged were the definition, the reasons why bad news is broken, the barriers to breaking bad news and the “softening” of prognostic information.

The definition of bad news to most oncologists was seen as the transition from curative care to palliative care. The participants wanted to break bad news to most if not all competent patients who wished to know their prognosis and the reasons they gave for this were mainly ethical: respecting the patient’s right to know, truth in the doctor-patient relationship and the patient’s need to plan. The most widely commented on barriers to breaking bad news were the influence of the family who frequently asked the oncologists to collude and the considerable effect of the participants’ own emotions: sadness, frustration and a sense of failure. The fourth theme that emerged from the data was “softening” of the news and the examples of this often involved the use of euphemisms.

The effect of “softening” the news is not known and how much patients actually understand would be a valuable subject for further study. Training in communication skills in Ecuador should be investigated and may be of benefit to the breakers of bad news by reducing their emotional burden and to patients by reducing barriers to honest and sensitive disclosure of the truth.
Abstract number: P01-182
Abstract type: Poster Exhibition

European Palliative Care Academy (EUPCA) – Leadership Course

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Aims: The European Palliative Care Academy – Leadership Course (EUPCA) is a joint project of 5 institutions in collaboration with the EAPC and currently in its second course run. It lasts 1.5 years and comprises one course week at each of the 4 European academic institutions, an “Observation Week” and an innovative personal project. The course for emerging PC leaders of all professional backgrounds from across Europe aims at advancing PC by contributing to closing the gap in further education.

Methods: Based on findings from an online needs assessment in 2012, a steering committee comprising partner institution professionals, supported by an advisory board of internationally renowned PC experts, determined the course structure. Up to 20 participants are selected according to determined criteria. Internal and external evaluations and a certification were conducted.

Results: The modules comprise Personal Development, Project Management, Teamwork, Research, Advocacy and Local Best Practice of each host country. The participants of the current program include 6 professions from 10 European countries. The 19 participants, with their personal projects, have ensured that the second course has continued to enrich PC in Europe. Both internal and external evaluations demonstrate the program has been well received. Following the evaluations, several course aspects were optimised. Furthermore, the course achieved certification on Master-level (27ECTS). Especially praised were the coherence of course structure, integration of theory and practice and international orientation, all of which foster skills for the participants’ employability.

Conclusion: EUPCA is a unique program, positioned well in the education and job market of European PC. It enables pioneers in the field to face new social challenges. An assessment of impact and alumni networks will be conducted. In order to secure long-term sustainability of the innovative program, a future strategy is being developed.
The Impact of Video on the Comprehension Skills of Palliative Care in Young People

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Background: Palliative Care education programs are emerging. There are numerous references on training medical students.¹² There are Universities that give the opportunity to visit hospice but no references found about the experiences with high school students.

Aims: To show to Palliative Care for High School Students of Healthcare and pharmacy assistant and to know the students’ perceptions

Methods: We show to the students, two a short film: a DFK6498 and Strike Zone Cameron Duncan’s film, a teenager diagnosed with cancer.

We discuss with the students after every film about Palliative care. This activity takes about 1 hour. At the end, students fill an anonymous survey to collect opinions and perception of their priorities. All of them give a verbal authorization to use dates of a survey. The study was conducted in October of 2016.

Results: Two high school Centers with 54 students visited our hospital. All responders were female with a median age of 30 years (range: 16–52).

Answer:
Like this activity: 89%
Recommend this session: 94%
Is possible to do that you have discussed: 76%

The main topics learned about Palliative Care were:
● Appreciate the little things in the life
● Respect every person with their characteristic
● Lose the fear of disease and death
● The care is important than medical treatment
● To care for the family
● Nobody dies alone
● Communication

Conclusion: High Education students need to learn aspects and more details of palliative care.

We need further comparative studies in another palliative care Units and increase the number of students.

We would recommend these specific educational visits in palliative care to improve the educational knowledge at the end of life.

Like this activity- 89%
Recommend this session- 94%
To do Palliative care for you- 76%

Investing in New International Education: An Evaluation of a Massive Open Online Course (MOOC) Linked to InSuP-C Project

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Background: There is limited access to palliative care education internationally. An EU funded study: InSup-C, examined integrated palliative care in advanced and chronic illness in 5 European countries.

Aim: To disseminate the results widely and to a mixed audience including professionals and members of the general public to maximise research impact and provide free palliative care education.

Methods: We developed a free Massive Open Online Course (MOOC) called ‘Palliative care: Making it Work’ which was open everyone. Preparation of the MOOC took about 12 months. It involved interviews with researchers and caregivers about key findings and videos showing examples of effective practice in Germany, The Netherlands, Hungary, Belgium and the UK. It was delivered online over three weeks incorporating findings from InSup-C and related literature. Course content also included short lectures, quizzes, discussion boards and links to open access papers and a free eBook summarising the findings of the study.

Results: Over 6000 people from 149 countries registered for the MOOC. The traffic to the InSup-C website increased by 1600% largely to access the eBook. There was also evidence of increased downloads of open access papers during the MOOC through ResearchGate. We linked to open access papers and publishers noted an increase in reads. The eBook was translated into Spanish and emailed to participants. Students were enthusiastic and engaged. Many commented on how the MOOC had introduced them to ideas and concepts around palliative care that were new to them or improved their knowledge and understanding.

Conclusion: A MOOC, although labour intensive to create, is a novel way to democratise research results that takes findings beyond the usual channels of conference presentation and published outputs. It allows for global interactivity that can situate findings for discussion in real life and varied contexts.

EU FP7 funded project (Project ref: 305555) & Lancaster University
Abstract number: P01-187
Abstract type: Poster Exhibition

Better Conversations – Better Care: Evaluation of Clinician Training within the Serious Illness Care Programme UK

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Background: The Serious Illness Care Programme UK involves meaningful conversations between doctor and patients with serious illnesses to identify what matters most to the patient including their goals and their priorities. It is based on an approach developed by a team led by Atul Gawande at Ariadne Labs in the USA.

Aims: To adapt & pilot training to enable and support clinicians to use the Serious Illness Conversation Guide UK effectively.

Methods: Training consisted of a 6 hour study day supported by a coaching framework. It included an overview of the Serious Illness Programme UK and the Conversation Guide. There was also an opportunity for each clinician to practice using the Guide with a simulated patient and then document the discussion. The training was run on 6 occasions in a tertiary cancer centre and 2 primary care settings involved in the UK pilot. Following the training, each clinician was invited to participate in a coaching programme. Evaluation included pre & post course questionnaires & a clinician acceptability questionnaire.

Results: 58 clinicians completed the training: 19 Consultant Oncologists, 1 Consultant Haematologist, 3 Palliative Medicine Consultants and 35 GPs. Initial analysis suggests that participants were overwhelmingly positive about the course. In depth analysis is currently being undertaken and includes: change in perceived level of skill pre and post training, the extent that training met objectives & level of importance given to the components of the training. The number of Serious Illness conversations undertaken by each clinician and the level of engagement in the coaching programme for 6 months following the training will be reported.

Conclusions: Clinicians who completed the training did go on to use the Serious Illness Conversation Guide and take part in the coaching programme. Evaluation showed that the training and coaching were valued by participants. Further evaluation of the UK programme is planned.
Confidence in Providing End-of-Life Care: a Survey Identifying Training Needs of Junior Doctors

Royal Free NHS Foundation Trust, London, United Kingdom

Background: Palliative care is increasingly incorporated into undergraduate curriculums in UK medical schools. Training needs of junior doctors who frequently provide care for dying patients, however, are less well elucidated.

Aim: We set out to assess junior doctors’ confidence in various areas of End of Life Care in order to identify specific training needs.

Method: We adapted the University College London Hospital Care of the Dying Questionnaire to focus on areas of End of Life Care relevant to junior doctors. We distributed paper and online versions of this questionnaire to trainees in acute, surgical and medical specialties at the Royal Free NHS Trust between April and June 2016. Results were compared to a similar survey distributed among the 2015 cohort of foundation doctors. The statistical significance of the difference between 7-point Likert scale medians was determined by Kruskal-Wallis tests.

Results: We received 95 responses from doctors in foundation (71%), core (19%) and registrar (10%) training years. Higher training grade was associated with increased confidence in providing End of Life Care, in particular in discussing dying and ceiling of care with patients and their family. All trainees were confident (Likert median = 6) in verifying death and writing death certificates. Trainees reported low confidence (Likert median = 4) in discussing the discontinuation of nutrition and hydration as well as in caring for a dying patient who becomes unconscious. The majority (67%) of foundation doctors only “occasionally” addressed hydration and nutrition during discussions with patients and their family.

Conclusions: Junior doctors are confident in skills routinely taught and tested during medical school. There remains a need for additional End of Life Care training, in particular for foundation trainees. To optimise the delivery of End of Life Care, this training should focus on areas of low confidence such as discussing nutrition and hydration.
Abstract number: P01-189
Abstract type: Poster Exhibition

Nursing Students’ Professional Growth When Caring for Dying Patients during Clinical Training

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Background: During clinical training undergraduate nursing students often encounter complex palliative care situations. In order to be better prepared for similar situations as registered nurses they need to confront death and dying under secure circumstances.

Aim: To explore third-year undergraduate nursing students’ descriptions of a caring situation with a dying patient during supervised clinical training, and to extend extant understandings of their experiences of participating in the care.

Methods: Critical Incident Technique was used to collect data and 117 students were invited to write down a situation, positive or negative, when they participated in the care of a dying patient during their clinical training. Qualitative deductive and inductive content analysis was used.

Findings: Our findings show that the students valued the relationship with the dying patient and their relatives; they tried to understand the transition from life to death, they involved their own emotions in the care of dying patients, they mourned the patient’s death, and they felt guilty when their ethical compass was not in accordance with the supervisor’s caring actions.

Conclusion: This study suggests that there is a great need to facilitate undergraduate students’ transformational and professional growth in order to prepare them for future encounters with death and dying, end-of-life communications and their own emotional stress. The students critically observe the nurse supervisor’s end-of-life caring actions and the supervisors need to talk about positive and negative caring situations with the nursing students.
The Importance of the Sanitary Education in the Management of the Subcutaneous Route at Home

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Background: Home care teams are an important support for primary health care in Catalonia. Our daily day focuses on high complexity patients independently of his pathology. Many of them are in situation close to end of life. An appropriate symptom control will need to use the subcutaneous (S.C.) route to deliver pharmacological treatments when patients are too frail to take medications orally. Once at home the responsible for the correct management of the will be the main career. Those are the true objective of sanitary education. The main objective of this study is to evaluate the effectiveness of the sanitary education administered to the main career when using the SC route in a domiciliary environment.

Methods: We carried out a descriptive and retrospective study based on the revision of patients attended by the home care team of our hospital and who needed the use of the SC route during 2015. Nursing team delivered appropriate information to the main career regarding the use of the SC route according to the Spanish Association for Palliative Care guidelines. In each home visit the following items were evaluated: doses given, reason for administration, reasons for not administration. Descriptive statistics were used.

Results: A total of 348 patients were included in the study. The SC route was used in 171 patients (49,14%) in both continuous and intermittent manner. Few errors were detected (only in 3% of the patients with the SC route). Fear to administer morphine and midazolam were the most frequently detected.

Conclusions: Through a correct sanitary education focusing the main career the SC route becomes an important tool that will help to achieve a good symptom control and thus to remain at home until death.
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Abstract type: Poster Exhibition

**Effectiveness of an Education Program on Advanced Dementia for Nursing Home Staff**

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**Background:** Poor training of health care providers is one of the many barriers to achieve optimal care people with advanced dementia in nursing homes. Few education programs have assessed their effectiveness.

**Aim:** To evaluate the effectiveness of an education program on palliative care for advance dementia to nursing home staff.

**Methods:** A 6 hour education program with specially designed written material was provided in 3 nursing homes. To measure the effectiveness of the program we translated, validated and used – before and after education – the questionnaire on Palliative care for Advanced Dementia (qPAD). This is a two-part instrument with 23 items to assess knowledge and 12 statements to assess attitudes, higher scores represent better knowledge and attitudes. Previous training or work with such patients and satisfaction with the education program were also recorded.

**Results:** 92 participants (63% were certified nursing assistants, followed by nurses, physiotherapists and other HCP) completed the qPAD before and after education. 30.4% of them reported previous training or experience working in this field. The education program was rated as very good or good by 98% of them.

Knowledge on advanced dementia increased after the program (15.3 vs 16.8 points, p=0.002), while we found no change in attitudes (46.0 vs 45.9). All sections of the knowledge scale scored higher after the intervention, but no part of the attitudes test changed with this education activity.

Knowledge and attitudes towards advanced dementia before the intervention were better among the staff that had received previous training (15.8 vs 15.7 and 46.9 vs 47.1), while there were no differences according to previous work (15.8 vs 15.7 and 46.9 vs 47.1).

**Conclusion:** Knowledge of nursing home staff on advanced dementia can be improved with an education program, but this program was unable to change attitudes.
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**Palliative Care as Continuous Educational Program for Nurses – An Example of Unitary Curricula Country Level Coverage**

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**Background:** In Eastern Europe there is a diversity of Palliative Care (PC) nursing curricula with PC modules that differ in content and duration between countries. In Romania, efforts are made to develop standardized PC educational programs, at all 3 levels of education, recommended by EAPC: A – undergraduate/introductory, B – post-graduate/advanced (continual educational PC program (CEP)) and C – specialized.

**Aims:** To increase access to quality PC for patients with progressive chronic diseases by improving the care delivered by nurses in different specialities through the rolling out of the unitary CEP at country level.

**Methods:** A top-down model has been developed through the initial designing of a curriculum for A level training (including interactive teaching methods) and training of PC trainers of the Romanian Order for Registered Nurses (RORN) for implementing at country level the unitary curricula of the level A continuous education in PC for nurses.

**Results:** The 18 hours level A CEP developed consists of 12 sessions of 90 minutes each. 44 PC trainers from the 36 (out of 42) county branches of the RORN were trained and afterwards they trained 660 nurses from 10 different specialities (oncology, radiotherapy, neurology, pulmonary diseases, intensive therapy, emergency unit, cardiology, internal medicine, geriatrics and psychiatry) in 6 months time. The increase in PC knowledge of the participant nurses has been monitored through pre and post tests, with a medium of 3 points difference. For pre-test evaluation the average of the grades was 5.35 and for post-test 8.67.

**Conclusion:** This initiative continues its impact and ensures provision of PC training and support of nurses towards gaining the knowledge, skills and attitudes specific to basic PC. The future challenges reside in developing, implementing and rolling out CEP at advanced level of education in PC.
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Mandatory End-of-Life Care Training in a UK Tertiary Cancer Centre

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Background: All healthcare staff caring for dying patients must ensure they are aware of and compliant with evidence-based practice and guidance. The development of comprehensive education in palliative and end-of-life care is therefore vital to ensure high-quality practice. Training needs to be tailored to the needs of learners, depending on their clinical role and exposure to palliative patients.

Aims: Design, implement and evaluate an education programme on end-of-life care for clinical and non-clinical staff at a UK tertiary cancer centre.

Methods: In April 2016, training in end-of-life care was introduced for all clinical and non-clinical staff. Training was stratified into three groups depending on contact levels with dying patients and their families. Training sessions for all staff included key priorities of care, individualised care planning and communication and bereavement support. Those with more patient contact received additional training in symptom control, advanced communication skills and communicating uncertainty.

Teaching methods used a blended approach of case studies, seminars, presentations and e-learning. Written qualitative feedback was received from all participants to aid evaluation.

Results: Out of 559 identified appropriate staff members, 142 have completed training in end-of-life care. A rolling programme has been implemented and aims to reach 80% of participants by April 2017. Positive qualitative feedback has been received from multi-disciplinary groups.

The process evaluation has highlighted challenges in offering tailored teaching to mixed ability multidisciplinary groups, as well as addressing concerns about the relevance of the teaching for ancillary staff.

Conclusions: Whilst content is well evaluated, the process of stratification has led to challenges in selecting teaching methods. Ongoing work is focussing on allocating groups based on exposure and prior knowledge, whilst optimising course content for multidisciplinary learners.
Educator Amnesty! Development of a Network Specialist Palliative Care Educator Development Programme

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Background: In 2014, 322 specialist palliative care (SPC) professionals responded to a network education strategy group (ESG) workforce scoping exercise. The majority spent at least 10–20% of their time educating, 70% in clinical frontfacing areas or at point of care, rather than from, or in, education centres, providing academic courses or online learning. Preparation for educating experienced by the majority was observation/experience (12%) or ENB 998 course, single module or Train the Trainer courses (30–40%). Less than 10% had educational qualifications.

Approach: Six main challenges for educators were identified – educating peers & those perceived to be higher in professional hierarchy; managing personalities; lack of knowledge of best practice in supporting adult learning; cultural differences; developing by teaching with others; lack of peer review. A successful bid for Multiprofessional Training & Education Monies (MPET) funded the 3 education centres to design, develop & deliver the programme, for 3 cohorts each, over a 2 year period, & an independent research evaluation.

Results: Educators from across the network worked together to develop a bespoke Educator Development Programme (EDP) to address the expressed needs & challenges of all (273) SPC professionals who did not already have educational qualifications or a development pathway in place & yet may have been teaching as part of their role, for a number of years. Doctors were excluded as separate funded mechanisms are already in place for formally training & recognising medical teachers.

Conclusions: EDP was designed as three modules, addressing each of ‘one to one’, ‘small group’ & ‘formal’ teaching; delivered over a period of one year to allow time for practice, reflection, peer review & mentorship; to increase knowledge, skills & confidence. The experience of the programme leads, mentors & first cohort to complete the programme will be available for this presentation.
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To Feed, or Not to Feed, that is the Question: Multi-professional Training on Food and Drink for the Dying Person

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Aim: Whether or not someone can, or should, eat & drink in the last hours & days of life is a dilemma faced by patients, their families & staff. A perception that food or drink has been withheld, and consequently contributed to death, can cause significant distress to bereaved relatives. This project aims to equip Health Care Professionals (HCPs) with the skills to assess the wishes & needs of dying patients, and develop a plan of care with patients & their ‘families’ regarding eating & drinking.

Design: Following review of local audits of care of the dying & initial training sessions with palliative care staff, a half-day interactive training session was developed focusing on:  
● Clinical assessment & benefits  
● Professional guidelines & the law  
● Ethical decision-making in clinical practise  
● Conversations & documentation.

The session was refined following feedback from participants, a teaching resource pack developed and team-teaching utilised to ensure consistent delivery by different facilitators. Training was offered to all HCPs working across a locality in the North of England.

Results: Training sessions were fully booked with 323 trained in the first 6 months. Participants were multi professional (nurse 38%, Health care assistant 25%, doctor 24%, other 13%) & from a variety of settings (care home 43%, hospital 32%, community 11%, hospice 14%). Feedback was excellent and comments demonstrated the session had been thought provoking and enjoyable.

Lessons learned: Participants report clinical decision-making & the accompanying conversations about eating & drinking for dying patients is challenging. Differentiating between ‘food & drink’ and ‘clinically assisted hydration & nutrition’ is valuable.

Uniting staff with different experiences stimulated excellent reflective debate & shared learning. Staff report increased confidence to develop & review plans in accordance with patients wishes.

This session is now part of ongoing end-of-life training locally.
A Longitudinal Mixed Methods Evaluation of the Transforming End-of-Life Care Training Course for Generalist Palliative Care Providers

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Background: Given population ageing and shortages of palliative care specialists, training generalist palliative care providers is essential to ensure end-of-life care (EoLC) is of high quality.

Aims: To evaluate the impact of a 2-day multidisciplinary course (Transforming EoLC) for generalist palliative care providers in the UK.

Methods: Longitudinal evaluation comprising a 12-item assessment of self-rated confidence and knowledge before the course (T0), immediately after (T1), and at 3- and 6-months (T2, T3) post-course, with an integrated qualitative focus group component. Quantitative analysis involved repeated measures ANOVAs and post-hoc tests using Bonferroni corrections. Focus group transcripts were analysed using directed thematic analysis informed by Kirkpatrick’s (1967) model for training evaluation. Quantitative and qualitative findings were then synthesised.

Results: The 252 course attendees included nurses (47%), doctors (17%), and allied health professionals (6%), and worked mostly in inpatient settings (72%). 240/252 completed T0-T1 assessments, 115 T0-T2 assessments, and 59 T0-T3 assessments. All items showed significant improvement at T1. 4/12 items declined significantly from T1 to T2, and 7/12 items declined significantly from T1 to T3. However, all T3 scores remained significantly higher than at baseline. Across 5 focus groups, trainees (n=26) praised the multidisciplinary training format and described changes in practice not captured quantitatively (e.g. altering services, asking more questions). However, they also reported a reduction in confidence and knowledge and recommended a ‘refresher’ course.

Conclusion: The Transforming EoLC course significantly improves self-rated confidence in, and knowledge of, EoLC, with potential benefits to clinical practice. Findings suggest training could be improved by adding a ‘refresher’ session. Further testing of effect on patient and family outcomes is needed.

Funding: Health Education South London
An Evaluation of the Impact of a Palliative Care Course on Medical Students’ Perception of Chronically Ill People and their Needs

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Background: In Poland training in palliative medicine is obligatory for undergraduate medical students. Our department provides a course, which involves 10h of seminars and 20h of exercises. Some of these classes take place in two hospices, where students have direct contact with patients. During the course, participants acquire knowledge and skills in pain and other symptom management, as well as in psychosocial support for seriously ill patients and their families.

The aim of this study was to estimate the impact of education in palliative care on students’ perception of chronically ill people and their needs.

Methods: A cross-sectional survey was applied. Students filled in the questionnaires prior to and one-week after palliative medicine classes. For statistical analysis $\chi^2$ was applied.

Results: 319 students participated in the pre-class questionnaire and 271 in the post-class.

After attending the palliative medicine classes, respondents believed that pain management in palliative patients was more effective than their previous estimations a week earlier. Moreover they claimed that the provision of palliative care for patients resolved psychological, social and spiritual problems to a higher extent than the level estimated before the delivery of the palliative medicine classes.

The no of respondents who approved the continuation of futile therapy in terminal patients decreased from 64% to 36% post-class, and the percentage of students who accepted euthanasia decreased from 58% to 42%. After classes, students indicated that the provision of support for families of palliative patients was more important than they had previously thought. It was found that there were significant differences between all investigated variables before and after classes ($p< 0,05$).

Conclusion: Teaching palliative medicine to medical students leads to changes in student perceptions towards palliative care and increases appreciation for the benefits it provides to patients and their families.

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Palliative Care as a Specialty for Nurses – A Model of Advocacy

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Aim: To determine the implementation of C level competencies for nurses (according to EAPC) by nurses working in Palliative Care (PC) services, in correlation with their previous education in nursing and PC.

Method: A quantitative prospective study assessing C levels competencies for nurses working in PC specialized services who serve both as clinical and educational centers for PC training in the country. Each nurse in the study was assessed through questionnaires, developed to include the EAPC recommendations for nurses’ education in PC at the C level, by 3 persons: the nurse herself (perceived practice), the chief nurse and the patient (implemented practice). The questions were defining the competencies and the answers were percentages of implementation of the competencies from 0 – not at all to 100% – in all cases. Descriptive and analytic statistic was performed.

Results: 9 PC specialized services were chosen. All nurses (122) and head nurses (9) in those services took part in the study alongside 122 patients. The respondents declared that nurses implement specialized PC competencies at very good level of competencies by 50% of the nurses and by 52% of chief nurses and at excellent level by 40 % of the patients. Out of 7 domains of competence, all 7 positively correlated with the general level of competency (p between 0.01 and 0.05). Significant highly appreciations exist in the implementations of competencies when the nurses: graduate nursing universities as basic level of education, graduate the master program in PC, have more than 10 years experience in nursing, have more than 10 years experience in PC, work for PC specialized services that have more than 5 years of existence, work for an non-governmental PC specialized service (p between 0.01 and 0.05).

Conclusions: There is still a need to increase the competency of nurses in the PC to develop and accredit specialized PC Educational Program and recognizing PC as a specialty in Romania is a must.
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**Abstract type:** Poster Exhibition

## Nursing: Basic Training Needs in Palliative. Are There Differences between Levels of Care?

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**Background:** The importance of training in palliative care is well-known. EAPC and AECPAL state that professionals who assist palliative patients must be trained on basic assistance. However, this kind of training is not available in all Spanish nursing universities.

**Aims:** To know if there are differences between levels of care (hospice vs. hospital) in: training, training needs and basic skills in palliative care in nursing.

**Methods:** Quantitative, descriptive and transversal study. Purposive sampling. Ad hoc survey based on literature, external review and piloting. May 2015. Inclusion criteria: nurses caring for patients with palliative needs. Variables: socio-demographic, perception by working with palliative patients, training, training needs, basic attitudes. Descriptive and inferential analysis with SPSS 17.

**Results:** 146 out of 202 nurses who met inclusion criteria completed the survey. 89.7% women. 46.5 years old on average (standard deviation ± 8.9). Statistically significant differences (p< 0,05): Training in palliative care, work preparation, needs and training areas, and attitudes.

The hospice nurses with greater substantial training and experience, felt more prepared. However, they demanded a similar type of training, except in spiritual and ethical aspects, perceived as the most necessary.

The hospice nurses use nonpharmacological measures and they value and serve family needs. In addition, they use scales more often. Nevertheless, they involve the patient and the family in decision-making to a lesser extent.

**Conclusions:** The training in palliative care is a need perceived by nurses regardless of the level of care, although there are differences in the areas of demand. This discrepancy may be due to the different level of training and experience.
Core Competencies in Primary Palliative Care. Nominal Group Technique with International Experts and GP Educators

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Background: Access to palliative care (generalist or specialist) for most people in need remains a key challenge internationally, even where specialist palliative care is excellent. Providing access is one of the fundamental principles of general practice (alongside with continuity of care and a comprehensive approach).

Core competencies in general practice and in palliative care are generally well defined. However, we still lack consensus on which core competencies have to be developed in primary care professionals (especially GPs) to provide generalist palliative care.

Aims: To identify core competencies to be included into education and training of primary care professionals in order to enhance patient access to and delivery of palliative care.

Methods:
1/ Narrative review of the literature and of existing curricula regarding core competencies in primary care, palliative care and primary palliative care;

2/ Nominal group technique with international experts in primary palliative care;

3/ Nominal group technique with GP educators at university departments of general practice in three different countries.

Results: We identified a list of core competencies for primary palliative care, to be included into education and training of primary care professionals: ability to identify people at risk of deterioration and approaching the end of their life; ability to communicate with patients about future needs and wishes; ability to perform basic multidimensional assessment of palliative needs; ability to recognize when referral to specialist palliative care is needed.

Conclusion and discussion: Early identification of patients who might benefit from holistic and future care planning is key to facilitate timely access to palliative care. Herein, primary care doctors and nurses play a significant role. Strengthening their core competencies is vital for enhancing appropriate care and health equity towards the end of life.
Experiences and Opinions of Teachers about Education in Advance Care Planning in ACTION Project

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Background: Evidence about the training of facilitators in advance care planning (ACP) is scarce. In ACTION project we have chosen the ‘Respecting Choices model’, where ACP facilitators are trained to help patients and their proxies understand and reflect on possible future treatment choices and document their personal preferences. Centralized training for teachers from six European countries (Belgium, Denmark, Italy, Netherlands, Slovenia and UK) was organized.

Aim: The aim of this study was to explore the teachers’ experiences and opinions about their advance care planning training process in all participating countries.

Methods: Focus groups with ‘Respecting Choices’ certified teachers participated. Focus group guide explored themes becoming a teacher and adapting the training to the European context. Data were thematically analyzed by two independent researchers.

Results: With nine participants 3 major themes emerged: tensions to follow prescribed interview guides, adaptations needed in different cultural, legislation and clinical contexts, and development of personal style of teaching with network of support. Participants did not have the realistic awareness concerning the demands which in some instances have led to lack of motivation and time.

Conclusion: The findings indicate that some aspects of the training process were rather simple, however, the overall process was very demanding in the international context and it required a lot of support and personal engagement but the teachers felt it was worth the effort.

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Impact of Prenatal Testosterone Exposition on Clinical Decision-Making of Undergraduate Medical Students

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Aim: Choosing the right treatment has a high impact on patients’ wellbeing. However, to counteract detrimental therapeutic choices, understanding unconscious impacts on medical decision-making is highly important.

It is known, that decision-making behaviour depends among others on prenatal testosterone exposition (PTE). Aim of this study was to research the influence of PTE on choosing and changing therapeutic goals for patients with advanced diseases in undergraduate medical students (UMS).

Methods: Patient with advanced cancer was presented to UMS (n=45, final year) with information about probability of outcome, palliation, survival and adverse effects with either anti-cancer treatment (ACT) or PC. They had to recommend (a) either ACT or PC. They were asked (b) how sure they were of their decision (VAS, 100mm), (c) if they were willing to change therapeutic goals given specific benefits for the patient and (d) to assess whether they were sure to know a therapeutic approach for PC patients.

PTE was determined by measuring D2:D4 by scanning the hand twice and using mean of measures. PTE can be determined by the ratio of the 2nd to 4th finger ray of the right hand (D2:D4): the higher the ratio the lower PTE.

Correlations determined by PEARSON test, significance level < 0.05.

Results: Higher PTE correlated with more certainty in choosing therapeutic goals (p=.02), predominantly choosing ACT (p< .05) and readiness to change therapeutic goals (p=.02). After an 18 hours PC course higher PTE correlated with higher conviction to know therapeutic concepts for palliation (p=.01).

Conclusions: PTE may have an impact on medical decision-making as in our study lower D2:D4 ratios correlate with being sure of one’s decision, being sure of one’s qualification, aggressive therapeutic goals and higher tendency to change therapeutic goals for possible benefits. More research is needed.
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Development and Approbation of a First Interdisciplinary Training Course “Palliative Psychology” in Armenia

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3000 people are in need of palliative care every day in Armenia. Mortality index was 27.717 in 2014, 60–70% of which need palliative care. In spite of this, palliative care isn’t considered as a part of compulsory medical care in Armenia. Nevertheless, certain steps have been made towards the development of the palliative care field and one of them is the education of specialists. Our team initiated the development of the Palliative Psychology Interdisciplinary training course with the purpose of providing students with essential knowledge and skills about main concepts, methods and frameworks of palliative psychology. This training course will be the basis for establishment of Palliative care specialization.

To achieve this purpose, a group of 2 clinical psychologists, a doctor and a social worker was formed: this is the first multidisciplinary team involved in the development of an academic course in Armenia. The training course consisting of 48 academic hours has been developed: 24 h. lectures on palliative psychology, 6 h.- on palliative medicine, 6 h.-social work within palliative therapy, 8 h. seminars, 4 h. of practice in Palliative care department, one additional open lecture with chaplain. This is the first academic training course for psychologists in the fields of palliative care in Armenia. The training course was mainly designed for students of 1st year of Clinical Psychology Master’s Program but was open also for the specialists of related fields. 123 persons – students from different universities and practical specialists were present at the first lecture (Sep. 5, 2016). The course will be finalized in December 2016 but even at this stage we can conclude that there is need for relevant education in the field of palliative care and there are potential specialists who are in interested in it. The Palliative Psychology course will become obligatory in Clinical Psychology Master’s Program. The project is implemented with the support of OSF-Armenia.
Talking in a Class about Loss, Illness and Dying. The Project “Begin by the End”

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Background: Nowadays conversations about death and dying has been turned into a taboo in in Western Countries. Nevertheless, copious studies have showed that early conversations on these topics, can facilitate young people coping with difficult situation in their future.

Aims: The main goals of the project “Begin by the End” was to improve knowledge of Palliative Care (PC) and promote open and honest conversations about death and dying with high school students.

Methods: 22 students of an high school class met healthcare professionals of a non-profit organization working in the field of palliative home care and talked with them about chronic illness, loss and different ways to copy with it. In addition, students had the opportunity to serve an internship in the non-profit organization, taking part in home care activities.

Before the beginning of the project, students compiled a questionnaire about their level of knowledge of PC. The same survey was compiled by student relatives and friends (N=139; age 12–79; 37% under 18; 42% over 30). At the end of the project students filled out a satisfaction questionnaire.

Results More than half of the sample (63%) had some informations about PC and the 57% of the sample knew the definition of PC. Whereas 65% didn’t know the Italian law governing PC; about half of the sample didn’t have a clear idea about which patients are entitled to receive PC. Most of the sample (76%) declared that information on PC must be more accessible.

Overall, students have evaluated the project interesting, even though critical issues relating to operational and organizational aspects were found.

Conclusions: This study highlight the need to spread the culture of PC across students and general population. Results underline the benefit of talking with teenagers about loss and illness clearly and the importance of structuring interventions tailored to this specific target.
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Developing an End-of-Life Care Education Strategy: ‘Recommended Core Education Standards for the Care and Support of the Person in the Last Year of Life’

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Background: The national report ‘Ambitions for Palliative and End of Life Care’ identifies that education and training is an essential foundation block for the six ambitions of palliative and end-of-life care. Currently in the UK, there are no comprehensive education standards available for the guidance of staff training.

Aims: This work aims to set out clear education competencies and learning outcomes required of all non-specialist palliative care staff working with patients in the last year of life in both the community and acute settings.

Design and approach: The “Ambitions” document was explored for learning needs which were then converted into competencies. The competencies, expressed as skills and abilities, were mapped against staff groups depending on the frequency of exposure to end-of-life care patients.

Results: Four of the six core “Ambitions” are used to title each of the main subsections of the document, with derived education competencies aligned beside them. These are: ‘each person is seen as an individual’, ‘maximising comfort and wellbeing’, ‘care is coordinated’ and ‘all staff are prepared to care’. Four levels of staff are identified based on how frequently they care for patients in the last year of their life. Clear criteria and examples are provided to guide staff group allocation, considering the level of expertise and specialism within a role.

Conclusion: This strategy identifies core competencies for the training of non-specialist palliative care staff in end-of-life care and categorises staff into levels depending on their professional role. With the dissemination of this document we hope to promote consistency in level-appropriate education across all settings and ensure the delivery of high-quality, compassionate care to support the person in the last year of life.
Abstract number: P01-209
Abstract type: Poster Exhibition

Early Palliative Care: Developing a Rationale for Different Conditions

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\textbf{Background:} Early palliative care may prolong life as well as improve its quality. But it is frequently only started in the last weeks or days of life and largely for people with cancer. Its huge potential to minimise and prevent pain and distress across illnesses is not realised.

\textbf{Aims:} To provide a rationale for early palliative care for people with all conditions. To suggest how and when palliative care might be integrated with disease modifying care.

\textbf{Methods:} We synthesised 12 papers reporting on 1411 in-depth serial interviews with people who had life-threatening conditions and their carers from studies we had carried out in the last 15 years. We innovatively displayed physical, social, psychological and spiritual needs graphically along a time line, to create images to help us describe display and communicate patterns of well-being and distress experienced by people with advanced cancer, organ failure and frailty.

\textbf{Results:} In people with advanced cancer, social decline typically parallels the physical, while psychological and spiritual well-being often dip together at four key times: around diagnosis, discharge, at disease progression, and in the terminal stage. Thus an early palliative care approach triggered by psychological distress around diagnosis may be indicated before physical deterioration. Similarly the multi-dimensional trajectories also indicate possible triggers for early palliative care in organ failure, with acute anxiety and social distress frequent around hospital admissions, and in people with frailty where psycho-social distress may well predate a physical decline.

\textbf{Conclusions:} An understanding of these multi-dimensional trajectories by clinicians can help them trigger and develop a form of early palliative care that is patient-centred and responsive to their changing circumstances. A core competency of all health professionals should be early identification of people who might benefit from palliative care.
Abstract number: P01-210
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The Last Aid Course – an International Project to Educate the Public about Death and Dying

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Background/aims: The need for Palliative Care at home will increase in the future due to the demographic change and the wish of many people to die at home. In order to meet this challenge the public needs basic knowledge and skills in Palliative Care and end-of-life care.

Methods: Between 2013–2014 an international working group of Palliative Care experts from Germany, Norway and Denmark designed a last aid course with 4 teaching hours (four modules with 45 minutes each). The four modules are about: 1. Care at the end of life, 2. Advance Care planning and decision-making, 3. Symptom management, 4. Cultural aspects of death and bereavement. Pilot-courses were used in all three countries to evaluate the course curriculum and the participant’s views about the course concept.

Results: So far more than 300 people have participated in last aid courses for the public.

The pilot courses have shown the feasibility of the course curriculum and its acceptance by the public. The results showed that most participants appreciate talking about death and dying in a comfortable and safe atmosphere. Most of the participants stated that they would recommend the course to others. Within the year 2016 there will be more than 160 educated last aid course instructors in Germany, 50 in Norway and 70 in Denmark. In Denmark the Hospital of Southern Jutland has planned to educate all health care personnel working in palliative care as last aid course instructor.

Conclusions: The first experiences with the last aid courses are very promising and the public interest in the project is rising in all participating countries. In 2016 implementation of last aid courses in four German regions has started. From 2017 a nationwide implementation in Germany is planned. More European countries will participate in the international working group from 2017. Further research on the implementation of the last aid course is planned.
Implementation of the Advance Care Planning Training Program (ACPTP) in Catalonia (Spain)

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Background: Advance Care Planning (ACP) facilitates the expression of values, goals and preferences of people with advanced chronic conditions and it enables the decision-making process in chronic and advanced diseases. Many benefits of ACP implementation have been described by the literature. Although, many difficulties are described and Training in ACP is being demanded by professionals. An ACP training program (ACPTP) has been designed and implemented in Catalonia (Spain), based on international and regional experiences.

Aims: The aims of training are: a) to promote awareness about the importance of ACP and; b) to facilitate the development of skills, knowledge and attitudes needed to implement ACP adequately.

Methods: The ACPTP is addressed to professionals working with people with advance chronic conditions and complexity in Catalonia. Two levels of training (basic and advanced) have been designed: 1) E-learning training (ET) for general contents and 2) Face to face training (FTFT) for specific contents.

Contents are focused on conceptual aspects of ACP, ethics, legal aspects, benefits, difficulties and barriers of ACP, and practical aspects of ACP implementation: who, when and how to lead the ACP process.

FTFT is developed as a 12h-course based on clinical cases, role playing and video simulation, with interdisciplinary participation. Most attendants are professionals who will lead future training on ACP.

Results: As for ET, more than 10% of professionals of health and social services (mainly, primary care) have received in 2016. Total coverage of ET for primary care professionals is aimed to be completed by 2018. Regarding FTFT, 22 sessions are already planned to be performed during 2017.

Conclusions: Acquiring training skills on ACP is a current challenge for those professionals taking care of people with advanced chronic conditions. The training program offers tools to the professionals, and guarantees a comprehensive implementation across Catalonia.
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**Clinical Reasoning and Examination Course for Specialist Palliative Care Nurses**

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**Aim/goal of the work:** To increase specialist palliative care nurses’ knowledge and confidence in history taking and examination skills, with particular focus on palliative care emergencies, in order to make more effective referrals.

**Design methods:** A four day ‘clinical reasoning and examination’ course was designed and delivered in conjunction with a local University department. Thirty specialist palliative care nurses participated, with 10 participants on each of three (identical) courses. The four days included a day of lecture style teaching on history taking and presenting using SBAR (situation, background, assessment and recommendation). The other three days focused on spinal cord compression, superior vena cava obstruction, hypercalcaemia and haemorrhage, including lecture style teaching on anatomy and physiology, and practical sessions on examination skills, with participants learning how to examine neurological, cardiovascular and respiratory systems. Participants also had access to online learning prior to the course.

**Results:** Feedback from all three courses was overwhelmingly positive. Several sessions to re-enforce skills took place following the course, and many of the nurses took the initiative to organise their own follow up sessions with colleagues. At a later date, nurses were formally assessed on their examination skills and presentation of a case using SBAR. Most nurses reported increased confidence in diagnosing emergencies, examining patients to confirm findings and presenting these findings to other health professionals.

**Conclusion/lessons learned:** Confidence and knowledge of the specialist nurses who completed the course increased, and case presentation has become more focused and efficient. Most have expressed an interest in further teaching, in particular abdominal examination skills. However, not all nurses completed the post course assessments, and a small minority remain under confident in their skills.
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e-ELCA Critical Success Factors

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Background: End of Life Care for All (e-ELCA), part of the award winning Health Education England e-Learning for Healthcare programme (HEE e-LfH), was launched in 2010 and has over 150 sessions grouped in modules: assessment, advance care planning, symptom management, communication skills, social care, spirituality, bereavement and integrated learning.

e-ELCA is freely available to all UK NHS, independent hospice and social care staff. Access can also be purchased, via eIntegrity, by anyone worldwide. In 2014, 25,587 sessions were launched and 24 million seconds of time was spent learning. In 2015 an online survey and a number of focus groups were undertaken to find out from users and non-users what was important to them.

Findings: There were four main areas of feedback:
1. Benefits of using e-ELCA within blended learning
2. Factors within organisations that can provide support to using e-ELCA
3. More help with access and navigation
4. Better communications telling people about e-ELCA

Actions: Access: e-ELCA became accessible via OpenAthens in summer 2016. eIntegrity have developed promotional information and amended pricing.

Navigation: Several learning paths have been developed to support specific learner groups, curricula and qualifications. Learning paths identified to support key policies such as the Priorities for the Care of the Dying Person.

Resources: ‘case’ examples of using sessions in a blended learning approach. ‘Top Tips’ are available to support trainers and mentors in integrating the vast resources of e-ELCA into their teaching.

Impact: In 2015, 86,432 sessions were launched and almost 86 million seconds of time was spent learning. International use has increased, most notably in Spain.

Conclusions: e-ELCA is a highly valued resource for learning about end-of-life care. It’s access has been improved with effects on usage. Profile raising and embedding in workforce development in the UK and Europe are ongoing ambitions.
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An Exploration of Doctors’ Experiences of Caring for Palliative Care Patients and Whether They Feel there is a Need for Further Training at Undergraduate Level

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Background: There is very little evidence from the developing world on the need for integrating palliative care training in the undergraduate medical curriculum. Doctors at all levels have a vital role in the provision of palliative care and also spend their immediate time after graduation in hospitals where they will encounter many patients with palliative care needs.

Aim: The study explored post qualification doctors’ experiences in taking care of palliative patients and whether they feel there is a need for further training at undergraduate level.

Methodology: Seven doctors working in medical and surgical wards in a busy referral hospital were recruited for the study. Qualitative-in-depth interview methods were conducted.

Results: Several themes emerged from the study. Understanding of palliative care/end-of-life care: comfort; counseling; spiritual care; relieving pain/suffering; given to patients with a terminal illness. Majority of the participants talked about their clinical experiences, expressed mainly as pain and symptom management and infection control. Other aspects of care (counseling; spiritual care) were mentioned as necessary but provided mostly by ‘those other people’, meaning counselors/nurses; a few participants described their experience as depressing. Time was mentioned by all participants as a barrier to providing care; lack of education especially on psychosocial issues Team work was also recognized as essential; Empathy was mentioned several times.

Conclusions and lessons learned: Doctors in Kenya do not receive adequate training in palliative care hence constantly experience many challenges in providing palliative care. The study displayed an understanding of the wider concept of palliative care but relatively a poor grasp of the doctor’s role.
Conversation Circle as Methodology Used in the Pre-congress Course “Palliative Care” during the Brazilian Congress of Geriatrics and Gerontology: Experience Report

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The Palliative Care (PC) education can happen in three levels: undergraduate, postgraduate and continuing professional development. So, The Brazilian Congress of Geriatrics and Gerontology (BCGG), as a space for continuing professional development, was chosen for the Pre-congress Course “Palliative Care”, which was coordinated by the Standing Committee on Palliative Care of the Brazilian Society of Geriatrics and Gerontology (SCPC).

Aim: Report the experience of the using the Conversation Circle Methodology.

Experience report: In the auditorium entrance door one constituent of the SCPC gave for each person a colorful ballon and asked them to hold it back, taking care for not to give the same colorful ballon for persons who came together. We started asking to inflate the baloon and then raise it up. With that we wanna show how many colors, how many people we need to achieve a good Palliative Care. After that, the Course started with the lecture “History of Palliative Care”. Than the first clinical case was presented and after that was asked for the audience to get together with the persons that had the same colorful ballon, this way we had four groups. For each group one constituent of the SCPC was responsible to conduct the clinical case discussion. During the Course were discussed four clinical case addressing themes about geriatrics palliative care. After each discussion was presented a lecture of 20 minutes to close the case. For evaluation of the course quality was used a survey that was analysed using the Software SurveyMonkey. 55,1% considered excelente and 42,86% good. Positive aspects: methodology used and the quality of the speakers. Negative aspects: number of persons in each circle, time limits for each discussion.

Conclusion: The Conversation Circle is a option of methodology for teaching palliative care. With that the audience can work together with the speakers and achieve an active learning through exchange of knowledge, experiences and reflections.
Abstract number: P01-216
Abstract type: Poster Exhibition

What Topics Should Be Included in a PC Undergraduate Curriculum? Medical and Nursing Student Perceptions

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Introduction: The need for undergraduate medical education in palliative care (PC) is widely recognized. The European Association for Palliative Care makes recommendations on specific topics to be included in undergraduate education, but it is unclear what topics students recognize as relevant for their practice.

Aim: To characterize the relative importance that students give to core PC topics for their future professional practice.

Methods: Descriptive study. Medical and nurse students who participated in a voluntary interdisciplinary 13-hour PC course were asked to complete a survey. Students assessed the level of importance of thirteen PC topics for their future professional practice and defined which of these topics should be included in a mandatory undergraduate PC curriculum. We analyzed the response rate, the perceived importance, and the need to include each topic in a PC curriculum.

Results: The class attendance mean was 90%. 71 out of 90 students responded the questionnaire, 70% (50/71) were medical students. 66% (47/71) reported not having PC training before. The most frequent topics reported as very or extremely important were: pain management 97% (68/70), diagnosis of death 91% (63/69), pain assessment 85% (60/71), use of subcutaneous route 85% (60/71), control of common symptoms 81% (57/70), and evaluation of symptoms 80% (56/70). Over 90% of students perceived that 11 of 13 topics reviewed should be included in an undergraduate PC curriculum, with the exception of basic nursing care (84%) and spirituality (77%). 92% (65/71) of students considered very or extremely important to have a course of PC, and 97% (68/71) of them is interested in continuing attending PC courses.

Conclusion: Students recognize that pain assessment and management, diagnosis of death and use of subcutaneous route are the most relevant topics that should be included in a PC curriculum. Students consider that PC should be included as a mandatory course in their undergraduate curriculum.
Do Canadian Family Medicine Trainees Intend to Provide Palliative Care to their Patients after Graduation?

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Background: Family/general physicians should be able to provide primary-level palliative care (PC). However, family medicine (FM) training may not prepare or encourage trainees to provide PC.

Aims: To what extent do Canadian FM trainees intend to provide PC after graduation and what was their self-perceived exposure to PalCare education?

Methods: Since 2013 all FM residents enrolled in a FM residency program in Canada are invited to complete a standardized survey that assesses the Triple-C Curriculum for FM residents. Surveys are completed at: start of residency (T1), end (T2) and 3 years into practice (T3). The T2 data for the 2013 cohort of trainees were analyzed.

Results: 15/17 schools provided data. 640/1164 (55%) responses were received; response rates varied across schools (22% to 93%). Overall, 59.5% of respondents felt that their exposure to PalCare training had been adequate or more than adequate during residency; ranged from 41.6% to 75.0% across schools. 64.2% of trainees indicated that they intended to provide (“somewhat” or “highly” likely) PalCare after graduation. Rates varied across schools (45.5% to 93.3%). Having a clinical supervisor that role modeled family medicine, and higher exposure to PalCare correlated with higher intention to do PalCare (p=0.01 and p< 0.001 respectively). Data allows for ranking of the residency programs based on adequacy of palliative care education opportunities and intention to provide PalCare. A relatively large number of respondents (112/640; 17.5%) intended to focus their practices (somewhat or highly likely) on PalCare.

Conclusions: There is room for improvement in several medical schools with respect to exposure to PalCare education and motivation to provide PalCare after graduation. The factors that influence residents’ intention to provide PalCare to their patients after graduation need exploration. The ranking system provides a starting point; e.g. What is different about higher versus lower ranking schools?
Robotic Technology and Palliative Care Education: The Development of a ‘Nao Robot’ Computer Program

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Aims or goal of the work: The potential application of robotics in palliative care education has not been explored. This collaborative project between Computer Science and Palliative Care aimed to program a robot to convey emotion in response to human interaction, in order to develop a robotics program for potential use in palliative care education.

Design, methods and approach taken: The Nao robot is an autonomous, programmable humanoid robot that is controlled by a Linux-based operating system. The robot has capabilities for voice recognition and sound localisation (in-built microphones), multilingual text-to-speech synthesis (in-built speakers) and vision, which include facial and shape recognition (in-built high definition cameras). The robot was programmed by a computer scientist to convey ten emotions (relaxed, angry, withdrawn/sad, lightly crying, heavy sobbing, happy/excited, scared, tired, laughing and dancing) through its posture, movement and speech, in response to human-voiced questions and interaction.

Results: The robot was successfully programmed to convey the ten target emotions in response to direct questions posed by a human subject. Discussions around the robot’s displayed emotions were explored (e.g., “why are you sad?”) to assess the potential of human-computer interaction. The robot continues to acquire a growing lexicon of vocabulary, in addition to an increasing number actions and responses. The robot acts both autonomously and through direct instruction of the operator.

Conclusion / lesson learned: We have successfully programmed a robot to interact with humans and display emotional responses. This technology could potentially be used to develop innovative ways to create opportunities for interactive educational activity. Consequently, further research can explore the potential to use robotic technology in palliative care for education, and to promote discussion with the public (e.g., children) and healthcare professionals.
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**About the Relevance of Palliative Care Education for Medical Students**

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**Background:** An attention to palliative care (PC) education is growing in Ukraine, as well as around the world. The role of the general practitioner (GP) is central in PC – 90% of these people will (and should) remain under the care of GP. It follows that every undergraduate medical student will need to learn about palliative care.

**Aims:** To offer some forms of PC training integration in the current system of undergraduate medical education.

**Methods:** Review of international organizations’ recommendations (e.g. EAPC), curricula of medical universities, and own survey on PC knowledge of 252 students of medical university (6-th course of study).

**Results:** Our research reveals lack of PC knowledge and skills among medical students. In order to improve training of future physicians two alternatives were compared. It was established that training within a certain normative educational subject (Alternative 1) has several positive aspects, but much more disadvantages in spite of integrated curriculum in PC (Alternative 2), which has next advantages: it isn’t demanded additional costs; hasn’t conflict with current Ukrainian undergraduate medical curriculum; students are not overloaded; based on corresponding to international recommendations principals of horizontal and vertical integration during all education, and other. As the result The Typical Integrated Curriculum on PC for students of medical university was created by our working group and then endorsed by the Ukrainian Ministry of Health (2014). Currently, the Curriculum is implemented in all medical universities in the country.

**Conclusion:** We expect to improve the knowledge and skills of students in palliative care by the end of the completion of their studies.
Please Mind the Gap: Developing Palliative Care Community Specialists to Bridge Primary and Tertiary Palliative Care Centers

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**Abstract number:** P01-221  
**Abstract type:** Poster Exhibition

**Aim:** High-quality secondary palliative care (PC) in community settings, where needs often exceed the skill of primary care providers and access to PC experts, is scarce. This paper presents proof of concept/initial data for a clinical, Interprofessional Master of Science in Palliative Care (MSPC) created by the University of Colorado in 2016 to meet this need. The MSPC is a hybrid program offered online with onsite weekend intensives. Faculty and course content are sourced from nursing, medicine, pharmacy, bioethics, social work, spiritual care, psychology, medical humanities and communication disciplines.

**Methods:** Proof of concept is demonstrated using a mixed method program evaluation process: learner self-assessments on 39 PC skills/tasks before, during, and after the program’s formal training; self-reports on type/amount of PC in their practice; standard course evaluations. Learning is evaluated by communication skills exercises with standardized patients, semi-structured interviews and others.

**Results:** Initial results indicate significant diversity in student disciplinary backgrounds, practice settings, and the inclusion of PC in their practice. Self-assessed PC skills reveal lower communication and spiritual/psychological support scores. A standardized patient-based communication skills assessment highlighted some challenges with initial meetings when patients/family holding divergent views. However, preliminary course evaluations are enthusiastic; evaluation data to date indicate the curriculum is meeting learning objectives.

**Discussion:** To our knowledge this is the first program in North America to specifically address the need for secondary PC providers. Preliminary data from two data points (before and at the conclusion of the first year) will be presented. Where results indicate, changes in program content and/or pedagogy will be described for the second cohort of students.
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**Undergraduate Curriculum in Palliative Medicine at Tampere University Increases Students’ Knowledge**

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**Background:** Education in palliative medicine (PM) at medical schools reveals a wide variation despite the increasing importance of palliative care. The benefits and detailed content of the total curriculum in PM are poorly described in many universities.

**Aims:** We evaluated the content and outcomes of the curriculum in PM at the University of Tampere, Finland, by using the recommendations of European Association for Palliative Care (EAPC) as a reference.

**Methods:** We searched the education in PM given by all the specialties from the syllabus and compared it to EAPC recommendations. Student’s knowledge was evaluated by a progress-test in three consecutive years (2014–2016).

**Results:** We found 53.5 hours of teaching in PM, which exceeds the recommendation of EAPC. Basics, symptom management, ethics, and communication skills were well established, while teaching in psychosocial/spiritual aspects, teamwork and self-reflection were below the recommendation. Out of the maximum of 4.0, the progress test mean scores in PM among the third, fourth, fifth and sixth year students were 0.1 (SD 0.71), 0.69 (SD 1.28), 1.38 (SD 1.46) and 2.53 (SD 1.26), respectively (p < 0.001). This growing knowledge was timely associated to the increase in the teaching provided by the discipline of PM. In addition, students who completed the optional course in PM achieved better mean scores (2.66; SD 1.27) compared to the others (1.33; SD 1.43) (p < 0.001).

**Conclusion:** The curriculum of PM at the University of Tampere complied well with the EAPC recommendations. The teaching led to increasing knowledge in PM among medical students.
Abstract number: P01-223  
Abstract type: Poster Exhibition

# DayOfTheDead – Attitudes towards Death, on the Internet and Social Media Microblogs

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The internet has been the biggest catalyst for change since the industrial revolution. It has changed the ways in which we communicate and now is changing how we prepare for death and remember our loved ones. Death and dying are still seen as taboo subjects in many societies, but social media microblogs appear to be bucking this trend. This poster will display datasets obtained from the Digital Death and Digital Legacy Infographic data collection 2016. In it, we highlight the impact these recent changes have had on attitudes and behaviours in those internet users that engage online.

The poster will be very visual. It will also include an interactive bar chart (made out of two pieces of transparent tubing). This will simply ask attendees “have you made any plans for your digital assets and digital legacy?”

The infographic can be found at:  
Innovative Approaches to Advancing Palliative and End-of-Life Care through Art and the Aesthetic Experience: A Scoping Review

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Background: Aesthetics offer an emerging field to engage healthcare professionals in advancing their knowledge and practice in palliative care. However, in the current evidence base, many interventions which use the aesthetic experience to promote staff development are inadequately tested and refined.

Aim: To map the workings of aesthetic training interventions used as a medium for staff development in palliative care.


Data sources: MEDLINE, CINAHL and ASSIA. Key journals and citation tracking.

Results: The final papers included in the review totaled 138 articles containing 63 different aesthetic approaches within staff development interventions. The intention of the interventions was to explore complex palliative care scenarios from a safe distance, often through emotive, abstract and philosophical thinking and discussion. Art forms were used to transport healthcare practitioners into an aesthetic experience that could be reflected in the lived experience of healthcare practice. The proposed learning, included the development of empathy and compassion; clinical and communication skills; the self; the awareness of others and the wider narrative of illness; and personal development.

Conclusion: The findings from the scoping review suggest that aesthetic interventions might be helpful in the delivery of palliative care staff development interventions. As researchers and practitioners continue to find solutions to understanding the efficacy of these interventions, we argue that the contextual factors of ‘how’ the interventions work (or not) are largely being ignored. Evidence from the review highlights the importance of developing a robust evidence base to determine how this learning is (or is not) transported into real life practice, and thus how it can contribute to improvements in palliative care.

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# Losses Loom Larger than Gains – Loss Aversion and Its Impact on Medical Decision-Making in Undergraduate Students

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**Aim:** To attribute different values to equivalent choices depending on perception as gain or loss is called loss aversion. The concept derives from economics: e.g. (a) would you accept a gamble that offers a 90% chance to loose 5€ and a 10% chance to win 95€? or (b) would you pay 5€ to participate in a lottery where you can win 100€ at a 10% chance? Even as chances are the same, (c) is perceived as a gain and it attracts more positive answers. We researched whether this concept of loss aversion may have an effect on decision-making in medicine.

**Method:** Study participants (SP, n = 232, medical students in final year) were assigned to loss group (L) or gain group (G). Patient with advanced brain tumor was presented with therapeutic options: tumor debulking (TD) or palliative care (PC) and probable pain palliation (PP), duration of survival (DS).

SP were asked whether they (a) decided in favor of TD or PC, (b) were willing to consider the alternative, and if so (c) how PP and DS had to change. Identical changes in outcome (e.g. PP in PC vs. TD) were formulated as a gain situation in G and loss situation in L (e.g. PP “how much has pain to improve with PC to change to PC” and “how much higher would pain have to be with TD to change to PC”). Comparison between L and G: by binary logistic regression; differences between demands for change: linear regression.

**Results:** 108 SP chose PC and 124 TD. Willingness to change therapy was higher in G than L both for TD to PC and PC to TD (p < .05, OR 3.36).

Demands for changes were different in G and L as in L SP needed a three times higher incentive to change therapeutic concepts than in G (p < .001).

**Conclusions:** Loss aversion has an impact on medical decision-making in undergraduate students. Change of therapeutic approach is 3 times more likely if perceived as “gain if therapy is changed” than as “loss if therapy is continued”. Benefit has to be nearly 3-fold to prompt an change in therapeutic approach if framed as loss compared with gain.
Abstract number: P01-226  
Abstract type: Poster Exhibition

**Improved Knowledge of and Difficulties with Palliative Care during 2008 and 2015 in Japan: Effect of a Nation-wide Primary Palliative Care Education Program**


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**Background:** Education is crucial to improving nation-wide palliative care.

**Aims:** This study investigated whether nation-wide primary palliative care education in Japan (Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education [PEACE]) improved physician knowledge of and difficulties with palliative care. As of the end of 2014, 54,844 physicians had undertaken PEACE.

**Methods:** Results from two nation-wide surveys in 2008 and 2015 were evaluated. Representative samples of physicians (n=257,523 and 14,125 in 2008 and 2015, respectively) were sent questionnaires to measure knowledge (using the Palliative Care Knowledge Test; higher values indicating greater knowledge) and physician-reported difficulty (using the Palliative Care Difficulty Scale; higher values indicating higher perceived difficulty). Scores were compared using unpaired Student’s t-test. Multivariate liner regression was used to adjust for differences in background. Propensity score matching was used to compare knowledge and difficulty scores between physicians who did and did not undertake PEACE.

**Results:** In all, 99,126 (37.1%) and 4814 (34.1%) physicians returned questionnaires in 2008 and 2015, respectively. Physicians who had no clinical experience in caring for cancer patients were excluded, leaving responses from 48,487 and 2720 physicians, respectively, for analysis. From 2008 to 2015, there were significant improvements in both knowledge (68 vs. 78; p<0.001; effect size [ES]=0.40) and difficulty (2.65 vs. 2.49; p<0.001; ES=0.29) scores. Cross-sectional analysis of 2015 data revealed that physicians taking part in PEACE had significantly better knowledge (86 vs. 74; p<0.001; ES=0.64) and difficulty (2.33 vs. 2.59; p<0.001; ES=0.42) scores.

**Conclusion:** Physician knowledge of and difficulties with palliative care improved in Japan from 2008 to 2015. The nation-wide primary palliative care education program could have contributed to this improvement.
Nursing Theories and Models of Care: Do We Have Any Specific Model for Palliative Care Patients?

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**Background:** Nursing theories and models of care (MC) are a solid conceptual framework in which nurses develop their daily care planning. Since patients who are receiving palliative care (PC) or end-of-life care often present life threatening and limiting conditions, it is required an adequate MC according to their needs. So far there have been described several MC for PC teams but not all of them are suited to nursing practice.

**Aim:** To do a literature review of the different Nursing theories and MC specifically oriented to PC or end-of-life patients.

**Method:** A literature search was conducted in Pubmed, CINAHL, Scopus and Google scholar. An inductive content analysis was performed to identify different elements of each MC and theory.

**Results:** Three different theories and four MC were identified. The core concepts that emerged in these MC are related to: acknowledgement of the patient’s uniqueness and dignity, holistic attention to the different dimensions (not only focusing on physical suffering but also on the emotional, social and spiritual suffering), patient-centered process, attitudes of the nurse towards patients (“be there” and non-judgmental approach) and it is also highlighted the importance of the nurse-patient’s relationship.

**Conclusions:** It is necessary to have a clear frame and knowledge regarding Nursing MC for PC patients. The appropriate implementation of these specific models would facilitate the clinical nursing process and improve the quality of care in this specially fragile population.
How Prepared Are Newly Qualified General Surgical Junior Doctors to Deal with Patient’s in the Last Days of Life?

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Aims: To understand how prepared newly qualified general surgical junior doctors (JD) felt at dealing with patients in the last days of life.

To better understand the culture in general surgery towards caring for patients in the last days of life.

Methods: A questionnaire to assess preparedness was created with input from a previously published work consisting of six questions13 based on a Likert scale of 1–5 (1 – Not prepared at all, 5 – Completely prepared). One further open question was included. Paper questionnaires were circulated to general surgical JD across two sites. The results of the first six questions were analysed in Microsoft Excel and the last question was processed in a word cloud.

Results: 32 out of 33 (97%) JD responded. The majority of JD felt less than somewhat prepared in managing: social issues, psychological distress, spiritual heath, and speaking to the family of a patient in the last days of life. The majority of JD felt more than somewhat prepared to speak to a dying patient and managing pain control. The most common first three words that came into JD minds when they were told that a patient was palliative and they needed to action aspects of their care included “4-letter expletive”, “Help” and “Sad”.

Conclusion: Newly qualified doctors in surgery on the whole feel less than somewhat prepared to deal with patients in the last days of life, in particular managing spiritual issues. The responses to the open question highlight the anxieties of JD when dealing with palliative care and these need to be addressed to better support the care of patients.

References:
Background: As a chronic illness, human immunodeficiency virus (HIV) disease now requires a paradigm shift in management strategy. Lack of retention in care is a significant predictor of individual patient outcomes and young men of color who have sex with men (yMSM) remain at high risk for morbidity and early mortality. The approach to care delivery used by outpatient HIV staff may be a contributing factor. We employed the palliative approach early (ePA) to assist non-palliative outpatient staff in improving outcomes for a difficult to engage and retain HIV population.

Methods: Grounded in US-based didactic and iterative educational content, a multidisciplinary coaching team offered elements of the ePA to a group of outpatient HIV staff, augmented with quarterly in-service sessions to diffuse information among all staff. An independent stakeholder advisory panel gave input throughout the process. Staff at one US HIV clinic received education from this curriculum, and a second HIV clinic served as the control.

Results: The ePA attends to holistic needs of HIV+ yMSM during life transitions and recognizes the need for self-care and resiliency in care providers when caring for emotionally challenging patient issues. We will present the full curriculum containing core palliative elements that outpatient HIV staff members were able to incorporate into care delivery. Environmental factors figured strongly in the ability of staff members to integrate these skills. As a result, trauma-informed skills were incorporated and we developed “Red Flag” indicators for healthcare workers to recognize what to consider when caring for this unique patient population.

Conclusions: Use of point-of-service self-care strategies remains critical when introducing new skills for seasoned health teams in outpatient management of chronic HIV disease. Time constraints and other environmental factors play a significant role in the ability to incorporate new concepts in outpatient HIV care.
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Abstract type: Poster Exhibition

**Development of an Online Palliative Care Medicines Training Series for Health & Social Care Support Staff**


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**Aim or goal of work:** Frontline support staff working in General Practice (GP) (i.e. receptionists), Community Pharmacies (CP) and Care Homes are likely to face issues concerning palliative care medicines amongst their patient group. Previous service evaluations by the authors found a need for sustainable and accessible palliative care training for these staff. A national online training resource on palliative medicines for health and social care staff was subsequently developed and is currently being evaluated.

**Design, methods & approach taken:** Various education and training materials for these staff groups were consolidated and re-developed into one interactive course, comprised of Core sessions for all staff (e.g. Introduction to Palliative Care) and discipline specific sessions i.e. Pharmacy (e.g. Dispensing Opioids) and Care Home (e.g. Palliative Medicines & Risk of Falls) staff. User feedback was obtained via a questionnaire measuring satisfaction, usefulness and impact.

**Results:** All 50 participants (11 staff from GP Practices, Community Pharmacies (n=9) and Care Homes (n=30)) agreed that the training was useful and with the correct degree of difficulty. Participants liked the delivery format and felt the training was “informative” and “easy to access”. Staff also reported that managers were supportive of them undertaking the training. The training provided a good introduction and, for some, a refresher to palliative care. Some participants provided real-life examples of how the training had been beneficial to (and applied by) them in the workplace.

**Conclusions and lessons learned:** This new training resource provides education in an engaging, accessible format to frontline health and social care multi-disciplinary teams. It will be available nationally from November 2016 to support the provision of palliative care by frontline staff at the point of need.

This project was funded by NHS Education for Scotland.
Bioethics in Every Day Palliative Care Practice: A Web-based Bioethical Deliberation Teaching Experience in Mexico

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Introduction: Depression, anxiety, and delirium are common psychiatric syndromes in palliative care setting; although these contribute to a substantial burden of suffering for patients and families, frequently are under-recognized or underappreciated, and often are difficult to differentiate in the setting of serious illness, due to symptom overlap with medical conditions. Palliative care psychiatry is an emerging subspecialty field, with a role yet to be defined; one of the main opportunities to be involved it’s the specialized view of one of the central tenets of modern palliative care, the concept of “Total Pain”, and the patient’s desire to hasten their death. However, far more common for terminal cancer patients is the desire to die as a consequence of poor symptomatic control. The purpose of this investigation was to explore the relationships between desire to die and depression, anxiety, and poor symptomatic control.

Methods: Patients’ referred for psychiatric evaluation (PE) between January to December 2015 at the Palliative Care Service of the Instituto Nacional de Cancerologia, with life expectancy of less than 6 months, cognitively intact.

Results: 182 patients were referred for PE, 7.1%, were send because desires to hasten death and 64.3% because of clinically major depressive syndrome; average age 49.9 y/o; 71.4% females. During the PE 43.8% expressed DOD; 92.9% of these were diagnosed with major depression, 21.4% anxiety and 10.7% substance abuse. A statistical significant correlation was found between DOD and major depression (p=>0.000).

Discussion: The patients in this sample had a higher rate of major depression that those reported by other authors. A general consensus that major depression can be effectively treated in the context of terminal illness requires further research. A major limitation of the study is that no instrument was used for the evaluation of the DOD.
Abstract number: P01-232  
Abstract type: Poster Exhibition

**A Palliative Care Curriculum Toolkit: A Practical Guide to Integrating Palliative Care into Health Professional Education Globally**

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**Background:** The integration of palliative care (PC) in education programs is a crucial component of health systems strengthening, emphasised in the WHA 2014 PC resolution. Health care curriculums are increasingly congested & newer designs focus on competencies & outcomes rather than stand-alone courses.

**Aim:** To develop a toolkit to support those responsible for health worker education in integrating core PC competencies into curriculum planning. It builds on existing PC competency frameworks. (EAPC, APCA, PCC4U) & suggests a framework of educational & assessment practice, with many practical examples. It’s aim is to support a comprehensive review of PC within current curriculums; to identify strategies to integrate PC components into established curriculum; & inform public education & advocacy;

**Method:** An expert group from 4 academic institutions & 3 global health & PC organisations was convened to review existing competency frameworks, draft an outline & develop the Toolkit.

**Results:**  
Section 1: Background & user-guide including discussion of competencies under 5 domains: Basics of PC, Pain & symptom management, Psychosocial & spiritual, Ethical & legal, Communication skills, Teamwork & professionalism.  
Section 2: Practical examples & signposts to other useful resources. This latter section includes strategies to integrate PC into existing courses, techniques for curriculum review in different settings, teaching & learning strategies for PC & mentorship, preceptorship & assessment. The toolkit & links to resources are available online through two open access global PC sites.

**Conclusion:** PC competencies can be delivered in different ways within health & social care curriculums internationally using these innovative & creative approaches, which recognise existing or hidden competencies as well as the value of developing new materials. Integrated PC education is a crucial building block for transforming practice & health systems strengthening.
Medical Education on Palliative Care (PC) has been worldwide recognized and has been formally introduced in medical curriculum in many countries. Clinical simulation is an active teaching-learning methodology applied to teach medical competencies, in a controlled scenario, leading to the development of the desired clinic competencies, which have shown potential in develop competencies for using in PC settings.

This review have intended to understand how clinical simulation has been used to teach PC competencies to future health care professionals.

A integrative review was conducted from the research question: ‘which has been the use and impact of clinical simulation on PC education?’ A search in Indexed Database engines was made: PubMed, Biblioteca Virtual de Saúde, ERIC, Scopus and Embase, between October 7 and 19, 2015, selecting articles published between 2006 and 2015, using the descriptors: “Clinical Simulation” and “Palliative Care” and “Medical Education”.

Seventy-nine articles were found and 12 remained after two independent reviewers read the abstracts applying exclusion criteria. These 12 articles were fully read using quality criteria of the Critical Appraisal Skills Program tools and, after that, 6 articles remained for analysis and final synthesis.

Most of articles described different uses of simulation, such as planning and test new approaches to end-of-life, palliative care or critical care. When excluded all this various uses for simulation, few studies actually apply clinical simulation as a teaching tool for PC education with methodological quality. The remained studies show that is necessary planning and adaptation when using clinical simulation for education. In general, they are described as positive educational experiences which must have continuous evaluation and improvement. So, Clinical Simulation has been used in PC education with positive results since applied the dynamic approach the method requires.
“Dancing on the Same Sheet of Music” - Implementation of an Educational Curriculum for Palliative Care Throughout a Healthcare System

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Background: This Healthcare system has twelve hospitals serving two states in the US. Ten hospitals have a palliative care program at various stages of development. Collaboration is essential in order to provide consistent high-standard palliative care services throughout the system. Standardizing our foundational knowledge of palliative care across all settings has been challenging.

Intervention: To meet this need, an EPEC (Education in Palliative and End-of-life Care) training committee was formed that includes 2 physicians, 2 nurse practitioners, 1 social worker and 1 pharmacist. These team members became certified EPEC trainers after attending the EPEC “train the trainer” program. An EPEC training curriculum was established with 14 one-hour dedicated sessions to cover all palliative care topics. The training was conducted via web-conferencing for all the palliative care teams twice a month - January to August 2015. The presentations were also recorded for viewing by those who could not attend the live web-conference. Completing all the modules by all team members was established as a requirement.

Outcomes: Post implementation survey results showed all the programs agree that every patient in the system should get access to the same standard of palliative care and these modules should be part of orientation when new members join the team. Based on this, EPEC modules are now a requirement during orientation of new staff and a reference for all team members.

Conclusion: Standardized clinical curriculum is vital for uniform implementation of palliative care in a healthcare system.
The GLOBAL IMEP INITITATIVE – Benchmarking the Outcome of International Undergraduate Medical Education in Palliative Care Confidence Levels and Self-perception in Palliative Care Issues of First Year Residents at Yerevan State Medical University (YSMU), Armenia

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Background: Palliative Care (PC) is slowly developing in Armenia. General medical curricula and residents’ programs do not include PC. In 2016 a first PC course was given to family doctor residents.

Aims: This first PC education outcome study in Armenia evaluates how confident newly qualified physicians feel to communicate with PC patients and manage their issues in a multidisciplinary team. It also assesses the residents’ feelings towards caring for PC patients.

Methods: 40 randomly sampled residents (graduated in 2015 at YSMU) of different departments worked in a questionnaire (translated into Armenian by EORCT criteria) on Self-Efficacy in Palliative Care Scale (SEPC, 23 questions, confidence in communication, management and multidisciplinarity; 0–100%) and Thanatophobia Scale (TS; 7 questions, 1=strongly disagree – 7=strongly agree).

Results: Only 4 of 40 residents stated any PC education. They felt more confident in managing than to communicate with PC patients [SEPC 64.38 (2.72) vs 45.48 (3.10)*; *statistically significant difference; p < 0.05]. The confidence level to communicate with a patient was lower than with the family [37.32 (3.78)* vs 45.00 (3.60)*]. The highest confidence level could be seen in pain and symptom management [72.45 (3.03)*], the lowest in the confidence to discuss death with the patient [37.32 (3.78)*]. Men felt more confident to discuss effects of cancer with the patient [55.06 (7.30)* vs 39.00 (4.43)*] than women. Men felt more confident to prescribe appropriate pain medication [80.56 (4.80)* vs 67.04 (3.56)*] as well as in the knowledge of therapeutic and side effects of analgesics [81.75 (3.84)* vs 65.83 (4.02)*] than women, who more agreed with “Dying patients make me feel uneasy” than men [TS 5.12 (0.29)* vs 3.88 (0.41)*].

Conclusion: The data suggest that residents’ level of confidence of caring for PC patients in Armenia is low. This study may serve as a benchmark for further studies after having established PC education.
Mapping Palliative Medicine Undergraduate Education in Spain: A Students’ National-wide Survey

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Background: It has been considered that a comprehensive undergraduate medical education is required to enable newly qualified physicians to safely care for patients with palliative care and end-of-life needs. Palliative Medicine is not currently a medical specialty in Spain and the status of Palliative Medicine teaching in the Spanish medical schools is unknown.

Aim: To describe the current undergraduate education (UE) of Palliative Medicine (PM) in the Spanish medical schools.

Design: Survey to the Spanish Medical Students Association members of each Spanish medical school. An ad hoc questionnaire was developed to gather relevant information: PM as compulsory or optional subject, length, school year, and availability of clinical practice. Students’ surveyed need to be taking or had took PM in their own medical schools, or at least they have a deep knowledge about its own medical school program. Standard descriptive analysis was used.

Results: Thirty seven students responded. Of the 41 medical schools in Spain, PM is thought as an independent subject in 8 (19.5%), as a part of other subject (mainly Geriatrics, Oncology or Primary care) in 24 (58.5%), and in the remaining 9(22%) PM is not taught at all. When PM is mostly associated to Geriatrics, Oncology or Primary care... Mean length of the subject is 40.6 hours (4 ECTS-credits), and PM is mainly read at the 4rd, 5th or 6th year. Eleven of 32 (34.4) medical schools provide compulsory PM clinical practices, and the remaining 20 (65.6%) PM clinical practices are offered aside the UE practicum.

Conclusions: 1) PM in the medicine UE programs is still low and suboptimal in Spain. 2) In the responder’s opinion academic authorities should to foster the inclusion of PM as a compulsory subject in every Spanish medical school.
Abstract number: P01-237
Abstract type: Poster Exhibition

# Palliative Care Training Needs in Spanish Residents

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**Background:** Palliative care education has gradually been incorporated into medical and nursing schools in accordance with the recommendations of several national and international associations.

Approximately half the medical schools have a course designed to Palliative Care in their graduate curriculum, in Spanish Nursing schools we see a different situation, all universities in our country teach subjects or modules on palliative care.

The subject of Palliative Care in both degrees is mandatory just in the half of them.

**Aims:**
- To know palliative care training needs in Spanish residents.
- To analyse the association between years of training and their needs.
- To describe their work experience in palliative care.

**Methods:** This study is conducted by cross-sectional survey, every resident who participates in the Working Day Of Palliative Care organized by the Valencian Society Of Palliative Care, in 2015 and 2016, were invited to fill in a questionnaire.

We collected the surveys and introduced them into a database.

**Results:** We collected 37 surveys, all of them well filled to study.

83,1% of attendees were physicians and the rest were residents of nursing, psychology and social work. No statistically significant differences were found in their training needs between residents with different years of training.

The 83,3% had had some experience in palliative care, most of them as a revolving with a duration of a month in 71%.

When they were proposed rate their knowledge in palliative care the media was 3,73±2,31. All of them were interested in having more training in Palliative Care.

Symptom control (83,8%), making decisions, emotional support, information and communication skills, management of own emotions, bereavement, ethical issues, espirituality… were the most demanded topics by residentes.

**Conclusions:**
Training is essential for learning palliative care Initiatives, sponsored by the administration, that allow residents to make contact with palliative care must go on.
**Abstract number:** P01-238  
**Abstract type:** Poster Exhibition

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**Prepared to Care? Emerging Categories from a Grounded Theory Study of UK Hospice Nurses’ Experiences**

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**Background:** Recent UK national publications have drawn attention to the need for all nurses to be prepared to give end-of-life care. However, attention is also drawn to the nurses’ lack of educational preparation, and whether nurses are ready, willing and supported to give end-of-life care. A literature review examining studies published between 1995 and 2016 found little research exploring how nurses prepare for this role. Studies reviewed focus mostly on the experiences of student nurses: all suggest a lack of preparation. Furthermore, there is limited qualitative evidence exploring hospice nurses’ experiences.

**Aims:** This Grounded Theory (GT) study aims to illuminate how hospice nurses have become prepared to care. This will help to address this gap in the literature, and offer some insight into how other nurses may be prepared for end-of-life care.

**Methods:** The qualitative study uses semi-structured interviews with hospice nurse participants, to gather rich data from their experiences of care. A GT approach is used to analyse the data and create codes and core categories. Together with field notes and memos, this forms the basis for new theory generation.

**Findings:** Analysis of the first ten interview transcripts revealed the emergence of several categories. The most prominent of these are: the importance of role models early in a nurse’s career; the impact of exposure to death and dying; the influence of previous experience; being able to ‘make a difference’, and feeling good at the job.

**Conclusion:** It is too early to finalise theory from these findings. In concordance with the GT approach, data collection and analysis will continue until theoretical saturation is reached. However, the GT principles of analysis and constant comparison are being used to guide theoretical sampling and shape further interviews. Provisional findings are presented here for discussion with peers and experts, to enhance this ongoing process and strengthen theory generation.
Abstract number: P01-239
Abstract type: Poster Exhibition

A Theme of the Month – A Way of Increasing Quality in Palliative Care

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Aim: A way for new team members with little experience of palliative care to receive knowledge of the palliative patient’s needs and problems.

Method: A development team consisting of nurses, social worker and physician are responsible for the presentation of the themes. When needed, external experts are consulted.

A specific theme related to palliative care are selected and presented each month.

Current theme is presented as exhibitions, workshops, lectures and discussion groups.

Examples of themes: oral health, professional approach, wounds and compression therapy, teamwork, COPD, pain and palliative rehabilitation.

Results: All professions in the team have an opportunity to give information about their area of expertise which will strengthen the team work and provide a common base of knowledge.

Since the themes include all dimensions of palliative care: physical, psychological, social and existential, the team members get a mutual approach.

Conclusion: In a palliative care unit with large employee turnover, it is important to continually emphasize the special problems the palliative patients suffers from and their palliative needs.

This way to work with a theme of the month, to increase the skills of the team members has so far been very successful.
May I Help You? Physicians’ Perceptions and Utilization of Palliative Care Services in an Acute Care Hospital in Spain

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Background: Hospital-based consultative teams may be under-exploited.

In Spain, 50% of patients in need of palliative care do not access to this service. In developed countries, most hospital palliative care programs are understaffed. We believe physicians’ perception about palliative care could contribute to these facts.

Aims: To understand perceptions of palliative care in an acute care hospital and identify barriers for utilization of palliative care services.

Methods: We conducted a cross-sectional study including 140 patients admitted to the hospital. 13 patients attended by our team were excluded. We analyse the medical transcripts to identify the patients in need of palliative care applying Experts Criteria. In identified palliative care patients we ask three questions.

Data were analysed using kappa test and description of patients characteristics and physicians answers.

Results: 41 patients (32%) had palliative care needings. Cohen’s kappa coefficient was 0.539 (p< 0.0007). Physicians consults mostly for control symptom management and care planification (63%). They did not consult because they did not know palliative care criteria (49%), due to relatives or physician refusal (27%), good symptom control (24%), knowledge (17%) and due to palliative care team overload (5%).

Conclusion: In our study the agreement between palliative team and physicians is moderate. Physicians’ perception is about control symptom management and care planification. Almost 50% of the patients didn’t were known to need palliative care. Improving education and communication from Palliative Team are needed to break the barriers, as support from the Managers to supply access to the service. This is a study in a small hospital from a team composed by a nurse and a physician. A multicenter study would help us to improve our knowledge.

[POSTER EXHIBITION]

[TABLE 1: QUESTIONNARIE]
Teaching Palliative Care in Partnership in Africa: Is it Sustainable?

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Aims of the work: This poster discusses the development of a transnational educational partnership between a UK university and a palliative care service in Africa over a period of 20 years. It includes the initial delivery of a Diploma of Higher Education course in Africa by UK lecturers, then its takeover by local African staff. It highlights this as a unique partnership, but identifies the many challenges the course faces, and asks whether this partnership is sustainable in the longer term?

Approach taken: The poster will discuss the course and the issues it raises for international collaborations and sustainability. The results of the partnership will be discussed in terms of the following outcomes of the course: numbers of graduates; how the course has adapted to African conditions; how it has helped develop individual careers and services, with the voices of graduates describing the impact it has had on their practice.

Results: International partnerships give African students access to the university resources of the developed world, and this has had a significant impact on practice. The developed world in turn can learn a lot from Africa about delivering effective palliative care with limited resources. However, there are inherent conflicts in this sort of partnership. Curricula from the developed world may not fit the African context. There is increasing competition for scarce resources, and recruitment has dropped due to reduced sources of funding.

Conclusion: Collaboration has to be two-way: both partners need to make a long-term commitment to the programme, and to learning from each other. The course has been progressively adapted to local African conditions and resources have been used flexibly to reduce costs. Both partners continue to invest time and resources in the course and intend to develop partnerships in research and service evaluation. However, the future of the course will depend on continued access to funding in an uncertain world.
A Community of Practice: Building Capacity to Provide High Quality End-of-Life Care in Dementia

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In recent years there has been a significant increase in policy and guidance, across many countries, to promote palliative and end-of-life care for non-malignant life limiting conditions. Most notably for people with dementia (PWD) at the end-of-life and facilitate better access to palliative care. PWD, particularly those in the advanced stages, may experience poor end-of-life care because they may not be perceived to have a terminal illness. There is concern in some settings and services that staff are ill equipped to care for PWD, in respect of knowledge and skills. In 2011, Hospice UK established the Commission into the Future of Hospice Care to explore the key challenges facing hospices. Concurrent to this Admiral Nurses within Dementia UK had developed a palliative approach in support of the families they worked with. Both Hospice UK and Dementia UK thus launched the ‘Dementia in palliative and end-of-life care Community of Practice’ to bring together practitioners keen, in the spirit of mutual learning, to share knowledge and practice and provide high-quality palliative and end-of-life care for families affected by dementia. In the inaugural meeting a nominal group technique was used to identify learning needs across both groups of clinicians. Thirteen learning needs were identified, of which five were ranked as priorities to be met during future meetings; these were communication in dementia; educating generalist colleagues; pain assessment and management; how to influence care policy at local and national level and improving dementia care in different settings. Shared learning through a community of practice is a way of harnessing the expertise across the two care domains, with the common objective of improving the lives, and deaths, of PWD and in better support of their families. We hold two community meetings a year and due to increase in engagement will be hosting a conference in 2017. Events are well evaluated and membership is growing.
“We All Have a Role to Play.” Enabling People to Be Willing and Confident to Give Emotional and Practical Support

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Goal: To design and deliver a course in our town to equip people to care for others approaching end of life, or bereaved.

Approach: Borne out of discussions with a doctor friend about the impending crisis in care due to the demographic time bomb of expected deaths, a probation officer galvanised action by saying “I will help you run a course.” This led to ‘The Omega Course – an Opportunity to Talk Freely about Death and Dying in a Friendly and Safe Atmosphere.’

The course, 4 Tuesday evenings in a local cafe and a Saturday, is designed for lay facilitation and covers one’s own life and death; needs of the dying and bereaved; and, built on these insights, trains in awareness and communication skills to enable more confident contact.

Results:
Participants were 25–82 yrs.
The evenings were enjoyable.
The best part was discussion times in small groups.
The confident realised what they did not know.

Social mores make the role of lay people wishing to ‘be there’ for the dying and bereaved more complex than that of professionals who have a defined purpose and of whom the recipient has defined expectations.

Even, and perhaps especially, the oldest community members enjoyed the learning and the role plays.

People discovered that it is better to talk to a distressed person than not to, even when unsure what to say.

The professional required flexibility to adapt techniques and follow the lead of the lay facilitator to train at the right level.

Facilitators realised the course is only the beginning. Ongoing town networks of support and care will be necessary.

Lessons learned: Lay facilitation keeps the course pertinent and accessible. It is possible to train lay members of the community giving them confidence to discuss and prepare for their own death, and to communicate with others. Delegates realised their unconscious incompetence and need for ongoing training and support.
Misconceptions in Undergraduate Palliative Care Education

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Background: Often students have alternative conceptions or misconception concerning different topics. As student’s knowledge on certain fields can be erroneous, misinformed or illogical, uncritical teaching can impede the learning process conception leading to even strengthened misconceptions.

Aims: Detection student pre-educational misconceptions in palliative care and adjustment while undergraduate medical education.

Methods: After achieving informed consent students of 6th clinical semester human medicine (n = 162) were asked to reflect on three different topics of palliative care medicine at the beginning of a seminar: assignment of palliative medicine, symptoms and symptom control, and what behaviors cause and avoidance of cancer. For each they were asked to name the respective most important aspect.

Results: The majority of the 162 students asked saw accompanying of the dying as the most important assignment of palliative care. Different symptoms were known, however their treatments uncertain and not always purposeful. Avoidance of cancer seemed almost always possible for the students. Only two comments denied the opportunity of cancer avoidance.

Conclusion and discussion: Misconceptions with regard to different aspects of medical care are common among medical students. They are challenging for teachers. So far, misconceptions remain mostly unregarded though they can impede the learning process, also in palliative care teaching. Misconceptions need to be identified and addressed closely.
Abstract number: P01-245
Abstract type: Poster Exhibition

Students and Educators Promoting Medical Education in Palliative Care at the National Level in Spain: A New SECPAL Task Force

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Background: In 2012, 14 of 39 Spanish medical schools had courses with a mandatory palliative care component (average of 3 CME credits), but only six of those universities had designated Palliative Care Courses. In June 2015, a working group of palliative care professors was created with the aim of increasing the quality and quantity of Palliative Medicine education at the undergraduate level in Spain. This communication describes the activities completed, to date, and preliminary outcomes of that group.

Methods: Periodic meetings with continuous work through online communications.

Results: Over the past 18 months, the following activities were completed: 4 meetings held; endorsement of the group by the Spanish Society for Palliative Care (SECPAL); appointment of the National Medical Students Council (CEEM) to the group; commissioning and publishing of an editorial in the Spanish journal of palliative care; review of a CEEM position paper that was also eventually published; six oral communications of students and teachers at an open workshop with more than 80 participants at the bi-annual national conference, presenting innovative experiences in medical education and preliminary findings of a mapping exercise of universities teaching Palliative Care. Currently, a network of educators, students, and staff is under development and, upon creation, will participate in future national surveys. Further activities planned include a new open symposium on palliative medical education to be announced in April 2017; a national award for the best final-year undergraduate thesis to be given out at the 2018 national conference; and a new online documentation center for educators.

Conclusion: Over the past 2 years, this collaboration of highly motivated students and educators has reported important outcomes in terms of publication and impact in both palliative care professionals and university community.
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Abstract type: Poster Exhibition

One Chance to Get this Right: Improving End-of-Life Care

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Aims: To create accessible multidisciplinary palliative and end-of-life education programme which will:
- Increase Staff Skills, knowledge and confidence in caring for those at the end of their life
- Improvement in bereavement survey outcomes - Increase in patients achieving their preferred place of death
- Decrease in the number of hospital deaths from those who reside in care homes - Increase in patients dying with and end-of-life care plan
- Strengthen relationships between the acute hospital and community settings.

Design: Health and social care staff from a variety of settings including the acute hospital, community setting, nursing homes and domiciliary care agencies were invited to attend a series of study sessions in relation to palliative and end-of-life care. Three separate programmes were designed aimed at; Medical staff, qualified staff and support staff including sessions on: communication, symptom control, caring for families, palliative care emergencies, recognition of dying, care after death, bereavement, Sage and thyme communication, personal resilience.

Each programme consisted of 4 sessions lasting 4 hours. The program was delivered in a multidisciplinary approach using staff from the palliative care team including Consultants, Speciality Drs, Clinical nurse specialists, Social Workers, Dieticians, and complementary therapy staff.

Results and conclusion: 495 staff delegates over 6 month period, questionnaires showed increased staff skills, knowledge and confidence.

Bereavement survey showed 13.5% increase in patients dying with dignity and respect also a 13.6% increase in relatives who were asked if they would like to be contacted if there was a deterioration.

26% increase in patients dying with an individual end-of-life care plan.

Funding: Health Education Wessex provided funding for the initial set up, the project is now sustainable with minimal financial support.
Abstract number: P01-247
Abstract type: Poster Exhibition

A Simulation Experience with Actors in the Formation of Palliative Care

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Background: The palliative care in the graduated formation is necessary to achieve health professionals with an holistic and integrative vision. Currently, it is using innovative simulation methodologies.

Aims: To explore the experiences of nursing students’ about the simulation workshops with professional actors into the Palliative Care Training Program.

Methods and design: Qualitative study with a phenomenologic perspective. The study was carried out between March 2015–June 2015. Study participants: 210 students at Faculty of Nursing Sciences had their palliative care training between these dates. On the last workshop, a simulation with professional actors to work different topics was organized: conspiracy of silence, stage of grief, child dying, family claudication, etc. The students were asked to write their experiences in a narrative. The data were analyzed by thematic analysis.

Results: 174 students were made theirs narratives. The themes identified from students’ turn around: a) the simulation technique, b) the personal dimension c) the professional dimension. For them, the “simulation” with actors is a pedagogical innovation that stimulates the practice into the theoretical education and who develop the reflexivity. It’s a technique to detect errors and strengths. In the “personal dimension”, the participants live the workshops in two opposite positions: like a satisfactory experience or like a stressful experience. These positions depends on that theirs evocations of real incidents and their emotional intelligence gap detection. This emotional gap leads to competencies gap detection in the “professional dimension”. Hear, the workshops help the students to discover the complexity in the clinical interview, in the relationship support, etc. Finally, more students thank the workshop because it reaffirms their professional vocation.

Conclusion / Discussion: The simulation with professional actors is a useful technique for the palliative care training.
**Abstract number:** P01-248  
**Abstract type:** Poster Exhibition

## Difficulties Faced by Young Japanese Doctors in Providing Care to Patients at the End-of-Life Phase

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**Background:** Hospitals, especially acute phase hospitals, provide medical care through acute to end-of-life phase, and treat various kinds of diseases. Often patients need to be shifted from critical to end-of-life care. In such cases, it is presumed that young doctors face difficulties in providing end-of-life care because of a gap in therapeutic knowledge.

**Aims:** To identify the difficulties faced by young Japanese doctors who provide end-of-life care to inpatients at acute phase hospitals.

**Methods:**

**Design:** A qualitative study.

**Data collection:** Young doctors with an experience of managing inpatients at the end-of-life phase were recruited as participants from an acute phase hospital in Japan with 550 inpatients. We conducted semi-structured interview with each participant and asked them about their experiences with the patients and to recall the dilemma, anxiety, and suffering that they experienced.

**Analysis:** From the data, the sentences referring to the difficulties faced by the doctors were extracted, coded by content, and then categorized based on similarity of content.

**Results:** Ten young doctors (seven men and three women, average age 28.4 years old) were interviewed. During analysis, 4 topics and 13 categories were identified. The topics and categories are shown in Table 1.

**Conclusion:** The topics “Communication” and “Perspectives on the end-of-life health care system in Japan” were extracted as the characteristic difficulties faced while providing end-of-life care. These topics are experienced by young doctors because they are emotionally closer to patients than senior doctors. Addressing these topics might help in improving end-of-life care.

<table>
<thead>
<tr>
<th>Topics</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>7. Difficulty in communicating with end-of-life patients and their family 8. Gap in the information and recognition of disease between the doctors and end-of-life patients/their family</td>
</tr>
</tbody>
</table>

[Table 1 Difficulties faced by young doctors]
The Palliative Academic Clinical Trainees Society: Description and Career Outcomes of a Novel Peer Support Programme for Academic Trainees in Palliative Medicine

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Background: The UK Integrated Academic Training (IAT) pathway exists to promote the development of clinical researchers. The National Institute for Health Research (NIHR), alongside other funders, supports pre-doctoral Academic Clinical Fellow (ACF) and post-doctoral Clinical Lecturer (CL) posts for trainees across all medical specialties. In palliative medicine, low numbers of IATs (14 palliative medicine ACFs 2009–2014 compared with 114 oncology) and geographical spread mean that trainees can feel isolated. The Palliative Academic-Clinical Trainees Society (PACTs) formed in 2012 to provide peer support and networking opportunities for this group. All palliative medicine IATs are invited to join PACTs. Annual meetings focus on group peer-support/mentoring, and addressing clinical and academic training needs.

Aim: To describe PACTs membership and outcomes of training for members.

Methods: Evaluation of IAT career outcomes, based on an online database of PACTs membership, and comparison with national data.

Results: Since inception, 23 IATs, including 17 ACFs and 6 CLs, have been members of PACTs. 6/9 (67%) completed ACFs have progressed to PhDs, compared to 60% of ACFs across all specialities up to 2014. 2/9 ACFs returned to clinical training and 1/9 completed training. 1/3 completed CLs has gained an NIHR Clinician Scientist Fellowship, one has an honorary senior lectureship and one has a clinical consultant post. In comparison, up to April 2014 76% of CLs in all specialities continued in an academic post. PACTs members have published over 100 research papers since 2009.

Discussion: A national peer support network for IATs in palliative medicine is important because the small number of posts limits local support. PACTs works well, and is considered helpful by members. Career outcomes for PACTs members compare favourably to national IAT averages. Similar peer support models could be used internationally to support clinical academic training in palliative medicine.
Antibiotics for Pneumonia and Artificial Hydration for Insufficient Fluid Intake in Advanced Dementia: An End-of-Life Decision Support

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Background: Burdensome interventions are still frequently conducted in persons with advanced dementia, although such approaches might not align with Palliative Care principles.

Aims: Therefore, the DemFACTS study aimed to develop and test decision supports called fact boxes, in order to inform decision-makers, who have to make burdensome treatment decisions at the end-of-life of people with dementia and either pneumonia or insufficient fluid intake. Fact boxes are innovative, as they present evidence-based data in an easily understandable way.

Methods: A randomized, controlled, pre-/post-intervention study was conducted to test the newly developed fact boxes in relatives of people with dementia (n = 103), professional proxies (n = 77) and physicians (n = 74). At pretest, participants were asked to make two fictional decisions concerning burdensome medical interventions in advanced dementia based on case vignettes. Four weeks later, at posttest, the intervention group received two fact boxes in addition to the two case vignettes, whereas the control group only received the case vignettes. The fact boxes’ effect on decisional conflicts (primary outcome), additional decision outcomes, knowledge transfer, and the appropriateness of the fact boxes (secondary outcomes) were assessed. Intervention effects and within-between group comparisons are currently conducting and will be presented by the time of the conference.

Expected results: Notably, an expected pre-post reduction in decisional conflicts constitutes the central hypothesis of this study.

Conclusion: The fact boxes could reduce the decision-makers’ decisional conflicts and enable them to better understand the treatment decisions. Future research should investigate if fact boxes could foster communication on Palliative Care between all decision-makers.

This study is funded by the Swiss Academy of Medical Sciences, the Stanley Thomas Johnson Foundation and the Gott trifired and Julia Bangerter-Rhyner-Foundation.
Learning to Fly: Experiences of a Fledgling Research Hospice

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Background: As a small hospice, whose only research activity had been individual staff undertaking masters degrees or local university collaborative service evaluation, opportunity of a national multicentre trial of short specialist palliative care intervention (SSPCI) in advanced neurological disease (AND) was exciting & daunting. Local neurological centre identified suitable patients, explained, consented, randomised & undertook research questionnaires. Hospice delivered intervention, following required training for involved staff.

Method: Collation staff/patient comments about study involvement.

Results: Staff reported pride being involved with high calibre institutions; anxious & keen to get it right; initially saw trial patients as different & lacked confidence assessing & evaluating their care; positive experience following patient (with long standing diagnoses, & excellent existing care/support at home) from admission to discharge; keen to demonstrate impact of SSPCI in AND patients; having named clinical lead nurse responsible for overall supervision of study proved beneficial & necessary; challenges talking to patients with long standing diagnoses about preferred place of care & future care planning. Patients reported feeling proud to take part; initial reluctance to attend hospice due to pre conceived ideas, but all now state look forward to coming. One participant decided participating was not for him & withdrew.

Conclusion: Significant multiprofessional staff time & effort involved in delivering intervention – more than expected for a similar number of usual referrals. Staff – recognised vital importance of thorough initial clinical assessment on admission; used some new educational & inspirational outcome measures; further educated in whole ‘research process’ & realise importance of adhering strict requirements; frustrated that unable to signpost patients elsewhere for support at end of interventions due to lack of available resources &/or funding.
Abstract number: P01-252
Abstract type: Poster Exhibition

Clinical Portraits: Humanities Elective for Medical Students

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Goal: Enriching undergraduate medical education via the arts.

Design: Clinical Portraits provides undergraduate medical students the opportunity to work closely with patients and families while encouraging and facilitating student reflection and creative expression.

Patients recruited by Division of Palliative Medicine faculty sign formal informed consent documents. Over several months, students visit and establish relationships with these patients and their families – at home or in the hospital.

Division of Palliative Medicine faculty provide supervision, guidance, and resources on relationship-centered care, visual literacy and the documentation of the patients' or caregivers' voice.

Using photography, drawing, painting, writing, film or other media, students create a portrayal of the lived experience of illness – a clinical portrait.

Results: Students gain insight into relationships in clinical medicine while exploring their own interests in creative expression.

The clinical portrait created by the student may serve as a legacy document for patients and their families, or the focus may be an exploration of meaning based on student interpretations of the patient-medical student relationship.

Lessons learned: Students enhance their ability to appreciate and articulate the patient’s story. This poster, using examples of student-created portrayals, describes the rationale and a process for enriching undergraduate medical education via the arts.
Abstract number: P01-253  
Abstract type: Poster Exhibition

**Exploring Greek Nursing Students’ Knowledge and Attitudes towards Palliative Care and Death Experience. A Pilot Study**

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**Background:** Evidence of inconsistency on palliative care (PC) education puts greater emphasis on integrated PC in healthcare professionals curricula. Since 2015 the optional PC course was introduced as compulsory and offered to 4th year university nursing students. This pilot study aims to explore university undergraduate nursing students' knowledge regarding PC and Attitudes towards Caring of the Dying patient (ACD).

**Methods:** At the end of the academic year 90 nursing students of 2nd, 3rd, and 4th year of studies (30 per year) completed the Palliative Care Quiz for Nursing and the Frommelt Attitudes Towards Care of the Dying Scale. Additionally, students’ demographic and educational characteristics were collected.

**Results:** The vast majority of students were female (83.3%), with a mean age 22.3±5.6 years old. Most of them had no death experience in personal life (61.1%) or clinical placements (54.4%). Almost all the students (97.8%) had insufficient PC knowledge (< 75% of correct answers). The 4th year students reported higher total PC knowledge, than 2nd and 3rd year ones ($\chi^2=43.5$, $p<0.0001$). Although personal death experience was not associated with total PC knowledge ($p>0.050$), students having death experience at clinical placements reported more correct answers regarding pain and symptom control ($z=-2.0$, $p=0.043$), and psychosocial and spiritual care ($z=-2.6$, $p=0.008$). All year students had positive ACD (112.1±0.3) (30–150). The 3rd and 4th year students had more positive ACD than 2nd year students ($\chi^2=11.0$, $p=0.004$). Students holding positive ACD reported more correct answers regarding total PC knowledge ($\rho=0.30$, $p=0.004$).

**Conclusion and discussion:** Despite their limited knowledge about PC Greek nursing students hold a positive ACD. The undergraduate PC/end-of-life education and training affect knowledge positively. Further research will reveal more factors associated with knowledge and attitudes towards PC and ACD, that could improve PC education.
Using Film to Foster Empathetic Partnerships between Care Providers and Family Caregivers

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Fragmentation in the US healthcare system has frayed the critical relationships among caregivers and healthcare providers. Yet, caregivers are on the frontlines: managing complicated chronic illnesses, assisting with day-to-day functioning, and providing direct palliative care to manage symptoms and improve quality of life. While meeting loved one’s needs, caregivers navigate an increasingly complex and confusing health system. Students and providers receive little, if any, training on the vital role caregivers play on the healthcare team and how, effective partnering optimizes patient care throughout the illness trajectory and at end-of-life. Building Caregiver Partnerships through Innovative Health Professions Education is an Arthur Vining Davis Foundation funded effort to create effective provider-caregiver partnerships that benefit patients suffering from complex serious illness. The educational initiative centers on a film that tells the compelling care giving journeys of four families. It was specifically crafted to heighten awareness while triggering learner emotions in response to these remarkable narratives. The film can be highly effective in evoking personal responses that can be translated into clinical practice. The key issue is constructing a safe space in which learners sense permission to be vulnerable as they explore their feelings about caregiving and the death of their own loved ones. This includes setting an accepting environment for an invitational discussion utilizing appropriate debriefing strategies. Instructors model the empathic partnering approach through their interaction with learners in this context of shared vulnerability. The film will begin the session followed perspectives and educational tools intended to help diverse trainees connect empathically with family caregivers for optimal palliative care. The presenter will discuss ways in which the film has been utilized most effectively for a variety of learners.
Family Medicine with Matrix Support from Palliative Care Experts: A New Training Strategy Implemented by Public Health System in Buenos Aires

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Background: Family medicine (FM) specialty embraces professional attitudes and skills needed to effectively address symptoms, needs and emotions around care of patient-family complex. The foundations and principles of FM also share with palliative discipline several key aspects: comprehensive and integrated care, interdisciplinary approach, health promotion at different scenarios (in/outpatient/home), empathy and a biopsychosocial approach.

Aims: To provide interdisciplinary “on the field” training to health members of primary care centres that belong to Ministry of Health with support of experts, following a structured 4 to 6 months training programme.

Design and methods: A core training programme based on Smeding-Kolb methodology (experiential education) began at public health primary care centres in Buenos Aires, focusing on early palliative care implementation, symptom relief, family support and proper end-of-life care. Contents and aims followed the EAPC white paper document. Meetings took place every two weeks during 4–6 months, based on interactive and collaborative learning. From November 2014 till now, 52 health care members from 3 different centres completed the programme.

Results: According Kirkpatrick’s model, evaluation of the programme was performed at different levels:
1) professionals scored high satisfaction (visual scale), with good engagement;
2) a pre-post test demonstrated they increased knowledge on main contents and they were able to solve most clinical problems with their patients;
3) they were able to identify early palliative care needs in an increasing number of patients they cared;
4) at one of the centres they created a palliative care team involved in ambulatory and home care, and replicating the teaching experience at their district.

Conclusions: This interactive and structured training programme at primary level of health care with matrix support of experts demonstrated efficacy in enhancing trainees competences on palliative care.
Contributions of the Discipline of ‘Nursing and Palliative Care’ in Professional Nursing Education: Experience Report

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Nursing in Palliative Care is increasing worldwide, requiring skilled professionals as mobilization, sensibility and encouragement. The approach of this content in the training of nursing professionals becomes imperative. This is an experience report that aimed to describe the experiences and the contribution of the discipline “Nursing and Palliative Care” from the Federal University of Pernambuco (UFPE) for the training of nursing students. This discipline was created in 2009, with 30 hours and mandatory character, the first course in Brazil with this format. In its contents are contemplated the ten core competencies in palliative care of the EAPC. Scientifically, ethical, philosophical and humanistic basis are worked the principles of palliative care, communication, control symptoms and quality of life, multidisciplinary care plan, loss, grief and bereavement, family and patient’ needs in the last hours of life. Thus, it was impossible not to see the patient terminal only as “someone who is dying” but as someone who should be provided better quality of life through emotional, social and spiritual support, decreased pain and other symptoms, respect for autonomy, family preparation for death, monitoring of bereavement and the certainty that the patient will not be alone in their last days of life. Students also organize the celebration of the World Day of Hospice and Palliative Care in Brazil, sharing knowledge with the entire academic community and raising donations for patients. We conclude that experience a discipline of Palliative Care led to reflect on the importance of assistance at the end of life and relief of suffering as an essential function of nursing and allowed us to understand the physical, emotional, social and spiritual needs of the patient and family, being indisputable their compulsory education in professional nursing education.
Assessment of the Satisfaction and the Degree of Competencies Achieved by Medical Students in a Basic Course of Palliative Care in Colombia

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Introduction: A World Health Assembly (WHA) resolution adopted in 2014 strongly encourages member states to integrate palliative care (PC) in undergraduate training for health professionals. A prestigious University in Cali-Colombia, offers a three-week PC course to students in 9th semester following national and international guidelines.

We aim to validate the methodology used in the PC course (supervised clinic and seminars) during the last three semesters.

Methodology: We asked Medical students (n=98) from the last three periods to evaluate the methodology and the principal competencies of the course.

They rated from 1 (minimum) to 5 (maximum) the grade achieved for each competency:
(1) Definition and Principles of PC,
(2) Identification and Control of Symptoms,
(3) End-of-Life Care,
(4) Ethical and Legal Issues,
(5) Psychosocial and Spiritual Issues, and
(6) Teamwork.

Each competency encompassed specific items. The first 30 questionnaires received were analyzed.

Results: Response rate: 36%. Average age: 22.9 ± 1.47 years. Sex: 60% female.

The overall grade of the competencies was 4.41 ± 0.32.

The competencies with the highest grade were: Definition and Principles of PC, Psychosocial and Spiritual Issues, Teamwork. The students agreed (mean 4.37 ± 0.67) with the methodology of the course. 63% suggested that the inpatient rounds should be improved.

Conclusions: Medical students are highly satisfied with the methodology and the competencies of the PC course offered by this colombian University. We plan a follow-up with this cohort of students.
Providing Evidence-based Care for the Dying: The CARESTool

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The educational deficits and emotional comfort issues many health care providers continue to require when attempting to provide compassionate, person-centered, evidence based care for the dying remains extensive. These issues can be affectively addressed with the use of an educational tool based on the five most common symptom management needs of the dying confirmed in literature as Comfort, Airway, Restlessness and delirium, Emotional and spiritual support, and Self-care. The educational tool is called CARES and is based on these identified needs. The CARES Tool is a pocket reference that provides medication suggestions, communication recommendations, and education prompts to be provided by the health care provider. It is adaptable to any age, sex, or cultural group. It can be easily individualized, readily recalled, and includes suggestions to help the health care provider address issues of professional grief and over-identification. An article written on the CARES Tool published in the May, 2013 issue of the Journal of Hospice and Palliative Care, was the most down-loaded article on MedScape for that month. A reference book published by Springer in 2015, based on the CARES Tool called “Compassionate Person-Centered Care of the Dying”, was awarded a “2015 Book of the Year” recognition in the category of Hospice and Palliative Care, by the American Journal of Nursing. The CARES Tool has been well received throughout the United States and Canada, has achieved unquestioned face and content validity, and continues to be utilized to assist in the international effort to improve care of the dying.
Palliative Care in Primary Care: A Journey Around the World

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Background: In the near future an increasing number of General Practitioners (GPs) will be asked to work in palliative home care, hospices or nursing homes. It is important to promote and enhance specific/palliative care training for junior GPs, to ensure the high quality of care in this particular setting. The Giotto Movement, a WONCA-affiliated association of Italian junior GPs, aims to address this challenge.

Goals: To be accomplished in the next two years:
1) to create a new part of the Hippokrates Exchange, which will focus on palliative care (called “Pallium Hippokrates”);
2) to create a dedicated European network, identifying the best practices for GP training with a special interest in PC;
3) to offer a broader vision of community-oriented primary care in different countries;
4) to involve junior GPs, who will complete a final report (REP) during the exchange programme.

Methods: Using the Hippokrates framework, enriched through specially-selected doctors, to spread the PC philosophy. Candidates will be required to complete a REPs which will be based on educational learning methods and will include a critical analysis of local health care models. At the end of the exchange candidates should be able to identify elements that can be transferred to their national primary care setting. The REPs would then be collected in an online database. Candidates will be asked to share their experience within the peer education model, and the REPs will ensure the educational value of the programme.

Results: The Pallium Hippokrates Programme was presented and discussed in June 2016 in Copenhagen at the WONCA European Conference. We have established a pilot exchange in The Netherlands and elected hosts. Every activity is NON-PROFIT.

Conclusion: GPs must be ready to face challenges that aging populations present as well as the increasing demands of PC. We wish to build a group of futureGPs/leaders who can establish strong bonds between general practice and PC in Europe.
Establishment of a National Board to Approve Nurses in the Specialised Palliative Care Field in Denmark

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Background: Palliative care is not an established medical specialty in Denmark. The need for a specialist education for nurses in palliative care is in demand. The EAPC taskforce on education from 2003 defines palliative nursing as an area of specific practice, requiring a strong educational foundation to ensure high-quality nursing services within the multi-professional teams. A competence program for nurses including the specialized palliative care (SPC) was established in 2012 and needs to be implemented nationally.

Aim: To establish a National Board to approve nurses in SPC.

The aim of the board: Recognition of both the individual nurses as well as the SPC in general, ensure uniform requirements for the approval, establish a competence profile, identify potential future education.

Design, methods and approach taken: The initiative to the National Board was taken by “The Danish Association of Nurses in Palliative Care” in co-operation with relevant partners. Leaders from all 66 SPC institutions were invited to a seminar. 35 leaders were represented, and they were all very supportive. After a round of applications, 8 nurses were selected to set up the National Board. Criteria for selection were based on conditions of employment within SPC, experience and academic level.

Results: The National Board has been set up. Their role now is to: Clarify the educational opportunities at a national level, set criteria for a disciplinary approval, approve applications from nurses twice a year, provide applicants with individual advice for education and training in case of refusal, Identify training needs on a national basis.

Conclusion: With the establishment of a National Board to approve nurses in the SPC field, we are setting a solid foundation to influence the ongoing development of nurses and their recognition and educational opportunities within the SPC in Denmark.
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**Needs in palliative care – procedures and educational solutions generated by Med&Lang Erasmus+ program**

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**Background:** Palliative care problems represent probably the domain in which collaboration between families and medical stuff is the most demanding need. It requires therefore common language and ability to interrelate with each other care interventions. This is regarded as a social responsibility of medical educational system as, intra-familiarly, the palliative care burden falls on to the one that also carry out for the economic grow and the progress of the society.

**Aims:** To increase skills level of the medical stuff actually involved in palliative care and to expand human resource open to deliver help to a palliative patient.

**Methods:** Built of a database of protocols validated by evidences and professional European expertise (Belgium, Italy, Spain, Romania – Brasov and Iasi centres) that is integrated in an innovative system of education that relies on a successively shift of roles between trainees – performer, receiver and evaluator as postures for learning.

**Results:** 20 procedures of palliative care (communicating “bad news”, end-of-life care, mapping patients network, address caregivers needs, own disease awareness, burn out syndrome prevention, terminal phase management, oral care, pain impairment assessment, pain management, management of pressure ulcers, patient bath, active listening – empathic response, conspiracy of silence, spiritual assessment, subcutaneous perfusion, feeding patient in bed, transferring patient in bed, urinary catheterization, paracentesis) were created as a written sequence of steps that must be followed in order to act for an ease of learning and a guaranty for quality. Each procedure associate a video format conceived as a massive open online course (MOOC) to be used by the professionals from palliative care, teachers, students but also by laic palliative care delivers.

**Conclusions:** Med&Lang Palliative Care Project succeeded to generate useful educational tools that worth to be disseminated to palliative care providers.
Integration of PC

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The objective is to promote best practice and high-quality palliative care services in all government hospitals. Integration of palliative care into government hospital is still in low priority, Ocean Road Cancer Institute palliative care team in collaboration with ICAP observed a gap in terms of quality of services provided. Training of health professional on Palliative care to government hospitals was done followed by Training of Trainees, so as to build capacity to local professional and maintain sustainability of teaching palliative care. Number of health professional received palliative care training increased, and opportunity for on job training and services implementation observed. Training is an ideal method to build capacity and ensure sustainability of Palliative Care services.
Who Do you Think you Are? Anticipatory Digital Legacy Planning and How it Can Work

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The adoption of the Internet and subsequent communication tools like smartphones and social networks has transformed our lives. There is real value and significant substance attributed to each individual’s digital assets and the information that they leave in a digital format when they die. This can be of significant value to palliative care professionals, and existing data suggest that legacy interventions are beneficial when approaching the end of life. Upon death much of this information will form part of the deceased person’s overall estate: in essence, it becomes their very own digital legacy and can be important in the grieving process. The information left behind (the digital remains) is stored on social media accounts, websites, blogs, PayPal accounts, an iTunes library and devices like mobile phones, hard drives, tablets and computers. The importance and value of this information is significant and can form part of a cultural heritage when accessible for future generations.

Most people, if they do any planning at all for what happens in the time after they die, focus on their physical possessions, and not what is stored digitally.

Should providing advice about such matters fall into the remit of the social, supportive and palliative care world? If so, how can this care be provided and to what extent? If not, who will carry out this task and then signpost patients to suitable areas of support? Palliative medicine teams are tasked to support the psychosocial, spiritual as well as the physical aspects of a patient’s care. Care is also necessarily targeted at supporting families. Providing legacy planning, including digital legacy work can be considered part of the realm of palliative care team engagement.

The Digital Legacy Association’s mission is to raise standards within end-of-life and palliative care in areas of digital asset and digital legacy management and planning. Much of their work revolves around training and defining best practice.


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Training of Palliative Representatives (PR) in Nursing Homes

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Many people in the end of life are cared for in nursing homes. Providing good palliative care require knowledge and dedication. The nursing staffs also need support. By giving nursing assistants special knowledge in general palliative care they will be able, along with the registered nurses, to spread the knowledge and give advice and support to their colleagues in their working place.

Goal of the work: To train Palliative Representatives (PR) to enhance the ability to clarify and improve quality of good and secure palliative care.

Trained palliative representatives should have obtained

- knowledge
- deeper understanding for palliative care and
- ability to be responsible to implement this knowledge in their working place

Method: Operations manager of the nursing home appoint who will be trained. After completed the training program a personal mission is given as PR.

The training is done in three parts (3 whole days) with identified learning goals based on National Guidelines. Trainers are registered nurses certified in palliative care nursing.

Results: During our first year 190 assistant nurses have been examined and the evaluations have been very positive.

Conclusion: We believe it is important to keep the basic palliative approach when it comes to training in both basic and more advanced levels. Sometimes we only see the physical symptoms even though we know that mental, social and existential aspects are just as important for a holistic approach.

Effective treatment of pain and symptoms is an obvious part of the work and will best be achieved through cooperation and teamwork. Communication and good relationship makes the work easier and improves wellbeing. Family members have their own crisis and need support in the palliative phase. The training of PR provides tools for this.
Factors Influencing the Conceptualization in Palliative Care

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**Aims:** Description of a conceptual map that brings together the principal concepts in palliative care for patients, family and health care team.

**Design and methods:** Literature review of the main concepts related to palliative care.

**Results:** The dimensions of palliative care have an holistic approach. The management of palliative care is influenced by:

1. The model of care, determined by the clinical context: homecare, hospital, hospice care or long term care.
2. The type of treatment determined by the type of disease suffered: cronic illness, cancer or degenerate illness.
3. The integration of palliative care depends of education received by the patient, family and health care professionals.

**Conclusions:** Dimensions of palliative care have to do with biological, psychological, social and spiritual aspects. The link we can observed between the context of the disease, the type of the disease and the education integrated in palliative care, helps to manage the quality of care we can provide at the end of life.
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**ASK ASK TELL ASK ASK PLAN: Adapting Breaking Bad News Teaching Resources for the African Setting**

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**Aim or goal of the work:** The ‘SPIKES’ model published in 2000 proposed by Walter F. Baile et.al in North America is a well established model designed to teach medical practitioners a structured protocol which guides them through the breaking bad news encounter. However it required some adaptation for use for teaching health workers in Malawi, Southern Africa.

**Design, methods and approach taken:**
The ‘ASK ASK TELL ASK ASK PLAN’ is as follows:

AS:K yourself
Do I have time? Do I have the right (and adequate) information?
Is this the right place? Am I the right person?

ASK: the patient
Do they need clarification about any terms or words used

What are their main concerns?

TELL: the patient
Slowly and clearly what is wrong with them avoiding euphemisms
Leave time for silence

ASK: the patient
What do they know about what is wrong with them

Would they like anyone else to be with them
Would they like to know more

PLAN with the patient
On the basis of their main concerns arrange next steps including follow up.

**Results:** The modifications highlight and incorporate some contextual issues of particular relevance in an African setting though the simple teaching structure maybe a suitable starting point for adaptation in a variety of settings. This model has been successfully taught to groups of medical students and other health cadres over the last ten years and is now examined on.

**Conclusion and lessons learned:** Health literacy and communication about difficult issues is poor in low resource settings such as Malawi where patients and families are frequently not told what is wrong with them. This simple six step breaking bad news model can help to improve generic skills and confidence for health workers in breaking bad news.
Education is as Well a Promotion in Providing Qualified Palliative Care (PC) Service for All People in Need

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**Goal:** To highlight: the importance of continuing education of health professionals (HP) on PC provided from “Mary Potter” (MP) team; the positive impact of the education of HP enhancing the quality of life for patients who live in areas where there are no PC centers, the challenges and further plans for the continuance of trainings based on the growing needs of the patients and their family members (FM).

**Methodology:** The data used are: the information and statistics gathered from MP center which provide trainings for all HP all over Albania, meetings and contractual agreements with the Ministry of Health and National Center for Continuous Education (NCCE) for the recognition and accreditation of the training activities, filled questionnaires from the participants before and after attending the training, reports and comments in the impression book and the information gathered from patients and their FM.

**Results:** MP center remains the only education center on PC in Albania, since 2007. There are organized trainings extended in 1, 2, 3 and 5 days, all accredited by NCCE. The attendees have been physicians, nurses, social workers and psychologists from the entire country, in total 2582. The participants’ evaluations have been overwhelming. Practical experience, as part of the training programs has been assessed as a very useful part of the trainings. Already, PC is promoted in a considerable territory of Albania. As a result of all these trainings, PC is known in all the country and HP have gained knowledge on PC and they provide service for all patients in need.

**Conclusions:** Education remains an important component in PC which runs parallel with the provision of this service. HP see PC service as a model and the providers, as the only resource of information on PC. The capacity building of HP on PC has a direct positive impact to the patients and their family members. Education has strongly contributed to the promotion and further development of this service in Albania.

**Keywords:** Education, HP, PC
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Self-efficacy in Palliative Care and Thanatophobia Scales – Translation and Adaptation to Brazilian Portuguese

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Considering the global need of Palliative care teaching and training for health professionals, turn available Self-Efficacy in Palliative Care (SEPC) and Thanatophobia (TS) Scales as a measure for palliative care competencies in different languages and cultural backgrounds would strengthen educational strategies in palliative care.

Translate and adapt the SEPC and TS from original English to Brazilian Portuguese for undergraduate students in Brazilian Medical Schools.

Translation was based on the European Organization for Research and Treatment of Cancer (EORTC) recommendations, according to the steps:

1. Two independent English–Portuguese translations;
2. Synthesis of these translations into a Reconciliated Translation version;
3. Back translation Portuguese–English, made for two independent native translators;
4. Report and Evaluation of the back translations by the Research team which created the original English Scales;
5. Evaluation of the Portuguese version by Palliative Care Specialists in Brazil through a questionnaire about the SEPC and TS on four aspects: clarity, applicability, objectivity and bias, rating their impressions in Likert scale (1 to 5), and their open opinion about the scales.

Suggested steps were followed and a Brazilian Portuguese version of the SEPC and TS were provided. These versions were sent to 17 Brazilian experts in Palliative Care, selected by convenience, and 5 sent back their opinion (response tax 29%), approving the Brazilian version with minor suggestions.

Steps 1 to 5 has been done and the Brazilian Portuguese versions on SEPC and TS are ready to the Pilot Testing. This Pilot will assure the comprehension about the scales contents and correct any misunderstandings, as suggested by expert’s opinion. After that, a final version will be ready to validation process in Brazilian Portuguese and could be used as a tool to measure the impact to Palliative Care teaching and strengthen these efforts on medical schools.
Physiotherapy Intervention for Fatigue in Palliative Care: A Systematic Review

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Background: Fatigue is recognized as one of the most prevalent, distressing and debilitating symptoms experienced by people in palliative care. Appropriate interventions may bring considerable improvements in quality of life to palliative care patients and their families, reducing physical, psychological and spiritual distress.

Aims: To evaluate the effect of physiotherapy intervention on fatigue in palliative care patients.

Methods: The research was performed in MEDLINE and PeDRO, and Cochrane Central Register of Controlled Trials (CENTRAL) databases on September 2016. Articles in English published from 2006 to 2016 were selected. We used the following keywords: “fatigue” and “palliative Care” and “physiotherapy” and “physical therapy” having as result 117 articles in MEDLINE, 7 in Cochrane and 2 in PeDRO. All studies that included physiotherapy intervention, exercise programs and other nonpharmacological interventions that can be included on a physiotherapy plan for palliative care patients or with advanced disease, were included. At the end 25 articles were selected.

Results: We found studies to control fatigue in palliative care patients with advanced stage in various types of oncology populations, fibrosis cystic, COPD, HIV and neurodegenerative diseases. Education programs (included teaching energy-conservation techniques), counseling, multimodal mind-body, walking, resistance training and aerobic exercise, massage and relaxation seems to reduce fatigue in palliative care patients or with advanced disease.

Conclusion and discussion: In summary, there is some evidence to indicate that strategies, that can be used in physiotherapy, to increase physical activity and functioning, like exercise programs, massage, relaxation techniques, counseling and education are associated with a reduction in fatigue in palliative care patients or with advanced disease.
Cachexia-related Risk Factors for Premature Death Following Chemoradiotherapy for Lung Cancer: The Potential to Inform Cancer Treatment Decision-Making and to Identify Candidates for Proactive Cachexia Management

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Background: Cancer cachexia is a debilitating syndrome affecting up to 60% of patients with lung cancer. It reduces tolerance to chemotherapy, necessitating dose reduction and treatment termination. However, it is not known how its presence should inform treatment decisions in the lung cancer clinic. Nor is it known which patients might benefit from cachexia management, either alongside or in advance of cancer treatment.

Aim: To determine the extent to which markers of cachexia at diagnosis are associated with adverse outcomes following chemoradiotherapy for lung cancer.

Methods: A retrospective cohort study of 197 patients with lung cancer who underwent chemoradiotherapy in South East Scotland from 2008–2010 was undertaken. Demographic and clinical variables including CT-derived body composition (sarcopenia, low muscle attenuation (MA)) at diagnosis were examined for prognostic significance using Cox’s proportional Hazards model and logistic regression.

Results: Median overall survival was 19 months (95% CI: 16.3–21.7). BMI < 20 and ECOG PS ≥2, proxies for refractory cachexia, were independent predictors of death within 90 days of treatment completion (p< 0.001). Patients with early signs of cachexia (weight loss and low MA), had significantly reduced overall survival (p< 0.001); individuals with weight loss and low MA (n=50/197) had a median survival of 13.9 months (11.4, 16.3) compared with 28.2 months (19.6, 36.8) for those who were not weight losing and had high MA (n=42/197, HR: 2.5).

Conclusion: Poor performance status, low BMI, weight loss and myosteatosis identify patients at increased risk of premature death following chemoradiotherapy. Awareness of risk factors should inform discussions with patients about the potential harms as well as intended benefits of treatment. They may also enable future cachexia interventions to be targeted to patients who are most at risk of adverse outcomes, but whose prognosis is long enough to benefit.
‘Everything is Affected and Everything is an Effort’: Experiencing Fatigue at the End of Life

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Fatigue is significant in patients’ physical and psychological lives, as advanced disease creates complex burdens of care. At the end of life, the body fades and tiredness assumes hidden meaning for patients and carers. Literature consensus is limited for causation or interventions, but some agreement appears for multi-modal approaches to improve patients’ perceptions and engagement in activity. A multi-focal fatigue intervention (4–6 Sessions) was developed by O.T.s and has been well received. While evidence based, it had not been formally investigated for patient experience or impact on informal carers.

A grounded theory study explored the experience of fatigue and intervention perspectives for patients at the end of life and their carers. Researchers interviewed patients and nominated carers on completion of the programme. These were transcribed, coded and analysed to identify fatigue impacts on quality of life, social roles and activity and acceptability of the programme.

Analysis identified the role of ‘adjustment to a changing normal’, impacting the fatigue experience, relationships, roles and intervention participation. ‘Being seen’ was a critical part of the holistic therapeutic relationship, often missing from other care. Recruitment was challenging, limiting depth of carer analysis.

This approach empowered patients and carers to be more active in managing fatigue; therapeutic approach and space for focused discussion were valued; fatigue impacted all aspects of life, but structure and/or focus (e.g. maintaining social roles) help to promote Quality of Life. However, some used strategies ‘in the moment’, limiting their self-management.

Results suggest the programme is valued by patients and informal carers as one strategy for living with fatigue. A further service evaluation is also planned to refocus the intervention to echo human occupation in O.T. and collate further goal setting and quality of life data, routinely collated with this intervention.
Quality of Life in Cancer Cachexia

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The cancer cachexia (CC) is characterized by intense metabolic, nutritional, immunological, inflammatory and neuroendocrine changes, with progressive functional impairment and reduced quality of life. This study aimed to evaluate the quality of life of patients with gastrointestinal cancer with and without CC. Cross-sectional study with 378 patients between 18 to 65 years old, schooling> 6y and KPS> 60. Patients were classified into Pre-Cachexia Group (Pre-CC, n = 53), Cachexia Group (CC, n = 122) and No-caquexia Group (No-CC, n = 203), as proposed by Fearon (2011). The quality of life was assessed by the EORTC QLQ C-30 and its scales. We used the ANOVA for comparison of variables. Most patients were men (55.3%), aged 53y (SD = 9); without metastasis or any current treatment. The most prevalent type of cancer was colon and rectum in pre-CC and No-CC groups; tumors of the stomach and esophagus were prevalent in CC group. The CC group had a worse score of quality of life (71.4 + 19.8; p = 0.007) when compared to Pre-CC (76.1 + 19.9) and No-CC (78.6 + 19.7) and higher average symptom scores (25.8 + 20.2, p < 0.001; 17.9 + 19.3 and 11.7 + 13.8, respectively). Pain, fatigue, nausea/vomiting, insomnia, lack of appetite and constipation, besides the physical condition and the financial impact of the disease or treatment had worse averages in the CC group (p < 0.001). The CC group showed better performance average (29.6 + 20.9; p < 0.001) compared to pre-CC group (26.5 + 23.6) and No-CC (17.6 + 11.1) in the functional scale. CC patients had a score of quality of life lower than patients No-CC, influenced mainly by worse average symptom. In addition to the physical condition and treatment, family and financial’ support and changes in performance roles become essential for multimodal treatments by the professional staff.
**What Is the Factor of Continuing Rehabilitation Until Dying Phase?**

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**Background:** There were several studies on the rehabilitation for cancer patients. However, there were few studies on this theme for terminal cancer patients.

**Aims:** This study aimed to examine factors that may affect continuing rehabilitation for cancer patients in dying phase (within a week of death).

**Methods:** The subjects were consecutive terminal cancer patients admitted to the palliative care unit and general wards over the past 2.5 years. The patients were divided into 2 groups; continuing rehabilitation on dying phase group (CR) and discontinuing rehabilitation before dying phase group (DR) for comparison. The following 4 items were retrospectively investigated in these patients:

1) performance status (PS) at the initial rehabilitation,
2) number of the days from initial rehabilitation to death (survival period),
3) contents of rehabilitation programs at the initial time and on dying phase, and
4) reasons for discontinuing rehabilitation.

A chi-square test was used for statistical analysis.

**Results:** There were 91 (77%) patients in CR, and 27 (23%) patients in DR, respectively. We continued rehabilitation until death in 54/91 (59%) patients of CR.

1) PS: 2/3/4 were 9/51/31 patients in CR, and 3/17/7 patients in DR (p=0.86).
2) Survival periods in CR/DR were 29 and 31days respectively.
3) Programs at the initial rehabilitation were low intensity exercise/ADL training (48%), and relaxation/stretching (48%). Programs on dying phase were relaxation/stretching in 90% (p< 0.0001).
4) The reasons for discontinuing rehabilitation in CR and DR group were deterioration with communication incapacity (84%, 37%), physical symptoms (13%, 33%), and psychological distress (3%, 22%), respectively (p=0.001).

**Discussion and conclusion:** It was important to provide rehabilitation programs based on the change of patients’ condition such as the level of deterioration with communication incapacity, and physical / psychological problems.

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The Prevalence of Laboratory Cachexia in Patients with Incurable Cancer Approaching Death

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Background: Amongst advanced cancer patients cancer cachexia is common and associated with adverse outcomes. The term however lacks a universally accepted definition and to this date there is no consensus regarding which variables are to be measured. The condition is generally defined as a certain percentage of weight loss over a certain period of time. In addition to this, “minor criteria” including alterations in laboratory measures such as C-reactive protein and s-albumin may also be applied. This study aims to add to the ongoing discussion regarding the definition of cancer cachexia and to study the role of C-reactive protein and s-albumin in this context.

Method: A 1-year cohort, consisting of 155 cancer patients enrolled in a specialized palliative home care team, that were deceased during the year of 2015 was studied. Laboratory measures were studied within 0–30 and 31–60 days prior to death. C-reactive protein >10 mg/L and s-albumin < 30 g/L was referred to as “laboratory cachexia”. Also, the number of days from the first found “laboratory cachexia” until death was noted.

Results: The prevalence of “laboratory cachexia” was 84% 0–30 days prior to death compared to 64% 31–60 days prior to death (p< 0.01). The majority of patients had an onset of “laboratory cachexia” within 0–120 days prior to death, with a median of 47 days. The median values for C-reactive protein and s-albumin within 0–30 days prior to death were 72mg/L and 23g/L respectively.

Conclusion: The prevalence of “laboratory cachexia” was 84% in the time period closest to death. The onset was found within 0–120 days prior to death for the majority of patients. As C-reactive protein and s-albumin values were remarkably abnormal and could not solely be explained by infections, their cut offs within the context of cancer cachexia may be further discussed.

This study was undertaken as a degree project, thus the medical school through which the study was performed accounted for the funding.
Correlation among Two Scales for Diagnosis of the Tumoral Asthenia in Primary Health Care Services

**Objective:** Diagnosis of fatigue in cancer patients in primary health care services: an opportunity for assessment and grading the fatigue with two scales, the International Classification of Diseases (ICD-10) criteria and the Karnosfky Index (KI).

**Design:** Observational study conducted in the Basic zone of Health of Utrera (Seville), includes seven care centres. Initially we studied 67 patients suffering from cancer disease, but finally only 61 were included. Inclusion criteria: agreement to participate in the study, adult and cancer diagnosis. Exclusion criteria: no agreement to participate, clinical evidence of non-tumour origin fatigue, cognitive impairment or severe psychiatric disorder.

Personal interview recording: age, sex, type of tumour, antitumour specific treatment in the last twelve months, terminal oncological disease, KI and tumour asthenia detection according to ICD-10 adapted, gradations being established between both scales. Statistical analysis: descriptive, and non-parametric correlational and inferential analysis.

**Results:** According to adapted ICD-10 criteria, fatigue is found in 70.5% of the cases and 78.7% presents a minor or equal KI index. The partial correlation between most common tumours, the adapted ICD-10 and graduated KI shows statistically significant differences in lung cancer, breast, prostate and colon and rectum, referring to the presence of fatigue in cancer patients. Moreover, there is a negative relationship between these two main instruments (correlation coefficient -0.902) as for breast, lung and prostate statistically significant (p< 0.001), proving the existence of a linear and inverse correlation between which is detected by adapted ICD-10 and graduated by KI.

**Conclusions:** Adapted ICD-10 criteria can assess and graduate fatigue in cancer patients and these results can be supported by using the KI as a complementary tool.
Developing Research Priorities for Palliative Care of People with Intellectual Disabilities in Europe: A Consultation Process Using Nominal Group Technique

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Background: Empirical knowledge around palliative care provision and needs of people with intellectual disabilities (ID) is extremely limited, as is the availability of research resources, including expertise and funding.

Aims: To develop an agenda for research priorities for palliative care of people with intellectual disabilities in Europe.

Methods: A two-day workshop was convened with 16 academics and clinicians in the field of palliative care and ID from 6 European countries. Day 1 consisted of round-table presentations and discussions about the current state of the art, research challenges and knowledge gaps. Day 2 was focused on developing consensus research priorities with 12 of the workshop participants using nominal group technique.

Results: A total of 40 research priorities were proposed and collapsed into 11 research themes. The most important research themes were: investigating issues around end-of-life decision-making; mapping the scale and scope of the issue; investigating the quality of palliative care for people with ID, including the challenges in achieving best practice; and developing outcome measures and instruments for palliative care of people with ID.

Conclusions: The identification of priority areas for future research in ID, death, dying and palliative care will help researchers to focus limited resources and research expertise on areas where it is most needed. The next steps are to cross-validate these research priorities with people with ID, carers, clinicians, researchers and other stakeholders across Europe; validate them with local and national policy makers to determine how they could best be incorporated in policy and programmes; and translate them into actual research studies by setting up European collaborations for specific studies that require such collaboration, develop research proposals and attract research funding. This work complements the work of the EAPC Taskforce on ID, which resulted in a White Paper in 2015.
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End-of-Life Care for Haematologic Malignancies: A Retrospective Cohort Study from the State of Qatar

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Introduction: Aggressiveness of cancer care at End of life (EOL) has recently emerged as an important indicator of quality of care in most oncology centers. It is well known that patients with hematologic malignancies are exposed to a higher percentage of aggressive care near EOL compared to those with solid tumors. The aim of the present study is to report on the quality of EOL care for patients with hematologic malignancies treated at the National Center for Cancer Care & Research (NCCCR) in the state of Qatar and to compare it to those with solid tumors over the same period of time.

Materials and methods: This retrospective cohort study included 97 patients diagnosed with hematologic malignancies at NCCCR who died as a result of their disease over the period from 1-1-2009 till 31-12-2013. Their EOL care was compared to 687 patients diagnosed with solid tumors who died during the same period. Indicators for aggressiveness of care were compared in the 2 groups. A p value < 0.05 was considered statistically significant.

Results: Hematologic malignancies constituted 12% of all malignancies. Patients with hematologic malignancies were significantly younger than those with solid tumors (median age of 48 years versus 60 years, p < 0.001). Patients with hematologic malignancies had significantly more ER visits compared to those with solid tumors (p < 0.024); more ICU admissions (p < 0.001) and were less likely referred to palliative care (p < 0.001). The composite score of aggressiveness for patients with hematologic malignancies decreased from 1.74 to 0.67 over the period of the study.

Conclusion: Patients with hematologic malignancies have significantly more ER visits and ICU admissions compared to patients with solid tumors. They are also less likely to be referred to palliative care. Earlier engagement with palliative care is warranted for those patients in order to improve the quality of their EOL care.
Palliative Care for the Homeless: Complex Lifes, Complex Care


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Background: Homeless people often encounter multiple problems and have a shorter life-expectancy. Little is known about how palliative care for this group is organized and can be improved.

Aim: To explore and describe aspects of the palliative care for homeless people in The Netherlands from the perspectives of the patients, their relatives and professionals. How do they perceive the provided care and what care is needed?

Methods: In this qualitative study nineteen cases of homeless people needing palliative care were studied. Eight persons were identified as in need of palliative care (using the ‘surprise question’) and eleven persons recently died. Semi-structured interviews were held in 2014–2016. For each case we interviewed on average 3 people: the homeless person (where possible), doctors, nurses and/or social workers (number of interviews = 55). All interviews were transcribed verbatim and analyzed inductively, using thematic analysis. Open coding, memo writing and constant comparison were supported by MaxQDA software.

Results: From the analysis three main themes were derived: ‘access’, ‘capricious trajectory’ and ‘complex care’. The first theme refers to the often limited access to palliative care, e.g. because people are ambivalent regarding accepting care. The second theme refers to the illness trajectory, which is often capricious and non-predictable. The third theme refers to the specific challenges in caring, for instance, with regard to pain and symptom management. This is often complex because of a history of addiction and the often severe physical, psychosocial and cognitive problems.

Conclusion: The life of homeless people is often hard, resulting in complex care needs at the end of their life. Cooperation between palliative care professionals and mental health professionals, is needed to improve care for homeless people at the end of life and to realize better access to palliative care.
Patient Well-being and Carer Burden in Long-term Neurological Conditions: Baseline Results from the OPTCARE Neuro Trial

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Almost 10 million people in UK are affected by long-term neurological conditions (LTNCs). Many have poor symptom control and social support with a high burden for informal carers. The OPTCARE Neuro trial is evaluating the effectiveness of short-term integrated palliative care (SIPC) for LTNCs patients and their carers. Here we explore the association between patient quality of life (QoL) and mental health and carer burden.

The sample included 80 patient carer pairs with complete data. Carer burden was measured using the Zarit Burden Inventory (ZBI-12). Patient QoL was measured using the EQ5D questionnaire and mental health using the Hospital Anxiety and Depression Scale (HADS). Associations between patient QoL and mental health, and carer burden were tested using linear regression models.

Carer burden ranged from no burden=0 to high burden=38 (mean=17.0, SD=8.8). Bivariately, poorer patient QoL (b=.80, p<.01) and higher patient depression (b=.43, p<.05) were associated with greater carer burden; no association was found for patient anxiety (b=.43, p=.10). After adjusting for carer factors (age, illness, gender, education, employment) and patient diagnosis and illness duration, the association between patient depression and carer burden was attenuated whilst patient QoL remained a significant correlate (b=.83, p<.01). The model explained 39.3% of the variance.

Our results support the idea that patient QoL is associated with carer burden. Improvements in patient QoL through the provision of palliative care, may have associated benefits for carers. The ongoing trial will provide further evidence to explore the impact of early palliative care in this population.

Funding: National Institute for Health Research (NIHR), Health Services & Delivery Research (HS & DR) programme and the NIHR Collaboration for Leadership in Applied Health Research & Care (CLAHRC), The views expressed are those of the authors and not necessarily those of the NHS, NIHR or Department of Health.
End-of-Life Care for Substance Users – Mapping the Contemporary Landscape?

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Background: There is a well-established social gradient in access to high-quality end-of-life care. Marginalised populations, such as substance users, often present late to health services through shame and stigma, and health services often struggle to engage them, limiting care planning. As life expectancy rises there is a growing population in the UK with substance problems in later life which is likely to contribute to the trajectory of their deaths. Service providers indicate a growth in numbers but little is known about the needs of service users and the gaps in current provision.

Aims: The aim of this study was to review the existing international research and wider literature in order to determine current responses to end-of-life care for people with substance problems and identify gaps in the evidence base.

Methods: A Rapid Evidence Assessment (REA) was conducted consisting of a review of the literature using systematic methods but with narrower parameters than a systematic review. The REA was supplemented by data from interviews with a group of key informants from health and social care.

Results: The literature review resulted in the identification of 161 papers clustering in five main themes; medication and the management of pain; ageing, death and substance use; health consequences of alcohol use; complex co-morbidities; and a small number of empirical papers exploring service provision.

Conclusion: Evidence suggests that substance users do not constitute a homogenous population but rather a range of overlapping and separate populations requiring different responses from services. Given the anticipated rise in substance use issues at end of life, services need to be equipped to respond appropriately.
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Withdrawal of Treatment in Patients Dying from an Acute Stroke

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Objective: To determine variables related with the decision of treatment withdrawal (TW) in patients dying from an acute stroke.

Methods: We conducted multicentric retrospective study among patients admitted with an acute stroke to two medium size hospitals located in the south Madrid area between April 2012 and September 2015. Descriptive, univariable and multivariable analysis where performed. A p value < 0.05 was used as cut off point for signifies.

Results: 87 patients were included in the analysis; mean age 83 (SD 9.5), 58.6% woman, 62.1% ischemic strokes, 36.8% hemorrhages. At admission: mean NIHSS score 20 (SD 7.6), 25.3% had brain stem signs and 82.8% any disturbance of consciousness. 56.3% where previously dependent and 35% institutionalized. Mean Charlson index 9 (SD 1.83), mean Profund index (PI) 6 (SD 4.6), mean Caring index 7 (IQR 3 –12). A nasogastric tube (NGT) was placed in 25.6%, 66.7% had any infection (93.1% respiratory) among whom 26% received no antibiotics. No-resucitation orders (NRO) where place in 75.9% cases; and within these, TW was decided in 72.7%. A next-of-kin was informed about the bad prognosis in 93% (100% in those with NRO). Drug use comparing TW-group and NoTW-group: morphine (97.9% vs. 57.6%), BZD (58.3% vs. 24.2%). Patients were divided in two groups for analysis purposes (TW and no-TW): in the univariable analysis, NRO (p 0.001), being institutionalized (p 0.041), previously dependent (p 0.002), PI (p 0.024), not placing NGT (p 0.01), use of morphine (p 0.001) and midazolam (p 0.001) were related with the TW group. In the multivariable regression analysis only being dependent: (OR 4; CI 95%: 1.1–10.8) and not placing NGT (p 0.05) and morphine use (p 0.006) remain significantly related with the TW group.

Conclusions: In patients dying from an acute stroke, a history of functional dependency, to be pluripathological, avoidance of NGT and the use of morphine were related to the decision of TW.
What Are Accepted Screening Criteria for Palliative Care Consultation? A Survey among ICU Physicians in Germany

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Background: Though palliative care support at intensive care units (ICUs) is often available its use is infrequent. Trigger-based approaches might be able to increase the rate of palliative care consultations.

Aims: To examine the acceptance and utilization of potential triggers for a palliative care consultation at the ICU among intensive care physicians in Germany.

Methods: In a multi-stage process we developed a quantitative questionnaire with 57 items and an additional free text option. We excluded physicians who worked less than a month at the ICU or did not have access to palliative care consultation. The survey took place in an intensive care workshop in Germany in September 2016.

Results: 190 questionnaires were distributed. 172 (91%) of those were returned, of which 60 responses were eligible for this study. Most of the respondents worked 12 months or less at the ICU (49/60, 82%). They often treated palliative patients (40/60, 67% strongly agree or agree, 1 missing value) though not all of them felt confident by doing so (21/60, 35% strongly agree or agree).

We discovered the three most accepted triggers for a palliative care consultation were “family request” (54/60, 90% agree, 3 missing values), “patient’s request” (53/60, 88% agree, 2 missing values) and “no curative options” (45/60, 75% agree, 2 missing values). The three most rejected triggers were “heart arrest” (47/60, 78% reject, 2 missing values), “ICU stay >1 month” (44/60, 73% reject, 2 missing values) and “>3 readmissions to ICU during the same hospital stay” (43/60, 72% reject, 2 missing values).

Overall, the ratio of accepted palliative care triggers (≥50% agree) was 29% (7/24).

Conclusion: Some important and in previous studies acknowledged triggers are not accepted in practice. However, ICU physicians felt not completely confident while treating palliative patients. ICU physicians might therefore need more training to perceive and address their patients’ palliative needs.
Complexities of the Processes towards Palliative Care for Patients with End-stage Kidney Disease: Physicians’ and Nurses’ Perspectives

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Background: End-stage kidney disease is life-limiting with high mortality rates. Patients undergoing haemodialysis treatment have a complex symptom burden due to both illness and treatment. Their end-of-life trajectories may involve decisions on haemodialysis withdrawal. Development of palliative care in collaboration with health care professionals is required to meet the needs of these patients and their family members.

Aims: To explore the perspectives of physicians’ and nurses’ on palliative care for patients undergoing haemodialysis treatment.

Methods: A qualitative design was used. Four focus group interviews with mixed professions were conducted: 5 nephrologists, 15 registered nurses (dialysis units, renal wards) and 2 enrolled nurses (renal wards) from two hospitals participated. Participants were encouraged to narrate and discuss their experiences of caring for patients treated with haemodialysis approaching end of life and views on palliative care. Qualitative content analysis was used to analyze data.

Results: Palliative care was predominantly viewed as end-of-life care and also stressed as equivalent to withholding or withdrawal of dialysis treatment. However, participants identified earlier needs of palliative care which correspond to a palliative care approach. Findings illuminated multi-faceted and intertwined processes for all involved in which interaction and communication stood out as challenges. The long relation between patients and the physicians and nurses in haemodialysis settings but also roles and the organization of care may complicate these processes.

Conclusions: There is a need to enhance the palliative care approach and support physicians and nurses in renal settings to integrate and adapt palliative care for patients with end-stage kidney disease and their family members. End-of-life communication is an urgent area in this work.
The Outcome and Place of Care for Stroke Patients at End of Life Following withdrawal of Nasogastric Feeding

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Introduction: Dysphagia is common after stroke and nasogastric feeding is often necessary. For some patients long term feeding by gastrostomy is inappropriate so withdrawal of nasogastric feeding and commencement of risk feeding should be considered. Little is known about the outcome of stroke patients following withdrawal of nasogastric feeding and the care they require. Our trust evaluated the care and outcomes of this patient group. This information will allow patients and families to be better prepared thus ensuring quality time can be spent with their loved ones. The Stroke MDT and Palliative Care team are then able to review the process and planning for preferred place and care during the final days of life.

Method: A prospective clinical case series was completed over 13 months on all patients admitted to the stroke unit with a diagnosis of stroke for whom a decision was made to withdraw nasogastric feeding. Data was collected on the type of stroke, co morbidities, type of texture modification for risk feeding, whether antibiotics were prescribed at the time of withdrawal, time from withdrawal to death and place of death.

Results: 51 patients had nasogastric feeding withdrawn (mean age 84, 71% female, 82% ischaemic stroke). The mean time to death following withdrawal was 11.1 days (range 1–49 days). This was reduced to 7.4 days for patients receiving antibiotics for aspiration pneumonia at the time of withdrawal. Patients not on antibiotics survived on average 16.7 days. Of those assessed for risk feeding 95% were placed on a puree diet and Stage 2 thickened fluids. 62.7% of patients died in hospital, 7.8% at home, 13.7% hospice, 15.7 % Nursing Home.

Conclusion: There are challenges when prognosticating this patient group however the data suggests that life expectancy is short following withdrawal of nasogastric feeding so patients and families should be prepared and given the opportunity to consider future care and discuss advanced care planning.
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Does a Pacemaker Lengthen the Dying Process or Postpone Death in Palliative Patients

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Introduction: Patients with a pacemaker and their family ask frequently if it is possible that the presence of a pacemaker will lengthen the dying process or postpone the moment of dying because the pacemaker will avoid or postpone a cardiac arrest. The existing literature does not yet answer this question scientificaly.

Material and methods: Eighty nine patients with a pacemaker died in the palliative care unit of the University hospital of Leuven in the last 15 years. For each pacemaker patient were 2 matched controlled non pacemaker patients found who died also in the same palliative care unit in the same year, with the same age, the same gender and the same pathology.

Results: The time between admittance to the palliative care unit and the date of death was only 6 days for the pacemaker patients but 11 days for the non-pacemaker patients (p = 0.0055). The survival curves between 5 and 30 days after entry in the palliative care unit show that pacemaker patients die about 10 days earlier than the matched paired non-pacemaker patients. This difference is present in patients below and above 80 years, in women and man.

Conclusion: Pacemaker patients die as palliative patients just a few days sooner than their matched controls non-pacemaker patients. The fear that a pacemaker will lengthen the dying process is thus not justified.

Discussion: Pacemaker patients have in general more cardiac problems than just an atrioventricular block that was treated with a pace maker and for that reason they die sooner than patients without cardiac impairment according the cardiologists view.
End-of-Life Conversations with Refugees and Immigrants through a Family Systems Lens

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The immigration experience shapes conversations that patients, families, and health care providers hold regarding the decisions that take place during advanced illness and end of life. Family systems theory and praxis can add to the dialogue and family dynamics surrounding these issues. We propose a theoretical framework that integrates family systems theory and cultural humility to the crucial conversations at the end of life.

Several studies have shown that immigrant communities are often on the periphery in the complex processes surrounding end-of-life care. Palliative care, as a field, is building a strong body of research on culture and its influences on the dying process. Unfortunately, increasing number of studies also highlight significant disparities in the quality of end-of-life care that minorities and immigrants receive. Immigration, as a non-normative transition in individuals and families, is a central contextual factor affecting end-of-life care. Therefore it is crucial to explore how the experience of being an immigrant, a displaced individual, shapes the conversations around life’s end. The dying process for the immigrant is in a real sense their final migration. A family reacts to loss as a system. Understanding end of life from a systems perspective is of utmost importance given the centrality of family and the collectivist nature in decision-making in many minority communities. Family therapists can play a very important role in the interdisciplinary team contributing to excellent palliative care and in attempting to close the mentioned equity gaps.

It is also important to frame these conversations moving from cultural competence as the “arrival” to the understanding of other minority groups, towards a lifelong journey of learning about others, cultural growth and humility. Difficult end-of-life conversations and decision-making often come with additional burdens for those belonging to displaced and frequently undeserved, immigrant populations.
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**Intervention of the Palliative Care Support Team (PCST) in the Amyotrophic Lateral Sclerosis Multidisciplinary Outpatient Service at the Puerto Real University Hospital**

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**Introduction:** The Palliative Care Support Team (PCST) has participated in the Amyotrophic Lateral Sclerosis (ALS) multidisciplinary outpatient service at the Puerto Real University Hospital (PRUH) since it started in October 2014. It is a specialized ALS outpatient service where in the course of a single consultation the patients and their families are seen by the different specialist doctors who are involved in the treatment of this illness (Neurology, Pneumology, Rehabilitation, Nutrition, Internal Medicine-Palliative Care and the Case Management Nurse).

When the progress of the illness makes it difficult for the patients to be transferred to the Hospital outpatient service, the PCST offers home care, thus maintaining the continuity of the treatment and the contact with all the specialist doctors involved.

**Objectives:** To describe the service provided by the PCST in the treatment of diagnosed ALS patients.

**Equipment and methods:** It is a retrospective descriptive study based on the histories of the patients diagnosed with ALS who have been treated by this outpatient service and on the activity log from October 2014 to October 2016.

**Results:** The PCST has intervened in a total of 11 consultations. 15 patients diagnosed with ALS have been treated, of which 8 needed home care. A total of 23 home care visits have been made. In all of them the care planning was approached in a progressive way. The home care team also organized the record of two Advanced Directive Documents. Five of the patients treated died in this period. Three of those deaths took place at home with the PCST intervention in patients’ last few days.

**Conclusions:** The PCST participation in the ALS multidisciplinary outpatient service allows the team to follow the progression of the illness in each patient, from the moment they are diagnosed. It is thus easier to provide a high-quality service when the patients require home care.
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Palliative Care for Adolescents and Young Adults with Cancer – A Statewide Clinical Pathway

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Background: Adolescents and Young Adults (AYA) are a standalone cohort in cancer care. Burdened with a unique distribution of higher morbidity and mortality malignancies, AYA are specifically challenged with poorer survival, poorer psychosocial outcomes and are increasingly recognised to endure higher toxicity of treatment and unique symptomatology.

Despite compelling evidence for early integration of palliative care, there remain barriers to access for AYA with cancer, including health practitioner reluctance to referral.

Aims: The primary aim of the project has been the development of an early integrated pathway of age-appropriate palliative care for Adolescents and Young Adults.

Method: A consortium of care providers across hospital, community and hospice palliative care settings, as well as AYA cancer care consumers, has been assembled to explore equity of access to palliative care across the state of Western Australia for AYA and design a model of early integrated supportive care.

Results: There is acknowledgement of the need for age specific supportive and symptomatic care for AYA with cancer. Where communication is appropriate, AYA consumers accept the input of palliative care services in their treating team. Early integration of palliative care enables trust and rapport, facilitating easier transitions across stages of care.

Conclusion: Despite the myths, palliative care is acceptable to young patients throughout the cancer experience. Young people should have access to early integrated palliative care, preferably incorporated into their age-appropriate multidisciplinary team.
Home Palliative Care of Amyotrophic Lateral Sclerosis (ALS) in Greece: An Exploratory Analysis

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Background and aim: Palliative care services have been reported as essential to ALS care. A unique collaboration of a Tertiary Academic Neurology Center, with hospital based multidisciplinary care, and a sub-urban, community based palliative care Unit was initiated, in order to provide palliative care home services to ALS patients and their caregivers, in Athens, Greece. The purpose of this report is the exploratory analysis of three patients’ journey, following the integration of palliative care.

Methods: Patients and caregivers responded to qualitative interviews. Clinical data were obtained and the Revised-Functional ALS Rating Scale was completed. Problems and needs were assessed, and home visits were performed from the interdisciplinary team.

Results: The 67 year-old male patient had a R-ALSFRS score 6. The female patient (aged 62) and the young (aged 25) male patient had scores of 18 and 21. A high problems and needs burden was found; pain, anxiety and depression, loss of independency and functionality, as well as unmet social and spiritual needs.

76 home visits were performed for the palliation of the first patient; 36 by the physiotherapist.

2 emergency visits by the palliative care physician and nurse: one due to acute urinary and fecal retention, managed with a catheter and laxatives, and the other for neck stiffness, because of increased anxiety, managed with benzodiazepines. The female patient was visited weekly; 38 home visits took place, 50% from the physiotherapist. 2 emergency visits were needed, due to pain and a suicide attempt; managed pharmacologically and non. All team members were equally involved at the care of the younger patient. Caregivers felt relieved due to the team’s ‘active presence and the non-abandonment’. No hospitalizations were required.

Conclusions: Home palliative care services could be continued in sub-urban areas of Greece. The physiotherapist plays a key role, while collaboration is active and all symptoms adequately addressed.
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Abstract type: Poster Exhibition

Medicinal Cannabinoids and Diversion for Recreational Use: A Systematic Review and Meta-analysis

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Introduction: The use of Cannabis for medical purposes has grown progressively in various regions of the world, leading to the search for approval by the regulatory authorities. In this context, it is important to assess the safety of this alternative in terms of its diversion toward recreational use.

Methods: A systematic search was performed in the MEDLINE, MEDLINE In-Process & Other Non-Indexed Citations, MEDLINE Daily Update, EMBASE, PsycINFO, Lilacs and Cinahl Plus databases, from the origin until January 2016. It was included observational design studies that reported diversion information toward recreational use of cannabinoids used for therapeutic purposes and were followed the standard methodological procedures expected by the Cochrane group.

Results: Thirteen studies met the inclusion criteria. Twelve of them had a cross-sectional design and one prospective. The percentage of patients with physical or mental conditions with reports of diversion of medicinal cannabis varies between 0% to 94.4%. Likewise, it was a percentage of 24% and 73.7% of people that divert the use of medicinal cannabis of patients with indication for use. There was no diversion when synthetic cannabinoids were used. The majority of studies analyzed had a moderate bias risk.

Conclusions: The evidence found is heterogeneous and causality cannot be established because the design of studies assessed. It is possible that the risk of deviation is minimal with presentations of synthetic cannabinoids.

Keywords (MeSH): Medical marijuana, Cannabis, Marijuana abuse, Prescription drug diversion.
**Peritonectomy Palliative Care Nurse – An Oxymoron??**

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**Introduction:** Review of the Peritonectomy Service at St George Hospital Sydney in 2015 by the Department of Health revealed an overwhelming need for a multidisciplinary approach to care of peritonectomy patients’ pre and post procedure. The inclusion of a Palliative Care CNC was mandated.

**Description:** Peritonectomy involves surgery to remove cancer from the peritoneal cavity. It usually incorporates heated intra-peritoneal chemotherapy (HIPEC) at time of surgery with or without early post op peritoneal chemotherapy (EPIC) The average operation takes 8 hours. Peritonectomy may be indicated in patients with Pseudomyxoma Peritonii, peritoneal disease from Metastatic Colorectal Cancer, Gastric Cancer, Ovarian Cancer as well as for patients with Peritoneal Mesothelioma.

**Where does Palliative Care fit in?** For patients for whom complete cytoreduction is not possible referral to Palliative Care is indicated. This is a challenging patient population. Removal of large portions of small bowel often leads to high output stomas, inability to effectively absorb oral medications as well as dehydration and malnutrition. Discharging these patients home with good supports is often equally challenging. Managing the emotional distress following unsuccessful surgery requires a collaborative approach. This is often a self-selected group of patients with high expectations of positive outcomes. The introduction of Palliative Care has meant that pain and symptoms are more effectively addressed and patient comfort improved.
Prognostic Value of Functional, Cognitive and Nutritional Status at Admission in a Acute Palliative Care Unit (PCU) of an Universitary Hospital

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Aims: To analyse the relationship between survival and functional, cognitive and nutritional status in patients admitted to a Acute PCU.

Methods, design, data collection and analysis: Prospective study including all cancer patients admitted to PCU January 2012–April 2015. Collected: functional status (PPS, Barthel Index), nutritional status (Subjective Global Assessment SGA) and cognitive status (Pfeiffer and Delirium through an interview CAM), and CAGE. Descriptive statistic and Cox regression analysis were made. OR and IC 95% were calculated.

Results: Out of the 1294 admissions, 959 patients met the inclusion criteria. The PPS at admission were : 60–100 (9%), 30–50 (83%) and 10–20 (8%). 58% had an PPS percentage fall > 30% from previous month to admission. 57% had a Barthel Index ≤ 35, 39% had 40–90, and 4% 95–100 (average 30), 75% showed a Barthel index percentage fall > 30%. 95% were moderately or severely malnourished (SGA B and C), 20% moderate or severe cognitive impairment (Pfeiffer Test ≥ 5).

37% delirium. 13% positive CAGE.

Table 1 summarizes the univariate analysis. In the multivariable analysis, factors that had an independent relationship were % of Barthel Index fall 1.004 (IC95% 1.00–1.02) P=0.002; SGA C [HR 1.58 (IC95% 1.06–2.36) P=0.024] and delirium [[HR 1.46 (IC95% 1.23–1.74) P< 0.001]

Conclusion and discussion: Performance status deterioration previous to hospital admission, severe malnutrition and delirium are very important factors in order to predict survival.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Survival Time (days) (IC 95%)</th>
<th>OR (IC 95%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>PPS at admission</td>
<td>0.96 (0.96–0.97)</td>
<td>0.001</td>
<td></td>
</tr>
<tr>
<td>PPS percentage fall</td>
<td>1.02 (1.01–1.02)</td>
<td>0.001</td>
<td></td>
</tr>
<tr>
<td>Barthel Index at admission</td>
<td>0.98 (0.98–0.99)</td>
<td>0.001</td>
<td></td>
</tr>
<tr>
<td>Barthel Index percentage fall</td>
<td>1.01 (1.00–1.01)</td>
<td>0.001</td>
<td></td>
</tr>
<tr>
<td>SGA A</td>
<td>63 (51.09–74.90)</td>
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<td></td>
</tr>
<tr>
<td>SGA B</td>
<td>26 (21.31–30.68)</td>
<td>1.91 (1.38–2.64)</td>
<td>0.001</td>
</tr>
<tr>
<td>SGA C</td>
<td>15 (12.38–17.61)</td>
<td>2.47 (1.78–3.41)</td>
<td>0.001</td>
</tr>
<tr>
<td>Delirium</td>
<td>10 (7.95–12.05)</td>
<td>1.93 (1.68–2.20)</td>
<td>0.001</td>
</tr>
<tr>
<td>CAGE Positive</td>
<td>15 (9.36–20.63)</td>
<td>1.23 (1.01–1.50)</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Table 1
Abstract number: P01-295  
Abstract type: Poster Exhibition

**Use of Bone Protection in Patients with Primary Intracranial Tumours on Long Term Corticosteroids**

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**Background:** Long term use of corticosteroids can be associated with significant morbidity, including development of glucocorticoid-induced osteoporosis and resultant fractures, leading to pain and disability. There are currently no specific standards or guidelines pertaining to the use of bone protection in patients on long term corticosteroids in palliative care. However, given that a significant proportion of these patients are on corticosteroids for prolonged periods, this is an area that should be explored further.

**Aims:**
- To ascertain current use of bone protection in a palliative cohort of patients with a diagnosis of primary intracranial tumour on long term corticosteroid treatment  
- To identify patients in this cohort who would likely have benefitted from receiving bone protection

**Standards:** Standards used were the American College of Rheumatology 2010 Recommendations for the Prevention and Treatment of Glucocorticoid-Induced Osteoporosis. These guidelines recommended for this cohort that patients on long term glucocorticoid treatment (dose ≥7.5mg prednisolone daily for ≥ three months) should be on bone protection therapy (bisphosphonate).

**Methodology:** Retrospective audit using chart review of patients with primary intracranial tumours on initial referral to Palliative Care.

**Results:** 32 eligible patients were identified. 37.5% were on steroids on admission, and had been on steroids for > three months on initial assessment and had greater than three months to live. 12.5% had > six months to live and were on steroids on first assessment, and 6.25% had been on >3 month course of steroids.

**Conclusions:** 62% patients who were initially assessed by palliative care team should have been considered for bone protection therapy prior to referral. 45% of patients were not suitable for consideration for bone protection treatment. This leaves 55% which could have potentially been considered for bone protection therapy by the palliative team following initial assessment.
Palliative Sedation in End-of-Life Care: A Retrospective Single-centre Study on the Use of Palliative Sedation at the End of Life in A Palliative Care Unit in Switzerland. Data from 2013 to 2016

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Introduction: Sedation is used in palliative care to treat distressing symptoms at the end of life when other treatments are unsuccessful. In case of insufficient symptom control the implementation of sedation may be considered. The primary objective of sedation is to alleviate patients’ suffering. The practice of sedation varies substantially. Questions regarding the use of sedation:
1. How often do patients require sedation at the end of life?
2. Which symptoms can be treated with sedation?
3. Which medication and dosage is required?
4. For how long is sedation medication administered?

Methods: A retrospective single-center study was carried out which analysed the histories of patients who died on the palliative care unit in the Kantonsspital Graubunden in Chur (Switzerland) from 2013 to 2016. An analysis and evaluation of the diagnoses, medication including doses as well as the duration of sedation and patients’ symptoms was performed.

Results: Data from more than 500 patients that had died from 2013 to 2016 was available for analysis. In about 12% of cases sedation needed to be carried out. Of this 12%, the highest frequency of sedation was in patients with a tumour and in particular in patients with a lung tumour. A high proportion of sedation was performed for patients with head and neck tumours as well as patients with motor neuron disease. Sedation was almost exclusively implemented with midazolam, in a mean dose of about 5mg/h. The duration of the sedation was on average about 30h.

Discussion: Sedation at the end of life is an effective treatment of patients with untreatable symptoms. The most common symptoms include agitation, dyspnoea and pain. Patients with lung tumours responded especially well to this form of treatment. Sedation is usually applied for a limited period of between one and two days. It was found that midazolam was required in lower doses in order to achieve the goal of a good symptom control.
**Successful Use of Intranasal Dexmedetomidine to Achieve Cooperative Sedation in Palliative Care**

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**Background:** Dexmedetomidine, a pure alpha₂ adrenergic agonist, licensed in Europe since 2011 for sedation + analgesia. It allows “cooperative sedation”, attenuates hypertension and tachycardia. The hypnotic action is similar to normal sleep with facilitated arousal. It causes no respiratory depression. It blocks the “sympathetic storm” arising in stressful situations. Intranasal (IN) bioavailability of dexmedetomidine is approximately 70%. It is used IN at doses of 0.5–1.5 µg/kg in adults and 2–4 µg/kg in children.

**Aims:** To assess whether intranasal atomized Dexmedetomidine 1 µg/kg could be safely and effectively used to support adult patients in a Palliative Care setting.

**Methods:**

Noted were:
- Diagnosis at referral
- Underlying diseases
- Preexisting anxiolytic, antidepressive, antipsychotic, analgesic medication
- Other current medication
- Follow up
- Outcome

**Results:** 27 patients were treated up to 129 days aged 34 to 93 years. 475 treatment days were documented. Most frequently a single dose per day was used on 213 days, followed by 2 doses on 134 days, 3 doses on 78 days, 4 doses on one single day.

The main indications for IN dexmedetomidine were: anxiety 23 (sleep disturbances 14, existential anxiety 7, panic attacks 7, MRI imaging 5, anger 3, raised intracranial pressure 1), delirium 10, dementia 4, addiction/withdrawal symptoms 10, pain 9, arterial hypertension 2. Indications for long term treatment were: dementia/delirium 7, raised intracranial pressure 1.

Half of the patients suffered from an underlying malignancy, the other half of a non malignant disease.

The intranasal application was well tolerated, 2 patients did not like it initially.

**Conclusion and discussion:** Dexmedetomidine IN induced an excellent level of reduced anxiety and better pain control with improved ability for the patient to communicate and cooperate. It helped to treat malignant arterial hypertension. Clinically significant hypotension and bradycardia were not observed.
The Factor Structure of a Symptom Measure for Patients with Long-term Neurological Conditions

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The OPTCARE Neuro is a multicentre trial investigating the effectiveness of a short-term integrated palliative care (SIPC) in patients with long term neurological conditions (LTNC). One of the outcome measures, IPOS Neuro-S24, focuses on a range of motor and non-motor symptoms. This study aimed to assess the factor structure of the IPOS Neuro-S24.

The IPOS Neuro-S24 consists of 24 items rated on a 5-level Likert scale for the symptom presence and severity. The exploratory factor analysis (EFA) was conducted on a sample of 140 patients with complete baseline data, followed by a confirmatory factor analysis (CFA) to verify the factor structure identified in EFA.

The EFA presented four factors onto which all but 2 items (difficulty sleeping and falls) loaded with factor loadings>0.3. In the CFA, following the removal of two further items which did not reach statistical significance (sore/dry mouth and constipation), 20 symptoms loaded onto four factors. These factors represented general LTNC, oral-, disability-, fatigue-related symptoms, explaining over 99% of the variance ($\chi^2=210.14$, $p=.03$). The final CFA model was a good fit; RMSEA=0.04, CFI=0.94, TLI=0.93 and SRMR=0.07.

All but four of the symptoms loaded onto at least one factor, suggesting a reliable four-factor structure of symptom experience in LTNC patients. Our results support the use of the IPOS Neuro-S24 in the OPTCARE Neuro trial, though need to be confirmed by studies with larger sample.

Funding: National Institute for Health Research (NIHR), Health Services & Delivery Research (HS&DR) programme and the NIHR Collaboration for Leadership in Applied Health Research & Care (CLAHRC). The views expressed are those of the authors and not necessarily those of the NHS, NIHR or Department of Health.
Efficacy of Melatonin to Prevent Delirium in Advanced Cancer: Feasibility of a Double Blind, Randomised, Controlled Trial (DBRCT)

Lawlor P.1,2,3, Bush S.1,2,3, McNamara-Kilian M.3, Momoli F.2,4, Tierney S.1, Lacaze-Masmonteil N.1, Dasgupta M.5, Agar M.6, Pereira J.7, Currow D.8, Studies to Understand Delirium in Palliative Care Settings (SUNDIPS)

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Background: Delirium is highly problematic in palliative care unit (PCU) settings. Melatonin is pivotal in sleep-wake cycle regulation, which is invariably disturbed in delirium. Data from various settings indicate a potential role for melatonin to prevent delirium, but no Phase III DBRCTs are reported in PC.

Aims: To assess the feasibility of a DBRCT (recruitment, retention) and to obtain preliminary efficacy and safety data prior to conducting a larger trial of exogenous melatonin to prevent delirium in PC.

Methods: Eligible subjects were adult, delirium-free, PCU inpatients with advanced cancer. Enrolled subjects were randomized to receive melatonin 3mg po (Group A) or placebo (Group B) at 9pm daily and followed for a 28-day treatment period or less if incident delirium, death, discharge or withdrawal occurred earlier. The Nursing Delirium Screening Scale was used to screen for delirium, which was confirmed by the Confusion Assessment Method (CAM). Efficacy endpoints in groups A vs B were compared using survival analysis: time (days) to 1st episode of incident delirium as an event.

Results: Over 16 months, 60/616 (9.7%) consecutively screened subjects were enrolled. The respective Group A (n=30) vs B (n=30) outcomes were: incident delirium in 11/30 (37%) vs 10/30 (33%); early discharge (6 vs 5); withdrawal (6 vs 3); death (0 vs 1); and 7 (23%) vs 11 (37%) reached the 28-day end point. The 25% survival times were 9 and 18 days (log rank, $\chi^2=0.62$, $p=0.43$) in Groups A and B, respectively. No serious trial medication-related adverse effects were noted.

Conclusions: A DBRCT is feasible, but our observed slow subject accrual and 28-day delirium incidence rates signal a need for multisite collaboration. Although it neither identified safety problems nor was powered for efficacy evaluation, our study’s statistically non-significant trend for shorter time to incident delirium in the melatonin group bodes for careful monitoring in a larger RDBCT.
Abstract number: P01-300
Abstract type: Poster Exhibition

Assessment and Management of Delirium at the End of Life

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Background: Delirium is defined as an acute confusional state which results from diffuse organic brain dysfunction. In terminal cancer patients, the prevalence of delirium may be as high as 85%. The diagnosis and management of delirium is complex and hindered by paucity of diagnostic tools and training. Existing national guidelines describe delirium management but excludes those in the last hours to days of life.

Aims: To identify the evidence base in order to recommend best practice in assessment, diagnosis and management of delirium in adults in the last hours to days of life.

Methods: The clinical questions were selected using the Patient, Intervention, Control, Outcome format to guide the systematic literature review. Electronic searches of Medline, Embase, Cnahl and Cochrane databases were carried out in August 2015. Of 368 articles, 16 were included following a process of step-wise critical appraisal.

Results: If delirium is clinically suspected, the confusion assessment method (CAM) algorithm is a helpful tool for diagnosing delirium [level 3] which follows the Diagnostic and Statistical Manual of Mental Disorders V diagnostic criteria [Level 1]. People diagnosed with delirium should have reversible causes assessed and treated [Level 4]. Non-pharmacological interventions should be optimized prior to commencing a pharmacological treatment [Level 1]. Side effects of neuroleptic medications are more common with prolonged use [Level 3]. There is no evidence for a preferred antipsychotic; equal evidence exists for the efficacy of haloperidol vs. olanzapine [Level 1] and haloperidol vs. chlorpromazine [Level 1].

Conclusions: These findings have informed an update of our regional palliative care guidelines. Future focus should be on training in recognition and diagnosis of delirium using tools highlighted in this review. More first line treatments for managing delirium at the end of life are recommended on the basis of this review and the available evidence.
What do Palliative Care Clinicians in the UK Consider to be Usual Care with Respect to Palliative Sedation?
A Qualitative Investigation for I-CAN-CARE

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Background: The I-CAN-CARE research programme explores care and assessment of dying patients in two under-researched areas: sedation at the end of life and prognosis. The sedation aspect includes investigating current practice and usual care.

Aims: To explore how palliative care physicians and nurses understand usual care with regard to palliative sedation, including their thoughts on using structured tools for observing and monitoring depth of sedation.

Methods: We conducted focus groups with experienced palliative care physicians and nurses in London, UK, working either at a hospice or on the palliative care team at a large teaching hospital. The groups were audio-recorded, transcribed, and analysed qualitatively.

Results: We ran four focus groups with ten physicians (consultants and SpRs), and four with fourteen senior nurses. Participants perceived that they used sedative drugs primarily for managing intractable symptoms, especially agitation and distress; aiming for patients to be “comfortable”, “calm”, “settled”, or “relaxed”, with sedation itself a side effect. They spoke of tailoring specific drugs and doses to the particular needs and histories of each individual patient, always seeking to “start small” (with the lowest effective dose). Several expressed concern regarding managing the anxieties of relatives and non-specialist clinicians, and the risk of patients being perceived as “dying at the end of a needle”. None used any structured observation tools to assess the effects of sedative medication on patients, and most strongly preferred using their own and their teams’ clinical observation and judgement.

Conclusions: Participants considered the role of sedation medication as primarily symptom management, and were concerned not to over-sedate and to manage the possible negative perceptions of relatives and non-specialists. They emphasised individualised care, and the use of clinical judgement for assessing depth of sedation.

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Prevalence and Variability of a Positive Screening for Major Depression in Palliative Care Cancer Patients. The Longitudinal European Palliative Care Cancer Symptom Study (EPCCS-study)

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Background: Prevalence in major depression (MD) in palliative care (PC) cancer patients are often examined in small sample sizes, as a clinical structural interview is conducted to assess a diagnosis of MD. Canadian and ASCO guidelines recommend that all cancer patients should be screened for symptoms of depression at periodic times across the trajectory of care with validated measures.

Aim: To estimate prevalence and variability over time of MD by using the Patient Health Questionnaire-2 (PHQ2) as a screener in a large sample of PC cancer patients and to study associated factors.

Methods: Data were collected as part of the longitudinal European Palliative Care Cancer Symptom study, including adults with incurable cancer enrolled in PC, with monthly assessments of medical and self-reported data for ≥3 months or until death. The PHQ2 assesses the degree of anhedonia and depressed mood in the past 2 weeks on a 0 (not at all) to 3 scale (nearly every day). Prior results showed high sensitivity (89–96%) in primary care. MD (PHQ2 cut-off score of ≥3) is analyzed using multivariate mixed logistic regression.

Results: A total of 1699 patients were eligible for analyses. Main diagnoses were digestive (31%), lung (20%), and breast (17%) cancer. Fifty-two percent of the patients (n=883) screened positive for MD at some point. At baseline, 36% of the patients screened positive, this decreased significantly to 17% at month 7 and 14% at month ≥8. Independent predictors for a positive screening of MD were pain, anxiety, lower physical functioning (PF) and lower performance status (PS) and the inverse relationship between PF and MD over time (OR=0.99 [95% CI: 0.99–1.00]).

Conclusion: In a longitudinal clinical study in PC cancer patients, the prevalence of a positive screening of MD is high, negatively associated with time, anxiety, pain and positively associated with PF and PS. Interestingly, there is a gradual but strong decline in a positive screening of MD over time.
Application of Mohs Chemosurgery Technique to Palliate Symptoms Caused by Malignant Fungating Tumor. A Pilot Study

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Background: Mohs chemosurgery (MCS) was originally established for the treatment of skin cancer. Mohs paste, which is used in MCS, contains zinc chloride, and it can chemically fix a cutaneous tumor when applied on a tumor lesion. Recently, MCS had applied in managing symptoms accompanied with malignant fungating tumor (MFT) in Japan. Although it is easily performed in clinical practice, but its evidence in palliative care setting is scarce.

Aims: To exploratory investigate the indication and safety of MCS in palliative care setting.

Methods: Prospective observational study. MCS was performed for patients with MFT to palliate symptoms including bleeding and/or exudate caused by MFT. The condition of the skin lesions and effect of MCS were reviewed.

Results: We obtained written informed consent from seven patients and five of them received a total of 16 sessions of MCS. Primary sites were breast (n=3), head and neck (n=1) and angiosarcoma (n=1). Target symptoms were bleeding (n=3) and exudate (n=2). Adverse events were controllable during each sessions of MCS. Both of the MFT lesions of two patients who didn’t receive MCS had large ulcerative lesions with much necrotic tissue. Bleedings from MFT in three cases were well controlled by MCS application, but symptoms caused by inflammatory breast cancer were hardly controlled.

Conclusion and discussion: MCS was safely performed in patients with MFT. MCS is thought to be effective in controlling hemorrhage from MFT, but indication should be carefully assessed. We are conducting a phase I study to investigate the safety of MCS (UMIN-CTR ID: UMIN000023418) and planning following study to confirm feasibility and efficacy of MCS.
Expressions of Guilt and Shame among Patients in Palliative Care: Nurses Observations

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Background: Nurses who care for patients with life-limiting advancing illness are often confronted with patients’ existential issues, which can be expressed as anxiety and/or discomfort. These expressions can stem from feelings of guilt and shame. Research about guilt and shame in this context is however sparse, but relevant as it may affect wellbeing at the end of life.

Aim: The aim of this study was to explore nurses’ observations of guilt and shame among patients in palliative care.

Methods: The study is qualitative, inductive and based on data, generated through group discussions with 14 registered nurses in three different specialized palliative care settings; all with various experiences. Data was analysed with systematic text condensation, a strategy for qualitative analysis according to Malterud.

Results: The findings reveal observations of guilt and shame, derived from patients’ life choices and actions that could be obstruct the process of existential life closure and reconciliation. Moreover, guilt and shame was observed in relation to bodily decline and bodily incapability. Guilt and shame, according to the participating nurses, seemed to lead to isolation and loneliness. The nurses’ descriptions of their role were comforting, aiming to diminish existential vulnerability.

Conclusions: This study contributes to an understanding of the complexity of guilt and shame, particularly pointing to the fragility of people with life-limiting advanced illness during their end-of life trajectories. Deeper understanding of various expressions of guilt and shame among patients is thus important in palliative care.
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Abstract type: Poster Exhibition  

**Subjective and Objective Chemosensory (Taste and Smell) Dysfunction in Treatment-Naive Cancer Patients**

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**Background:** Chemosensory dysfunction (CD; a defect in taste and/or smell) in cancer is associated with chemotherapy and radiotherapy or may occur as a result of cancer itself. CD can increase risk of weight loss and malnutrition as a result of food aversions and reduced dietary intake.

**Aims:**
1. To subjectively and objectively assess taste and smell in newly diagnosed non-head and neck cancer patients.
2. To examine nutritional status in those with taste and smell changes.

**Methods:** Consecutive pre-treatment cancer patients were recruited from radiation oncology clinics in a prospective observational study. A 12-item Taste & Smell Questionnaire evaluated the presence, severity and characteristics of taste and smell dysfunction and the Abridged Patient-Generated Subjective Global Assessment (abPG-SGA) measured nutritional status and symptoms. Burghart Taste Strips® and ‘Sniffen’ Sticks Olfactory Test® assessed taste and smell identification.

**Results:** Twenty newly diagnosed (<3 months) patients were recruited. Diagnoses included breast cancer (9), gynaecological cancer (7) and colorectal cancer (4). Over half (n=12, 60%) reported subjective taste or smell changes. Nine were identified as being at risk of malnutrition (abPG-SGA score ≥ 6). Four of them reported subjective taste or smell changes only while another two had both subjective and objective changes.

**Conclusions:** Subjective and objective taste and smell testing were well tolerated. The majority of patients had subjective or objective TSC abnormalities before treatment. This is consistent with a previous study. Subjective assessment identified more TSC than objective. Those with TSC appeared to be at higher risk of malnutrition.
Comfort at End of Life: Can Bispectral Index Monitoring Add to our Understanding?

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**Background:** Palliative care patients entering unconsciousness preceding death are often managed with a subcutaneous infusion of an opioid and sedative. Dose adjustments are based on clinical assessment and observational measures of comfort and sedation. Following reports that these measures may be misleading, this study compares their validity against an objective measure of sedation, the Bispectral Index score (BIS).

**Aim:** To determine the validity of the Richmond Agitation-Sedation Scale (RASS) and the Patient Comfort Score (PCS) in assessing sedation and comfort in unconscious patients.

**Methods:** Ethics approval: University of Wollongong Human Research Ethics Committee.

When patient unresponsive: BIS monitor connected via a sensor applied to fronto-temporal region.

Data: Measures of sedation (RASS) and comfort (PCS) recorded 4th hourly by nurses. Correlation coefficients examined their relationship with time-matched BIS, using the Bland and Altman method.

**Results:** Forty consenting patients were monitored from the time of unconsciousness until death. Mean age was 74 years (range 41–97); 15 females and 25 males. Mean duration of subcutaneous sedation was 3.7 days (range 1–14). Mean duration of monitoring was 22.4 hours (range < 1–91). The relationship between BIS and RASS was highly significant, p< 0.0004. The relationship between BIS and PCS was weaker, but also significant, p=0.003. However, detailed analysis of 17 patients monitored for a full 24 hours before death showed wide variations in BIS scores (level of awareness), when RASS and PCS suggested they were deeply sedated and pain-free.

**Conclusion:** Clinically unresponsive patients may be more aware than observational measures suggest. RASS and PCS appear to be relatively blunt instruments at the lower end of their respective scales. Caution should be taken interpreting and making clinical decisions based solely on these observational measures. Further research is required to guide clinical practice.
Assessing and Addressing Constipation Symptoms According to Physical Changes in the Structures of Normal Continence

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Constipation symptoms persisting despite laxatives are common in palliative care. Gastroenterologists consider constipation symptoms to be the result of slow colon transit or impaired pelvic floor function or both. This study’s aims were to investigate if similar physical changes affect palliative care patients and whether targeting laxatives to these changes improves constipation symptoms. Consenting participants underwent assessments of colon transit time using marker studies and the pelvic floor with anal manometry. Those with slow transit were prescribed senna tablets and those with pelvic floor dysfunction were prescribed bisacodyl suppositories according to gastroenterology recommendations for 14 days. Treatment effects were assessed by comparing the mean patient assessment of constipation (PAC-SYM) and patient assessment of constipation-related quality of life (PAC-QOL) scores. Compliance with trial laxative prescription and the daily use of laxatives at the beginning and end were also considered. 29 participants were investigated with 19 having only impaired pelvic floor function, 10 having slow transit and impaired pelvic floor function, and 1 having slow transit alone. Pre and post PAC-SYM and PAC-QOL data was available for 22 participants revealing no significant differences between the mean baseline and exit PAC-SYM (p=0.183) and PAC-QOL (p=0.225). 25 participants provided data regarding their use of laxatives with 60% (n=15) reducing the daily number of laxatives and 52% (n=13) continuing to comply with laxatives tailored to the physical changes. In conclusion, physical changes of the structures of defaecation are usual in palliative care patients with numerous factors likely to contribute to these. No significant improvement resulted from tailoring laxatives highlighting the complexity of the problems faced by palliative care patients with distressing constipation symptoms.
Abstract number: P01-308
Abstract type: Poster Exhibition

Cancer Patient and the End of Life – Signs and Symptoms

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Introduction: As the overall cancer prevalence increases exponentially it is essential to adapt the care and health professionals to understanding the needs of terminally ill oncological patients. In these patients, death is expectable, however it is more commonly preceded by a clinical progressive and gradual deterioration.

Objective: Evaluation of uncontrolled symptoms in terminally ill oncological patients hospitalized at the end of life.

Methods: A retrospective, single-center study, held between January 2013 and December 2015. Evaluation of oncologic patients with active disease who died in an internal medicine ward (demographic characteristics, type of cancer and not controlled symptoms)

Results: In this study we identified 150 patients (51.3 % male gender), with a median age of 74 years (min 28, max 95), average hospital stay of 12.3 days. 13.3% had inaugural diagnosis of oncological disease during admission (25% lung, 20% colorectal, esophageal / gastric and unknown primary). Of these, 55% were diagnosed in an advanced staged and had no benefit for antineoplastic therapy, staying on Best Supportive Care (BSC). 86.7% had previous diagnosis (23.8% colorectal, 13.8% esophagus / gastric, 7.7 % lung and 6.6 % prostate) with 79.2 % having stage IV disease. These 74.6 % were on BSC. In regards to uncontrolled symptoms the most commons were: 82% pain, 45% dyspnea, 37% delirium / confusion, 30% vomiting and 10 % cachexia. We also highlight that 82% were admitted for an infectious disease, 36% due to tumoral fever, 12 % ileus, 6% thrombotic events, 3% with hepatic impairment and 2% with massive bleeding phenomena.

Conclusion: In terminally ill oncological patients is important to identify and anticipate symptoms, in order to avoid either negligence or therapeutic cruelty providing a dignified end of life.
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**Oral Health Symptoms that Interfere with Eating and Drinking among Hospice Patients**

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**Background:** Oral discomfort is a common complaint among patients in hospice facilities and may affect quality of life. However, little is known about how symptoms of oral discomfort impact patients’ eating and drinking.

**Aim:** To determine the association between symptoms of oral discomfort and problems with eating and enjoying food among patients in hospice.

**Methods:** This cross-sectional analysis describes baseline data from cancer patients reporting symptoms of oral discomfort and participating in a larger trial. Patients responded to 12 items about oral discomfort selected from the 17-item Oral Health Quality of Life Questionnaire Phase III version (QLQ-OH17) developed by the European Organisation for Research and Treatment of Cancer (EORTC). Responses were rated on a 4-point scale and were dichotomized as either severe (quite a bit or very much) or not severe (not at all or a little).

**Results:** Of the 82 patients (mean age 65±11 years, 73% female) with baseline data, 18 (22%) reported having severe problems eating solid foods during the last day and 38 (46%) reported severe problems enjoying meals during the last day. Patients were more likely to report problems eating solid food if they also reported severe problems with sticky saliva (37% vs 13%, *p*=.021) or oral sensitivity to food or drink (45% vs 14%, *p*=.005). Patients were more likely to report severe problems enjoying their meals if they reported severe problems with dry mouth (52% vs 22%, *p*=.032), oral sensitivity to food or drink (68% vs 40%, *p*=.027) or change in taste (67% vs 31%, *p*=.003).

**Conclusion:** Our findings underline the importance of systematically evaluating palliative patients’ oral discomfort, particularly among those who report eating problems or are at risk for malnourishment. Since eating is a basic need and closely associated with oral discomfort, we advise including oral discomfort in systematic assessment of palliative patients, e.g. when using the Edmonton Symptom Assessment Scale (ESAS).
“Palliative Sedation”? Dying with and without Continuous Sedatives on a German Palliative Care Unit

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Background: Despite the existence of guidelines there is still a lack of consensus regarding the concept of “palliative (pall.) sedation (PS)” and a wide range of reported frequencies of “PS”.

Aims: 1. To compare characteristics of patients (pts) with and without continuous (cont.) administration of sedatives (sed.) in the last 7 days of life on a pall. care unit (PCU). 2. To determine factors associated with use of the terms “(pall.) sedation” in medical records.

Methods: Retrospective analysis of medical records of pts who died on a German PCU 8/2014–7/2015. Definition of sed.: benzodiazepines, levomepromazin, haloperidol≥5mg, propofol; given continuously or according to duration of action. Explorative statistical analysis with SPSS 23, α-level 0.05.

Results: 149/192 pts (78%) received cont. sed. within the last 7 days of life.1 Survival after admission to the PCU was significantly longer in pts with cont. sed. than in the group without it (median (range) 6 (0–28) vs. 4 (0–20)). Delirium or agitation was documented significantly more frequently for pts with cont. sed. than for those without at admission (35% vs. 16%) and on the day before death (58% vs. 42%). The groups did not differ significantly regarding age, gender, malignant disease or the documentation of anxiety, pain or dyspnea.

For n=22/149 pts with cont. sed. the term “(pall.) sedation” was used in the records.1 The pts with documentation of these terms had significantly higher total daily midazolam doses (median (range) 20.5 (1–210) mg vs. 12 (1–80) mg) and higher frequency of pain (72% vs. 50%) on the day of death than those without documentation of these terms. The groups did not differ significantly regarding age, gender, malignant disease, survival after admission to the PCU or the documentation of agitation, anxiety or dyspnea.

Conclusions: Multicentre empirical and conceptual analysis is needed for a sound definition of sedation practices in the pall. care context.

1Schildmann et al. EAPC 2016
Predictive Symptoms for Anxiety in Hospice Patients. Which Patients Are at Risk?

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**Background:** Anxiety is present in 30% of patients with incurable cancer. Previous studies showed a variety in symptoms as predictors for anxiety in advanced cancer patients. No evidence is available about which symptoms are associated with anxiety in patients admitted to a hospice.

**Aim:** To determine the influence of symptoms and unwell-being on anxiety in hospice patients.

**Methods:** A retrospective cross sectional observatory design was used to analyze symptom burden of cancer patients who were admitted to a hospice and died < 3 months after admission. Symptom burden was measured by the Utrecht Symptom Diary, a Dutch adapted version of the ESAS to self-assess the 11 most prevalent symptoms and un-wellbeing on a NRS (0–10). A multivariate regression analysis was performed.

**Results:** 211 patients were included, 42% were men, median age was 71 years (31–95), 25% had an anxiety score of >1, 14% had a clinically significant anxiety score (>3). After correction for age, gender and marital status, depressed mood (p=0.00) and dyspnea (p=0.01) were independent predictors of anxiety and explained 23% of the variance.

**Conclusion:** Although it is established that depressed mood and dyspnea are associated with increased anxiety in previous studies, the findings are inconsistent. The comparability of previous studies and meaning in practice is a challenge due to heterogeneity of populations and methodological considerations. The results suggest that anxiety in hospice care is only partly predictable by physical and psychological symptoms. Future studies should pursue uniformity in methods to ameliorate comparability and move to a body of knowledge. Meanwhile, professionals need to be aware of the predictors and their interaction. In this case, depressed mood and dyspnea need to be further assessed. Treatment and support of these symptoms should be part of adequate anxiety management tailored to individual needs and increase quality of life/dying for anxious cancer patients.
Abstract number: P01-312  
Abstract type: Poster Exhibition

The Effectiveness of Artificial Hydration and Nutrition Therapy for Terminally Ill Cancer Patients Based on the Japanese Clinical Guideline

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Background: Recently, there has been a growing interest in the use of artificial hydration and nutrition therapy (AHNT) for terminally ill cancer patients.

Aims: The guideline for the use of artificial hydration therapy in the terminally ill cancer patients (GL) was published by Japanese Society for Palliative Medicine in 2007 and revised in 2013. This study aimed to conduct AHNT based on this revised GL, and clarify the effects on the alleviation of various symptoms and QOL.

Methods: Of the terminally ill cancer patients who admitted for palliative care over the last 2 years, 105 patients presented with symptoms of overhydration or nutritional problems. Of these patients, 81 patients who were judged “inappropriate hydration and nutrition therapy” were prospectively analyzed. We performed GL-based AHNT with standard medication, and we examined the effects on the alleviation of hydration-related symptoms, appropriateness of nutritional therapy and QOL, using MDASI (a numeric rating scale), nutritional indices (albumin, transthyretin, etc.), and item30 of EORTC QLQ-C30 to compare values measured before and one week after AHNT. We also evaluated patient satisfaction and the feeling of benefit from hydration and/or nutrition one week after the study commenced.

The Wilcoxon signed-ranks test was used for statistical analysis.

Results: Hydration-related symptom (nausea: n=20, abdominal pain/fullness: n=18, peripheral edema: n=32, and dyspnea: n=16) were significantly improved after performing GL-based AHNT (p< 0.05). Total parenteral nutrition was appropriately quitted in 15 cases. General QOL scores, global satisfaction and the feeling of benefit were also significantly improved after performing GL-based AHNT (p< 0.001).

Conclusion and discussion: The provision of appropriate GL-based AHNT could contribute to alleviating hydration and nutrition related problems and improving QOL in terminally ill cancer patients.

The author received no financial support.
Abstract number: P01-313  
Abstract type: Poster Exhibition

**Characteristics of Oral Problems and Effects of Oral Care in Terminally Ill Cancer Patients**

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**Purpose:** Various distresses appear in the terminal stage of cancer. Oral problems including dry mouth, stomatitis, and oral candidiasis are one of the important problems which should be resolved. The purpose of this study was to investigate oral problems in this stage and improvement of dry mouth by oral care.

**Methods:** The study subjects were consecutive terminally ill cancer patients admitted over the past 2.5 years. The patients were divided based on the status of oral food intake into good (>/=30%, Group-A) and poor (< 30%, Group-B) groups for comparison. The following 3 items were investigated:

1) incidences of these oral problems,
2) severity of dry mouth and complication with other oral problems (severity: 3-grade, rating from 1(mild) to 3(severe)), and
3) involvement of dry mouth by these interventions using standard oral care by nursing staff (StC) and specialist oral care including dental surgeons (SpC) as needed.

Chi-square test was used for statistical analysis, and differences resulting in P values lower than 0.05 were considered statistically significant.

**Results:** There were 136 and 178 patients in Group-A and Group-B, respectively.

1) Incidences of dry mouth and oral candidiasis were significantly higher in Group-B (38.2% vs 80.9%, p=0<0.0001, 6.6% vs 23.6%, p=0.0002, respectively).
2) Moderate-severe cases of dry mouth (grade-2&3) were noted in 20.0% and 65.2% in Group-A and Group-B (p<0.0001). The oral candidiasis complication rate was significantly higher in Group-B (6.6% vs 23.6%, p=0.0002).
3) The rate of dry mouth improvement by oral care (StC+SpC) was 100% in grade-1, 84% in grade-2, and 82% in grade-3.

**Conclusions:** Oral problems occur in many of terminally ill cancer patients. Accurate diagnosis of oral problems and corresponding appropriate interventions are important for improving oral cavity condition and quality of end-of-life care. The author received no financial support.
Ileus and Intestinal Obstruction in Palliative Care Setting

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Background: Ileus, subileus and intestinal obstruction are severe complications usually accompanied with high symptom load. The median survival in palliative setting can be short, depending on patients status, disease, overall life expectancy and patient’s wishes.

Aims: We aimed to characterize retrospectively patients with ileus and intestinal obstruction, which were referred to palliative care ward of the University of Rostock (PC UMR).

Methods, design, data collection and analysis: Of the 86 identified patients with ileus and intestinal obstruction in their history 51 fulfilled the criteria and an ileus could be verified. Those patients were included and analysed retrospectively which were referred to the PC UMR between 2010 and 2015. The analysis included patients’ characteristics as sex, age at time of diagnosis, time of referral and hospitalization, therapy, and overall survival.

Results: Patients median age at diagnosis was 67 years (range 38–86 years), almost 53 % female. The majority of patients suffered from gastrointestinal malignancies (60,8 %). Intestinal obstruction was the most common type (66,7%). Only 6,7 % were affected by paralytic ileus. Of the patients with ileus and intestinal obstruction 35,3 % underwent an abdominal surgery as ileus intervention. Surgery led to a survival benefit (41 d versus 17 d), the inpatient period in PC increased significantly (28 d versus 15 d respectively). Almost all patients (98%) died within observation period. Most patients with ileus and intestinal obstruction died on palliative ward (52%).

Conclusion and discussion: Patients with ileus and intestinal obstruction usually suffer from high symptom load. Course of disease might be difficult to predict. Surgery leads to a survival benefit in some cases of intestinal obstruction, time in hospital however increases.
Abstract number: P01-315
Abstract type: Poster Exhibition

Topical Strategies for Bleeding Control in Malignant Wounds in Breast Cancer: A Systematic Review

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Background: Alginate is the most common topical strategy to control the bleeding from malignant wounds, but evidence related to the use of alginate is weak.

Objectives: Identify topical strategies to control bleeding in breast cancer malignant wounds.

Methods: Systematic review was undertaken. MeSH terms and words related to bleeding were used, malignant wounds and breast neoplasms made up the search strategy which was performed on Medline, Pubmed, Cinahl, Lilacs, Embase, Scopus, Web of Science, Google scholar and Cochrane in August 2016. The inclusion criteria for papers were: topical strategies to control the bleeding in breast cancer malignant wounds, and published in English, Portuguese, French or Spanish languages. Exclusion criteria was: studies which had approached surgery, radiation therapy and chemoembolization as a strategy to control the bleeding. Studies were analyzed according to: design, topical strategies used, outcomes and evidence level.

Outcomes: 468 abstracts were recruited, and 7 from these abstracts were included in the analysis. Two were cohort (28.6%), two were case report (28.6%), two were case report with an update (28.6%), and one was only an update (14.3%). Topical strategies: alginate, oxygenated water, haemostatic, adrenaline, non adherent or silicone impregnated dressing, mohs’ paste, paraffin gauze, silver nitrate and applying pressure. In five studies the authors had reported satisfactory control of bleeding and in one study they had evaluated the time required to control the bleeding. Two studies had showed algorithms for bleeding control. Highest levels of evidence had been provided by the cohort studies.

Conclusion: Alginate de cálcio and Mohs’ paste were found as topical strategies which showed better evidence to control in the bleeding in breast cancer malignant wounds and this points out to the need of more intervention research and assessment studies in the clinical practice.
Review of Sedation in a Palliative Care Unit (PCU): Is there a Difference between Oncological and Non-oncological Patients? Is it Frequent a Difficult Sedation?

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Objective: Report the frequency of sedation in agony in a PCU, the relationship to the type of disease and the symptoms that required sedation. Review the difficult sedation cases. Analyze the pharmaceuticals used and time until death.

Method: Retrospective study of deceased patients at the PCU between Dec 1st 15 and Sept 30th 16. Fisher’s exact and t-test were used.

Results: 299 patients were included (age 75.8 years, SD 11.2).

There were 234 oncologic patients (78%), principally lung cancer (26%). 63 patients (21%) were non-oncological, mainly with pluripathologies (40%).

92 patients required sedation in agony (31%): 84 oncological and 8 non-oncological patients. There were statistical significance (p< 0,001) between sedation in oncologic and non-oncologic patients.

The main symptoms for sedation were: Delirium (34), Spiritual suffering (15), Unknown (14).

The main pharmaceuticals used for sedation were: Midazolam (93%), levomepromamine (50%) and combined use of benzodiazepine and neuroleptic (67%). The dose at the time of death was 40.6 mg/d (Midazolam) and 90.5 mg/d (Levomepromamine). Time between sedation and death was 2.4 days (SD 1.7).

The 4 cases of difficult sedation with propofol were significantly younger (age 51.7 years, SD 8.9, p=0.01) and a longer sedation time until death (6.5 days, SD 2.6, p=0.05).

Conclusions:
- Oncological patients were more frequently sedated.
- Delirium and emotional suffering were the main reasons used to justify sedation in agony.
- The cases where unknown reasons were used for sedation caused an improvement in the PCU data intake.
- It is frequent to use benzodiazepine and neuroleptic together when sedating in agony.
- Patients with difficult sedation (propofol) were significantly younger and had longer sedation time until death.

<table>
<thead>
<tr>
<th></th>
<th>ONCOLOGICAL</th>
<th>NON-ONCOLOGICAL</th>
<th>BOTH</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEDATION</td>
<td>84</td>
<td>8</td>
<td>-</td>
<td>92</td>
</tr>
<tr>
<td>NO SEDATION</td>
<td>150</td>
<td>55</td>
<td>2</td>
<td>207</td>
</tr>
<tr>
<td>TOTAL</td>
<td>234</td>
<td>63</td>
<td>2</td>
<td>299</td>
</tr>
</tbody>
</table>

[TABLE 1]
Variability in the Treatment of Positive Symptoms in a Cohort of Advanced Cancer Patients Assessed at an Outpatient Palliative Care Clinic

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Background: Advanced cancer patients (ACP) report multiple symptoms. Limited data exist about how palliative care (PC) physicians prioritize symptom management.

Aim: To describe the number of treatments that physicians recommend for symptoms in a cohort of ACP assessed at an outpatient PC clinic.

Methods: ACP attending an outpatient PC clinic were enrolled in a longitudinal observational study. Intensity of nine symptoms was assessed at baseline using the Edmonton Symptom Assessment Scale (ESAS). After the consult, treating physicians reported the symptoms for which they recommended treatments. Between 14 and 34 days after the initial consult patients’ symptom intensity was reassessed. For each symptom, a smaller ESAS was considered an improvement.

Results: 106 patients were included at baseline. Mean age was 62, 58% were female. A symptom was positive with an ESAS ≥4. The most frequent positive symptoms were fatigue, pain and appetite (Table 1). Positive symptoms that were more frequently treated were pain, nausea and depression. Positive symptoms that were less frequently treated were drowsiness, fatigue and appetite. 71 patients were reassessed at follow-up. Treatment of nausea, depression and sleep was associated with symptom improvement (p< .05).

Conclusion: Pain and nausea were most often treated symptoms. Other symptoms were much less often given specific interventions. Further studies are needed to examine the reasons for lack of treatment recommendations.

<table>
<thead>
<tr>
<th>Symptom</th>
<th># of positive symptoms (ESAS ≥4) N(%)</th>
<th># of positive symptoms treated N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>56 (53)</td>
<td>52 (93)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>67 (63)</td>
<td>12 (18)</td>
</tr>
<tr>
<td>Nausea</td>
<td>22 (21)</td>
<td>13 (59)</td>
</tr>
<tr>
<td>Depression</td>
<td>32 (30)</td>
<td>10 (31)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>27 (25)</td>
<td>6 (22)</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>46 (43)</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Appetite</td>
<td>51 (48)</td>
<td>9 (18)</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>25 (24)</td>
<td>5 (20)</td>
</tr>
<tr>
<td>Sleep</td>
<td>39 (37)</td>
<td>9 (23)</td>
</tr>
</tbody>
</table>

[Table 1: Positive symptoms & treatments]
Memorial Delirium Assessment Scale (MDAS): The Art of Delirium Diagnosis

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Background: Delirium is a frequent neuropsychiatric syndrome in Palliative Care (PC), with prevalence higher than 80% in some series. It causes physical and emotional suffering to the patient, and an important distress both to caregivers and medical teams. Memorial Delirium Assessment Scale (MDAS) has shown a likelihood ratio>5 when employ for delirium diagnosis (Wong et al.), and its use and utility was purposely analyzed in PC health professionals (Fadul et al.).

Methods: We conducted a research of the literature on the MDAS in order to recognize its clinical utility in advanced cancer patients.

Results: The MDAS scale was develop by Breitbart et al. in 1997 following DSM IV criteria, in order to evaluate delirium severity in Palliative Care Settings (PCS). This scale, with a cut off score ≥ 7 has a great reliability for delirium diagnosis, as demonstrated by a high sensibility (98%) and specificity (96%) (Lawlor et al.), and it also is able to evaluate the phenomenology of this syndrome (De la Cruz et al., Lawlor et al., Bosio et al), and through factor analysis two main areas have been proposed – neurobehavioral and cognitive items (Noguera et al.).

In the last twenty years has been validated in different settings, languages and countries: Breitbart et al. in EEUU, Mastuoka et al. in Japan, Grassi et al in Italy, Kazmierski J et al. in Poland, Shyamsundar et al in India, Noguera et al. in Spain.

MDAS is a perfect tool in PC, because its simplicity, rapid administration, repeatability over the time (De et al). Regarding to research in PCS it has been employed in different trials as for evaluate incidence, frequency, characteristics and outcome of delirium, and in particular the possible improve of the syndrome after the treatments (De la Cruz et al; Boettger et al; Tanimukai et al.)

Conclusion: For its psychometric properties, clinical utility, and research capability MDAS seems to be a very useful scale in PCS.
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**Releasing the Pressure: An Audit of Paracentesis**

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**Background:** Palliative medicine malignant ascites management aims to effectively reduce symptoms of increased abdominal pressure and improve quality of life. Despite evidence for efficacy of paracentesis there is little evidence regarding the best practice for the procedure. A 2010, 12 month audit of 23 procedures, in a hospice in NW England, set 20 standards for future practice. The current audit aimed to assess whether these standards for paracentesis are being consistently met in practice.

**Method:** A retrospective analysis of all patients undergoing hospice paracentesis in 2015, was carried out by searching the electronic record. The documentation was analysed for data relating to each standard and collated on an Excel spreadsheet.

**Results:** 41 procedures for 10 discrete patients (av. 4/patient) were identified. Primary diagnosis – 90% malignancy: 10% non malignant liver disease. 98% were preceded by ultrasound compared to 43% in 2010. Drain removal, and therefore the time for which drain remains in situ was sometimes poorly recorded. Complications – drain fell out on 3 (7%) occasions, 4 (10%) occasions of symptomatic hypotension, leakage from the drain site post procedure 14 (34%) and discomfort at the drain site sometimes disrupted sleep. One patient died during, but unrelated to, the procedure. The average percentage of standards met per procedure was 83% (range 60–90%). 64% procedures met at least 85% of the standards required for paracentesis.

**Conclusion:** There was a 78% increase in procedures with ultrasound now being used regularly to identify a safe drainage site. Frequency of observations in stable patients (especially overnight) and prevention of leakage from drain site post procedure need review. Consistency of documentation especially of drain removal, preemptive prescribing of ‘as required’ analgesia and consistency in observation recording, all need improvement and alteration to the template completed to record the procedure has since been undertaken.
Urological Tumors along Three Years Attended by a Palliative Care Support Team

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Background: Patients with advanced urological tumors (AUT) often need attention by Palliative Care Support Teams (PCST).

Aims: To describe the clinical characteristics of patients with AUT tracked by our PCST.

Methods: We conducted a descriptive study. Data were obtained from medical records of deceased patients with AUT treated by our PCST from 1/January/2012 to 31/December/2014. Number of patients with AUT, gender, average age, main symptom, strong opioids intake, the average number of days until death and place of death were analyzed. If patients died at home we analyzed if they were sedated or not. These results were compared with those from the total of patients treated.

Results: Along the study 41 patients with AUT died (bladder cancer, 16; prostate cancer, 14; kidney, 8 and ureter, 3); 10,35% of the total (396). The average age was 67.9 years old and 87.81 were male (81.48% male if patients who died of prostata cancer are excluded) vs 62.63 years old and 62.63% of male overall. The main symptoms for referral were pain, 48.78% (66.29% if only patients with prostata cancer are considered) and malaise, 24.39% vs 36.62% and 25.51% respectively in the whole group. Strong opioids were used in 29 patients; 70,73%, (77,78% if patients with prostata cancer are excluded) vs 70,71% in the overall group. The average days to death was 66.27 days (48.48 days if patients with prostata cancer are excluded and 100.57 days if only patients with prostata cancer are analyzed) vs 54.52 days from total. Died at home 27 patients (65.85%) and up 59.25% of them (n = 16) required sedation (vs 64.39% and 54.90% respectively)

Conclusion: In our series of patients with AUT highlights the high number of men. (even when excluding patients with prostate cancer). Pain is the main symptom for referral in almost half of the cases. The programme stay in patients with prostate tumors is much higher than the average.
What’s in a Name? Early Review of the Impact of Name Change on Palliative Care Team Activity at a Specialist Heart and Lung Hospital

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**Background:** Associating ‘palliative care’ with end-of-life-care (EOLC) can deter referrals for symptom control and supportive care in patients who are not at the end-of-life. Yet there is no consensus on an alternative name for teams providing the array of services that specialist palliative care provides in acute hospitals, where the focus is on acute admission for active management rather than EOLC. Consequently many patients are not benefiting from timely referrals provided by their acute hospital palliative care teams.

**Aims:** Evaluate the immediate effect of a name change from ‘Palliative care team (PCT)’ to ‘Specialist Supportive and Palliative Care team’ (SSPCT) in an acute cardiopulmonary hospital in the UK.

**Methods:** Retrospective audit of team referrals: 4-months before and 4-months after name change from PCT to SSPCT. Patient notes and Electronic data were analysed.

**Results:** Before name change:
83 patients, aged 17–86, were referred for: Advance Care Planning- ACP (13, 16%), family support (12, 14%), and EOLC (8, 10%), but symptom control featured alongside all referral in 50 patients (60%). Disease origins were: cardiac i.e. heart failure (34, 41%), respiratory i.e. asthma (39, 47%) and metastatic cancer (10, 12%). 18 patients died in hospital (22%), 59 (71%) were discharged to usual residence, another hospital (4) or hospice(2).

After name change:
95 patients, aged 17–88, were referred for: ACP (7, 7%), EOLC (4, 4%), family support (12, 13%) symptom control (72, 76%). Disease origins were respiratory (23, 24%), cancer (3), and cardiac (69, 73%). 10 (11%) patients died in hospital, (76, 80%) patients were discharged to usual residence, another hospital (5) or hospice (4).

**Conclusion:** Widening access to the holistic care provided by acute hospital palliative care teams may require the addition of ‘Supportive’ +/- ‘Symptom control’ prefix. This may increase referrals however further studies are needed to evaluate the impact and implications for services.
Prevalence of Venous Thromboembolism and Use of Low Molecular Weight Heparin in a Palliative Care Unit

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**Background:** Venous thromboembolism (VTE) is a serious complication in advanced cancer patients.

**Aims:** Primary aim: to determine the prevalence of VTE in patients admitted to a Palliative Care Unit. Secondary aim: to evaluate the use of low molecular weight heparin (LMWH), for thromboprofilaxis or treatment, in these patients.

**Methods:** Descriptive and retrospective study. All patients admitted to the palliative care unit during the year 2015 were included. Demographic and clinical data collected from the clinical charts were: history of pulmonary thromboembolism (PTE) or deep vein thrombosis (DVT), presence of recent diagnosis of PTE and DVT (within 3 months before admission) or in the PCU, LMWH prescription during admission and doses, and hemorrhagic complications. Descriptive analysis of the variables was conducted.

**Results:** A total of 507 patients were admitted to the PCU during 2015 and included in the study. Median age was 76 years, 298 patients (59%) were male, 449 (89%) were cancer patients, and gastrointestinal was the most common (30%), median stay was 15 days and 467 (92%) died in the PCU. A total of 35 (7%) patients presented diagnosis of VTE: 23 (4,5%) PTE (20 recent and 3 during admission) and 15 (3%) DVT (9 recent and 6 during admission). LMWH was used in 97 patients (19%), 48 (9,4%) for thromboprofilaxis, 28 (5,5%) for treatment of ETV and 30 (6%) for other reasons (e.g. arrhythmia). 11 out of 15 patients with DVT were prescribed LMWH (most common dose was Enoxaparin 60mg/day) and 17 out of 23 with PTE were prescribed LMWH (most common dose was Enoxaparin 120mg/day). LMWH was used in for thromboprofilaxis in 48 patients (9,5%) (most common dose was Enoxaparin 40mg/day). LMWH was discontinued due to hemorrhagic events in 8 patients (1%).

**Conclusion:** The prevalence of ETV in the PCU was 7% (35 patients) and 2% (8 patients) were new events during admission. LMWH was used in 97 patients (19%), 48 (9,4%) for thromboprofilaxis and 28 (5,5%) for treatment of ETV.
Comfort-supporting Care for the EOL Patient in an Institutionalised Environment

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Background: In the Czech Republic, four quarters of the population die in an institutionalized environment, where end-of-life (EOL) care is most often provided.

Aims: To ascertain the frequencies in a set of activities supporting different dimensions of patient’s comfort in an institutionalised EOL care.

Methods: Secondary analysis; four studies dealing with nursing interventions Spiritual Support and Dying Care for EOL patients, which were carried out in the CR between 2011 and 2014. The activities were divided into four sets according to the dimensions of comfort they address. The sample includes 907 nurses (mean age 37.8 years; mean practice 15.4 years; education level – secondary nursing school 71.4%) from intensive, acute, long-term and hospice care. Mann-Witney and Kruskal-Wallis tests, Spearman’s correlation, logistic regression and an exploratory factor analysis were used for statistical processing.

Results: The highest and the lowest frequencies were reported in the physical (mean 4.23±0.56) and the social dimension (mean 3.86±0.67). Major predictors for a high frequency of activities in the physical dimension were long-term care facility (OR 1.54; 95% CI 1.04–2.27; p=0.030), hospice care (OR 10.4; 95% CI 3.17–34.10; p=0.0001) and nurses’ age (OR 1.01; 95%CI 1.00–1.03; p=0.045). Hospice environment was also a predictor for a high frequency of activities in dimensions: psychological (OR 3.1; 95%CI 1.76–5.50; p=0.0001), spiritual (OR 18.0; 95%CI 6.38–50.76; p< 0.0001) and social (OR 8.95; 95%CI 4.27–18.76; p=0.000). Four factors have been identified and were defined as Physical comfort; Respect; Listening and Reassurance.

Conclusion and discussion: Czech nurses focus their interventions mostly on physical comfort. Courses of palliative care for nurses in clinical praxis could increase the usage of the activities aimed at other dimensions of patient’s comfort in an institutionalized EOL care.

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Hypercalcemia in Cancer: Association with Malignancy Type and Effect on Mortality

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Purpose: Hypercalcemia is an electrolyte disorder found in cancer patients which can complicate the disease and hasten death. It is classified by a blood serum calcium level of 2.6 mmol/l and above and its incidence is related to malignancy type. The object of this study is to explore the distribution of hypercalcemia amongst different cancer forms and to record the effects on mortality. The study investigates the same factors with regards to moderate and severe hypercalcemia.

Methods: Medical records for 2048 patients admitted over a five year period (2008–12) to the National Centre for Cancer Care, Qatar, were retrospectively reviewed to establish calcium levels.

Results: Chi-square distinguished multiple myeloma, renal cell carcinoma and lung cancer as the most common malignancies associated with hypercalcemia in our sample. The malignancies that most commonly resulted in severe hypercalcemia were multiple myeloma, head and neck and renal cell carcinoma. Univariate analysis identified hypercalcemia, age, gender and cancer type as predictive factors for survival over the period of the study. These factors were used to build a multivariate model which revealed cancer patients with hypercalcemia were three times more likely to die than patients with normal blood calcium levels. Expiry was also more probable in those above 65 years of age and unexpectedly, females. Another unanticipated finding was that the effects of moderate and severe hypercalcemia on mortality were similar.

Conclusions: The present study demonstrated that in a hospitalized cancer population, age, gender, cancer type, and hypercalcemia are prognostic factors for increased mortality. The marginal differences in mortality between those with moderate or severe hypercalcemia suggest that early detection and treatment of such electrolyte imbalance is warranted regardless of calcium severity.
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Patients Attended by a Palliative Care Support Team along Three Years

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Background: Home care for palliative patients is an option increasingly used.

Aims: To describe the characteristics of population attended by our palliative care support team (PCST).

Methods: Descriptive retrospective study. Data were collected from the medical records of patients who died attended by our PCST between 1/January/2012 and 31/December/2014. We analyzed the number of patients, average age, gender, if cancer or not, primary tumor, main symptom reason for referral, use of strong opioids, days average stay and place of death. If they die at home, we determine whether or not require sedation.

Results: During the study 396 patients died, 62.63% were male. The average age was 71.36 years old. Cancer patients were 96.97%. The most common tumors were lung, colon-rectum, pancreas and breast (84, 71, 26 and 22 cases respectively). The main symptoms for referral were pain (36.62 %) and malaise (25.51%). Strong opioids were used in 280 cases (70.71%). The average number of days until death was 54.52 days. Two hundred fifty-five patients died at home (64.39%), 160 were male (62.75% of the deceased at home). Palliative sedation at home was used in 140 patients, 54.90% of those who died at home (55.79% of women and 54.38% of men who died at home)

Conclusion: Half of patients attended by our PCST have one of these cancers: lung, colon-rectum, pancreas or breast. Poor control of pain determines a third of referrals. The average stay in the program is almost eight weeks. Nearly 2/3 of the patients die at home of which more than 50% require sedation.
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Our Experience with Indwelling Pleural Catheter

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Background: Nowadays, indwelling pleural catheter is used as an alternative treatment to palliate some of the symptoms of certain malignant pleural effusions, almost all studies about the benefits of using this type of catheter, have been performed with an indwelling tunneled catheter connected with one-way valves to a vacuum collection systems, which have the problem of high cost. In our service we have implemented a new drainage systems wich consist of an indwelling pleural catheter with a Heimlich valve connected to a free-fall gravity collection bag, reducing considerably the cost.

Objective: To evaluate the Quality of Life of one outpatient with malignant pleural effusion who was treated with an indwelling pleural catheter with Heimlich valve. Questionnaire compliance was analyzed.

Methods and design: An observational study. Quality of Life was assessed at two different time points (before catheter insertion and at 30 days post-insertion) using the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire QLQ-C30. Patients: One patient with recurrent malignant pleural effusion treated with an indwelling pleural catheter with Heimlich valve.

Results: Scores showed a significant improvement in symptoms scales at 30 days.

Conclusion: Indwelling pleural catheter with Heimlich valve and free-fall gravity collection bag improved the quality of life of a patient with recurrent malignant pleural effusion with low cost.
Use of Elastomeric Pumps for Palliative Sedation at Home. Have We Changed over the Years?

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**Background:** Palliative sedation at home by using elastomeric pumps is a common practice in Palliative Care Support Teams.

**Aims:** to compare in two periods with a gap of twelve years the main indications for sedation at home so as the drugs used for it and time until death.

**Methods:** Descriptive retrospective study about patients who died at home in tracking our Palliative Care Support Team in two periods, the first between July, 1st of 2001 and November, 30th of 2002; and the second between September, 1st of 2013 and May, 31st of 2014. We analyze the total number of deceased patients, number of patients who die at their home, number of patients who need sedation using an elastomeric pump, age, gender, tumor, cause for sedation, time until death (< 24 h, 24–48 h and > 48 h from the beginning of sedation) and drugs used.

**Results:** In the first study period 131 patients die, 76 of them at their home, 21 using an elastomeric pump for sedation (vs 102, 68 y 29 respectively in the second period). The average age was 66.58 years old and 66.67% were male (vs 73.79 years old and 55.17% male). The most common tumors were lung and colon in the two periods. The main causes for sedation were agony and delirium (57.14% and 9.52% vs 68.96% and 24%). The time until death was < 24 h: 23.81%, 24–48 h: 33.33% and >48 h: 42.86% (51.72%, 24.14% and 24.14% respectively). The most used drugs were morphine, midazolam (85.71% each one), haloperidol and scopolamine (61.90% each one) in the first period vs midazolam, scopolamine (79.31% each one) and morphine (65.52%) in the second.

**Conclusion:** We have not found changes about cause of sedation and drugs used at home by our Palliative Care Support Team in the last twelve years. Sedation at home using an elastomeric pump has been increased in the last years.
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Infection Management at the End of Life: A Single Hospice Study

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Literature on the management of infections at the end-of-life is scarce. We performed an observational study on 134 patients with clinically diagnosed infection (123 with an advanced cancer, 67 men, mean age 70 (33–91) years), out of 1458 (9.2%) admitted to the hospice between 1 Sept 2013 and 31 Jan 2016. 172 cases of various infections were documented (two, three and four times in 25, 5 and 1 persons respectively). The mean time period of care was 75.1 (1–484) days.

(in comparison with the average of 22.3 days of all admitted).

The most prominent infection risk factors identified were cancer (88.4% of episodes), low performance status – Palliative Performance Scale score of 40 or less (68.4%), prolonged steroid therapy (37.0%), previous antibiotics used within 6 months before the admission (23.7%) and bladder catheterisation (23.1%). The most common type of infections were pneumonia (43.0%), end-of-life pyrexia of unknown origin (EOL-PUO; 17.4%), urinary tract infection (UTI; 17.4%) and antibiotic associated diarrhoea (12.2%). Antibiotics most often used were gentamycin (given only once) in EOL-PUO (27.7% of episodes), ceftriaxone in pneumonia (17.3%) and levofloxacin in UTI (15.6%). In 17% of cases a combination of two antibiotics was required. In 4% of episodes only a symptomatic therapy was continued. Clinically meaningful improvement in the course of the treatment was seen in 70.3% of episodes, no change in 25.0% and worsening in 4.7%. The cost of antibiotics was 16.7% of all drug expenses. Antibiotic therapy in this study appears to be a valuable although expensive symptomatic management at the end-of-life.
Utility of Paediatric Palliative Screening Scale (PaPaS scale) as a Screening Tool to Identify Children Requiring Specialist Palliative Care

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Background and aim: Cost-effective utilization of limited resources signpost the need for a standardized tool to identify those who would benefit from intensive multi-disciplinary support by paediatric palliative care. One such tool developed and validated to predict needs of children for palliative care is PaPaS scale.

This study primarily aims to assess the effectiveness and feasibility of PaPaS scale as a referral tool to access home-based specialist paediatric palliative care service (PPCS). The secondary aim looks at PaPaS scale to determine continuation of palliative care service after one year.

Method: Analysis of
1) referral letters to PPCS,
2) discharge summaries from referral institutions and
3) continuation notes by healthcare workers on our PPCS was performed to compute PaPaS scores retrospectively, with reference to time of admission.

Study population included all patients referred from 2012 to 1 July 2016, and excluded patients who had a total of less than two home visits. Distribution of the computed scores was analyzed with box plot.

The secondary aim compares two patient groups—those who continued to receive the service for more than a year and those who were discharged within a year by PPCS team using its own working criteria. PaPaS scores were similarly computed retrospectively and analyzed with box plots. Statistical comparison was performed using t-test.

Result: Out of 228 patients referred, 29 patients were excluded. 98.5% of remaining 119 patients had scores 15 and above with mean score of 26. There was statistically significant difference between the two groups who continued more than a year (mean=20.9) and discharged within a year (mean=8.6).

Conclusion: PaPaS scale may be an alternative means to characterise both referral to specialist palliative care and continuation of service that offers benefits of transparency and consistency. This evaluation also proposes suggestions to improve clarity and tailor PaPaS scale to the local context in Singapore.
Insights about the Perspective of Children with Life-limiting Conditions

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Background and aims: Most of the children and adolescents receiving palliative care have a life-limiting condition. In the US about 500,000 children are coping with life-limiting illnesses every year. In Germany there are nearly 60,000 children and adolescents suffering in the same way. The number is increasing. Little is known about about their experiences. This paper presents results from a qualitative study focussing on the experiences of seriously ill children and aims at reconstructing these from different perspectives.

Methods: Following ethical approval, qualitative in-depth interviews were conducted with eight seriously ill children and adolescents, with their siblings, their parents and their professional caregiver (n=23).

A grounded theory approach was chosen and the interpretation of the interview data involved a process of continuous reflection, analysis and elicitation.

Results: The range of diseases includes all four categories of life-limiting conditions. All the children and adolescents are being nursed in a home care setting, but under different conditions. Seen from the perspective of the ill children, three central concepts exist: balancing good and bad days, creating unobstructed space and perceiving oneself from within. All of these concepts have interdependencies and show the readiness and strategies with which the children actively plan their daily routines – within the limits of their possibilities. The analysis indicates that understanding children’s self-perception and strategies is the key to support coping with bad days.

Conclusion: The results give helpful advice for a deeper understanding of children with life-limiting conditions in (palliative) care situations; they illustrate that our healthy adult view and perception differs fundamentally from the insider(s’) view of the ill children. This implicates the need of creating possibilities for children to play an active role in their care.
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Palliative Care Pathways: Bottlenecks in Palliative Care Pathways for Adolescents and Young Adults

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**Background:** Integration of palliative care in mainstream care is still a goal that needs to be achieved to offer optimum care for many people. In other settings there is the additional care system of traditional medicine used by many South Africans. Adolescents and Young Adults may use traditional medicine due to cultural and family influence.

**Aims:** This paper draws on selected health care providers’ views and experiences to reflect on the palliative care pathways of adolescents and young adults who have a regulated voice with decisions made on their behalf by family elders.

**Methods:** Employing the qualitative method of process mapping, one-on-one discussions about the process maps done by healthcare professionals were conducted. The participants – 16 HIV and oncology health care professionals from the 4 healthcare levels in South Africa (primary, district, province, and tertiary care setting) were selected to provide in-depth information about the care pathways of AYA with cancer and HIV.

**Results:** Rural people have limited access to specialist and generalist palliative care and resort to the cheaper option of traditional medicine. Culture is relevant to AYA’s behaviour, affecting choices, goals and treatment decisions where through obedience to parents and community leaders, they may consult with traditional healers in the first instance. Health care professionals do not have the confidence to involve palliative care early enough for young people to receive support.

**Conclusions:** In rural South Africa, there is a need to integrate traditional medicine in palliative care in order to engage communities who may still have custodial responsibilities of AYA. Working alongside traditional healers may open up communication channels and offer inclusive care that considers the cultural beliefs of the family. Healthcare professionals have to develop skills and strategies to negotiate access to AYA in order to involve them in decisions about their care.
Experiences with the First Hospice for Children and Adolescents in Denmark

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Palliative care for children and adolescents is developing rapidly in Denmark. The first hospice and five regional palliative care teams for children and adolescents were established in 2015/2016. There was a great deal of political and professional debate about whether there was a need for a hospice for children and adolescents in a country as small as Denmark before the opening of Lukashuset children’s hospice in October 2015.

The purpose of this study is to provide an overview of the characteristics of the children and adolescents admitted to Lukashuset children’s hospice, and to describe their families’ experiences with the hospice.

Data collected during the study included:
1) a quantitative overview of the children and adolescents admitted (including ages, diagnoses, lengths of stay etc.), and
2) a qualitative exploratory interview study with their parents/close relatives. The data was collected between 01.11.2015 and 30.09.2016.

The study was approved by the Danish Data Protection Agency and Danish Research Ethics Committees. The study complies with the WMA Declaration of Helsinki.

Preliminary results/conclusion: The first part of the study show that 12 children and adolescents were admitted. Ages: 6 children < 1 year old, 2 children 1–3 years old, 2 children 4–9 years old and 2 children 10–17 years old. Diagnoses: 5 metabolic disorders, 3 neurological disorders, 2 with congenital malformations and 2 with cancer. Seven of the children died during the study period. The second part of the study consists of interviews with 10 parents and 1 close relative. These interviews show that a hospice stay improved both the daily and overall quality of life of the whole family. However, interviewees expressed some concern about issues of privacy and the well-being of siblings.

The study was funded by Sankt Lukas Stiftelsen and The Danish Knowledge Centre for Rehabilitation and Palliative Care, The University of Southern Denmark.
Palliative Outpatient Care in Children with Yet Undiagnosed Syndromes

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Background: Pediatric palliative care (PPC) seeks to relieve suffering and to reduce distress for children and their families. A clear diagnosis is important for information, support, treatment options, prognosis, and advance care planning. However, some children are presenting with signs and symptoms suggestive of a still undiagnosed syndrome. It is unknown, how many children in PPC fall into this category and how care is best tailored for them.

Aims: The aim of the study was to determine the clinical characteristics, needs, and the process of decision-making in children without a diagnosis.

Methods: This study was conducted as single center analysis of patients cared for by a large specialized PPC team (PPCT). Information included demographic data, primary and secondary diagnoses, number of patient contacts, symptoms, and medications.

Results: In the study period (01/2013 – 06/2016) 196 patients were cared for by the PPCT. Of these, 27 (13.8%) children were without a primary diagnosis at the start of PPC. A definite diagnosis was ultimately only achieved in three children. 18 (66.7%) children were male, median age was 11.6 years (range 0.6 – 28.1 years). Median duration of care was 492 days (range 2 – 2561) and mean number of home visits was 22. Most patients are still alive (21; 70.4%), 6 children died at home/in hospice. Median number of administered drugs was 8 (range 2 – 19), antiepileptics were given most frequently.

Despite not having a clear diagnosis (and thus prognosis), 13 parents (48.1%) decided - faced with their critically ill and clinically worsening children - for a DNI/DNR order.

Conclusion: Children without a clear diagnosis are relatively common in PPC and have – as all other patients – a right to best possible and symptom-adapted palliative care. Our data shows that parents can accept to limit therapy even without a clear diagnosis as the children’s signs and symptoms can be used as a surrogate for their prognosis.
Children and Adolescents who Died of Cancer: A Survey in Brazilian and Spanish Pediatric Oncology Units

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Background: In pediatric oncology, cure and survival rates have significantly improved in recent decades. Despite better cure rates, part of the children and adolescents are not cured and die.

Aim: To characterize the children and adolescents with cancer who died at two university hospitals in Brazil (2005–2015) and Spain (2010–2015), according to sociodemographic and clinical variables and palliative care.

Methods: Retrospective, descriptive and exploratory study, with data collection from a secondary source. To analyze the data, simple and relative frequency distribution were used. The study received approval from the Research Ethics Committees.

Results: Among the 48 Brazilian deaths, 50% were male, with low socioeconomic level. The most frequent cancer was acute myeloid leukemia and the main treatment was chemotherapy and radiotherapy, with care delivery by physicians, nurses, physiotherapists, psychologists and occupational therapists; among those who had a family history of cancer, the most common was breast cancer. Among the clusters, headache, vomiting, nausea and pain stood out. In most cases, death occurred after the disease recurred and due to a cardiorespiratory arrest. The period of life between the diagnosis and death ranged between 1 and 143 months. Among the 96 Spanish deaths, 51% were male; among those who had a family history of cancer, the most common was breast cancer. The most frequent types of cancer were leukemias and the main therapeutic was chemotherapy and radiotherapy, with care delivery by physicians, nurses and social workers. Among the clusters, neutropenia, fever, mucositis, sepsis and pain. In most cases, death also occurred after relapse and due to a cardiorespiratory arrest and multiple organ failure. The period of life between the diagnosis and death ranged between 1 and 137 months.

Conclusion: The study results can support the planning of palliative care units, based on this population’s true needs. Funding by CAPES and CNPq.
Evaluation of the Need for a Paediatric Palliative Care Service in the West of Scotland: A Mixed Methods Analysis

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Aims: To determine paediatricians’ perceptions of the palliative care needs of their patients, how well these are currently met, and to explore their experiences of current services.

Methods: A semi-structured survey, containing 22 questions, was sent by email to all senior paediatric doctors working in NHS Greater Glasgow (GGC) between October 2014 and April 2015 (107 recipients). Data were analysed using a mixed methods approach. Quantitative analysis was performed using Microsoft Excel; qualitative data were reviewed independently by the authors, common themes were identified, and higher order categories created.

Results: 76 (71%) recipients responded; the majority were consultants, (n = 72, 95%). Most cared for children with palliative care needs (n=74, 98%), and for most (n=54, 71%) this constituted < 5% of their work load. Barriers to palliative care provision included lack of: resources, time, a lead clinician, and coordination of services. The most common palliative needs of patients were immediate end-of-life care (n=58, 91%), family (n=54, 84%), nutritional (n=52, 81%), and social/emotional support (n = 53, 83%). Most (n=67, 88%) considered that GGC would benefit from an in-hospital paediatric palliative care service, including a lead clinician, integration of services, staff education and bereavement counselling. Recipients wished to engage with such a service by: individual consults (n=56, 77%), telephone advice (n= 49, 64%), and shared care of specific patients (n= 49, 64%).

Conclusions: Paediatricians from a range of specialties lack the time, resources and skills to provide the palliative care children need, and would benefit from a dedicated service.
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‘Place Bonding’ – Parents’ Journeys towards a Sense of Rootedness in Children’s Hospice Care

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As the number of children in the UK with life-limiting and life-threatening conditions are increasing, providers of palliative care services, such as children’s hospices are considering how best to support families. However, evidence suggests that only a small percentage of parents of children with such conditions choose to access hospice services. The aim of this study was to explore parents’ perspectives of existing hospice services, the types and characteristics of hospice services parents wanted, the barriers and facilitators to accessing services, and how best these services could be delivered to meet the needs of the population of children with life-limiting and life-threatening conditions living in one region in England.

A two phase qualitative study underpinned by a constructivist grounded theory methodology was employed.

In Phase 1 focus groups were used to collect data from twenty four parents of children accessing services at the hospice. In Phase 2 in-depth semi-structured interviews were conducted with seven parents of children who did not use services at the hospice and with a further seven parents who had either previous experience of the hospice or were using a hospice outside of the region.

From the findings of the study a new framework has been proposed which illustrates the bonds which develop between parents of children with life-limiting conditions and the hospice. When elements of place familiarity, place identity, place belongingness, place association existed the idea of place rootedness in the hospice reflected the sense that parents had finally found a place where they belonged and where they felt at ‘home’. For parents who had no experience of the hospice finding a place which met all the characteristics for belongingness was something they aspired to but had not yet found; these parents continued to stay in the safety of their own home, choosing not to enter the hospice.
We Need to Talk about Trisomy 18

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Background: Trisomy 18 (T18) is the third most common chromosomal disorder and a life-limiting condition. Recently, major surgical interventions have been related to longer survival. When should we consider curative and palliative care?

Aim: To describe the treatment performed for patients with Trisomy 18 in a Tertiary Neonatal Intensive Care Unit (NICU).

Methods: Retrospective cohort of newborns with confirmed diagnosis of Trisomy 18 by karyotype. Results: During a 19 months period, 2074 newborns were admitted; 13 had Trisomy 18 (6.3:1000 live births). The average time of hospitalization was 44 days. There were 9 (69,2%) deaths; 4 (30,8%) infants were discharged to their homes. The average age of death was 35 days of life. All the patients of the sample died before 1 year old. Non-invasive ventilation was used in 6 (46,2%) for an average time of 15,2d. Invasive ventilation was used in 4 patients (30,8%) for an average time of 12,5 d. Cardiac surgery was performed in 2 (15,4%) patients; 1 died after the surgery, the other was discharged, but died with 7 months of age. In 2 (15,4%) patients, the prostaglandin use was discontinued after discussing the options with the families. Abdominal surgeries were performed in 3 (22,6%) patients with esophageal atresia(2) or omphalocele(1). Gastrostomy was performed in 8 (76%) patients. The goals of care were discussed with the multidisciplinary team and the parents were encouraged to participate in all decisions.

Conclusions: In most patients, the treatment included mechanical ventilation and surgical procedures. A palliative care protocol to approach Trisomy 18 is necessary. All possible disclosures and treatments should be discussed with the parents considering the high morbidity and mortality of each intervention made.
The Role of Chaplaincy in the Paediatric Multidisciplinary Team (MDT), an Observational Cross Sectional Study

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Background: Care of children with life-limiting illnesses integrates both psychological and spiritual aspects of care. Despite this, chaplains may not be included as an integral member of the MDT resulting in failure to recognise the spiritual needs of children and their families.

Aim(s): To explore staff knowledge of and attitudes to the role of chaplaincy in a tertiary children’s hospital; chaplaincy participation in the MDT; and timing and method of referral to chaplaincy.

Method(s): A cross sectional survey of staff using both a written survey (made available in all clinical areas) and an online survey.

Results: 96 respondents (56% nurses; 37% doctors; 5% allied healthcare professional; 2% other).
91% agreed that spiritual care is an important part of patient care. Most were confident that they understood the role of chaplaincy (78%). There was strong agreement that the role of chaplaincy includes bereavement support (96%); the spiritual needs of terminally ill children and their families (98%), and providing education to the MDT on spiritual issues (86%). However only 42% felt that chaplaincy should attend MDT meetings.
48% agreed that chaplaincy should receive a formal referral however 26% disagreed, with 26% remaining neutral. 88% agreed that it is important that chaplaincy be made aware of the patient’s medical condition and likely prognosis. 93% disagreed with the statement that “There is no need to involve chaplaincy unless a patient is imminently dying or has died”.

Conclusions: A majority agree spiritual care is important and that they understand the role of chaplaincy. However a minority agree chaplaincy should attend MDT meetings. Most agree that early chaplaincy involvement is beneficial.
Abstract number: P01-340
Abstract type: Poster Exhibition

What Can we Learn from Adolescents and Young Adults Having Cancer Treatment in an Adult Hospital in Order to Improve Provision?

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Background: Every year 2,200 teenagers and young adults (TYAs) aged 15–24 are diagnosed with cancer in the UK. The majority of TYAs do not access specialist age-appropriate services, and undergo treatment amongst adults of all ages.

Aim: To understand the perspective of TYAs having cancer treatment in an adult setting and explore their experience in this environment.

Methods: The study employed a qualitative methodology. Telephone interviews were conducted with seventeen participants recruited via cancer charities and social media. The resulting data were analysed using thematic analysis.

Results: Having treatment in an adult hospital reinforced the sense of abnormality as a young person with cancer. Four themes contributed to the negative experience: the lack of peer group support; exposure to challenging issues on adult wards, particularly death and dementia; the lack of staff empathy towards TYAs; and the inappropriateness of the environment for young people, such as the lack of privacy and wi-fi.

Discussion: This is the first study to ask TYAs with cancer about their experience of the adult setting. The adult hospital is not a supportive environment for young people negotiating illness and adolescence concurrently. A cultural shift is required if TYAs are to receive age-appropriate care in this setting. Professionals should be aware of the unique needs of this cohort and adapt their approach accordingly. Creative ways of improving their care, such as adapting the environment and assisting TYAs to connect with their peers, should be implemented.
Nasogastric Tube Feeding in Children with Cancer as a Part of Palliative Care

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Background and objectives: Many pediatric oncology patients lose weight because of their inability to consume adequate caloric intake orally. Poor nutrition is associated with malnutrition and poor prognosis of the disease. Thus nutritional support is an important element of palliative care. Enteral nutrition (EN) is the preferred method as long as if the gastrointestinal tract is functioning. We aimed to demonstrate whether EN is feasible in daily practice of these patients.

Design and methods: Nutritional records of children with cancer treated between May 2011–Jan 2016 at Bezmialem Vakif University Pediatric Hematology and Oncology were evaluated. Patients with poor oral intake were fed with commercial use formulas by the oral route, by the nasogastric tube (NG) and by percutaneous endoscopic gastrostomy (PEG). Patients who lost weight under the support of oral route were fed by NG. Weight of the patients were checked at every week. Children with diffuse pontine glioma (DPG) after losing gag reflex, were fed by PEG. No other patients had PEG.

Results: A total of 125 (81.6%) among 153 patients required nutritional support. Forty-eight (38.4%) of them were fed by oral route, 67 (53.6%) patients were fed by NG only. Ten (8%) DPG patients initially fed by NG had PEG later. Median duration of oral supplementation was 106 (68–154) days. Median duration of NG was 23 (7–96) days. All the patients other than DPG gained or maintained their weight. No major complication occurred in the patients.

Conclusion: Weight loss is an important problem in patients with cancer. Patients who lost weight under the support of oral route should be fed by NG. Palliative enteral feeding by NG tube is safe, inexpensive, and has a low complication rate. NG feeding, rather than PEG, could be a more appropriate method of enteral feeding in children with cancer.
Paediatric Palliative Care in Denmark: A Nationwide Study of Causes and Places of Death in Children and Adolescents

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Background: Specialized palliative care for children and adolescents is a new area in Denmark. In order to implement and organize a rational specialized palliative care for children and adolescents in Denmark, it is necessary to carry out a national survey of causes and places of death.

The aim of the study: To investigate causes and places of death in children and adolescents from 0 to 18 years of age in Denmark between 1994–2014.

Method: It is a retrospective study obtained from the population-based Danish Register of Causes of Death. Data collected was composed by the causes of death of all children and adolescents in Denmark from 0–18 years, who died between 1994–2014. Causes of death were classified by ICD-10 diagnosis codes.

Results: A total of 9462 children and adolescents from 0–18 years died in Denmark during this period. However, the prevalence of all causes of mortality decreased with almost 50% (1994: 619 and 2014:321, respectively). The most frequent causes were congenital malformations, deformations and chromosomal abnormalities, cancer and conditions originating from the perinatal period. In all, 61% died in the first year of life. Regarding place of death, 75.5% died in hospitals, 10.5% at home, 8% other places, and 6% was unknown.

Conclusions: The study has provided a national overview of causes and places of death in children and adolescent, which is the first step required for the organization and implementation of specialized palliative care in Denmark. Next step will be to identify the relevant diagnoses that require specialized palliative care.

Acknowledgement: The Danish Child Cancer Foundation for financial support.
Children’s Understanding of Illness, Death and Dying: A Qualitative Study in the USA and Haiti

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Background: The WHA resolution endorses the need for culturally appropriate children’s palliative care (CPC) services, yet little is known in different cultures with regards to children’s understanding of illness, death & dying. A Delphi study identified children’s understanding of death & dying as the top priority for research in CPC.

Aim: To increase the knowledge base surrounding children’s understanding of illness, death & dying in diverse cultural settings & gain insight into how they communicate their ideas on these issues.

Method: Qualitative research methods using semi-structured interviews with children with life-threatening illness &/or their siblings. Interviews were supplemented with demographic data collated through a parental survey. To date, following ethical approval, 15 interviews have been completed in the USA & 10 in Haiti.

Results: Themes have been identified across three age ranges: 5–8 years, 9–13 years, & 14–18 years. Overarching themes include: (1) illness experience: medical, emotional expressions & the community; (2) death & dying: experiences & processing; & (3) coping: friends/family, personal time, reassurance & encouragement. Differences between children in the USA & Haiti include the type of exposure to death & dying, avoidance of the topics, community among sick children, faith & decreased knowledge of illness. However similarities exist such as worries about death & dying, the experience of loss, understanding of death & during, protection of others, sense of responsibility, the importance of family, friends & community, desire to play & to be positive & resilience.

Conclusion: There are many similarities as well as differences in children’s understanding of illness, death & dying in different countries & cultures. Replication of the study in other sites, e.g. South Africa, is ongoing, in order that we can provide CPC services that meet the need of the child & their family.
Factors Contributing to Renal Complications in Children with Neurogenic Bladder

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**Background:** 2/3 of children in our service suffer from conditions which involve severe psychomotor impairiment. They frequent present neurogenic bladder (NB) leading to urinary tract infections (UTIs) and a number develop upper urinary tract deterioration (UUTD). There are very few studies looking at the factors contributing to UTIs and UUTD in these categories.

**Aims:** The present study aims to analyse the frequency of UTIs and renal deterioration in children with NB cared by our service, and the factors which may contributed to this complications.

**Methods:** A retrospective chart review of all patients with complex neurological diseases from our service was performed (data collected from medical history, physical examination, urinalysis, serum level of urea and creatinine, renal tract imaging, frequency of monitoring). We analyzed the data using SPSSv20 to see if the UTIs and UUTD correlate with age, sex, diagnosis, level of disability, socioeconomically status, and medical follow-up.

**Results:** We included 97 patients: 68 with cerebral palsy (CP), 14 with spina bifida (SB), 9 with Muscular Dystrophy (DMD), 4 with Spinal Muscular Atrophy (SMA) 1 with Spinal Injury and 1 with Hydrocephalus. 29 children presented UTIs: 16 in the CP group (23.5% of this group), 12 in the SB group (85.7%), 1 child with spinal injury. The patients with UTIs were followed closely at 2 to 4-month clinically and paraclinically. In 7 children UUTD was diagnosed : 5 in SB group, 1 with CP, 1 with spinal injury. In CP group more UTIs were found in older children, correlated with severe motor dysfunction, and in children from poor environment. Lack of follow-up after UTIs contributed to renal deterioration.

**Conclusions:** The majority of children with SB presented recurrent UTIs and an important percent of them evolve to renal deterioration. Children with CP need to be investigated for urinary dysfunction and the high incidence of UTIs suggests they need to be screened also for UTIs.
Clinical-epidemiologic Characteristics at the End of Life of the Children with Terminal Conditions

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Background: Little is known about the profile of the children with incurable illnesses when the end of life comes. This is important, to provide a quality care.

Aim: To describe clinical and epidemiologic characteristics of children died in program of palliative care.

Method: Descriptive, retrospective, observacional study, through the analysis of the medical history of palliative program of Children’s Hospital in Seville, between 2011–2014.

Results: Die in hospital 40 and home 10; oncological illness 31/50 and not oncological illness 19/50; 11 symptoms appear in terminal conditions and the most frecuent are fatigue(n=41), poor appetite(n=39), pain (n=38) and dyspnea (n=35). Converge in the same child up to 9 symptoms. The intravenous route is used in 47/47, subcutaneus 7/47, orally 2/47 and transdermal 11/47. The drugs used to control symptoms are analgésics 94%, antipyretic 68%, steroids 38% and anticonvulsivants 36%. The route for administration of analgesics most frecuent is intravenous 47/47. The adequacy of the therapeutic effort is agreed whit parents 48. After presenting refractry symptoms like dyspnea(n=34), convulsions(n=8), pain(n=5) and hemorrhage (n=1), in 48 children proceeded to the sedation at the end-of-life whit Midazolam (n=44). 7 necropsies are realized.

The comparative results between oncological illnesses and not oncological are: pain, headache and constipation are more frequent in oncological illnesses and dyspnea in not oncological. The support measurements in oncological illnesses are chemotherapy and radiotherapy and not oncological nutritional support. The steroids are drug use in oncological illnesses until the end of life and anticonvulsivants in not oncological. 6 necropsies are realized in not oncological illnesses.

Discussion: These results are not comparable with other studies, since there are few publications and these refer to oncological illnesses.

Conclusion: Identify the characteristics of attention at the end-of-life help planning care.
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Abstract type: Poster Exhibition

Challenges in Pediatric Advanced Care Planning Discussions: A Qualitative Study

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Background: Discussions between physicians and parents of severely ill children are a key-element for successful pediatric advance care planning. Yet, these discussions are often perceived as extremely challenging for both physicians and parents-mainly due to communication problems, different needs and expectations, and emotional strain.

Aims: The research project focused on the pACP discussion process, aiming to identify difficulties and barriers in view of the development of a conversation guideline for physicians.

Methods: Data were collected by a qualitative approach. Qualitative participant observation took place during pACP discussions between professionals and parents of children with a life-limiting illness. Discussions were audio-taped. Additionally, problem-centered interviews with the parents and the facilitators took place after the pACP sessions. Data were analyzed by qualitative content and conversation analysis using the software MAXQDA11.

Results: So far, pACP discussions were observed in 6 families out of 10 planned. Based on preliminary results, data analysis will focus on:

- key situations within the discussion process
- different discussion techniques and their helpfulness, such as ways of opening and closing the discussion, the way of questioning and introducing new topics, handling the emotions of the parents, disruptions and misunderstanding, leading and structuring the discussion, parents and facilitators perception of and satisfaction with the discussion process, supporting and hindering conditions such as the time frame, the place of the discussion, number of participants.

Conclusion: In pACP processes, facilitators are facing several challenges. They must take into account multiple different perspectives, anticipate and deal with difficulties, misunderstandings and conflicts, and reflect constantly their own beliefs and preferences. The results of this study will be used to develop a structured conversation guide for pACP discussions.
What Matters to Children and Young People with Life-limiting and Life-threatening Conditions? A Systematic Review

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Background: A recent review found no valid person-centred outcome measure (PCOMs) for paediatric palliative care (Coombes 2016). Development should be informed by outcomes that mirror children and young people’s (CYP) and family priority symptoms and concerns.

Aim: To identify and appraise the evidence on symptoms and concerns that matter to CYP with life-limiting and life-threatening conditions.

Methods: Systematic review in accordance with the PRISMA guidelines. The search strategy combined the terms associated with “symptoms and concerns” with keywords for CYP; life-limiting and life-threatening conditions. We excluded single case studies, studies on pharmacological interventions or family carers alone and mixed samples without disaggregated results for CYP. Included studies were assessed for quality and reporting rigour using the Hawker quality assessment checklist. Narrative and thematic approaches were used for data analysis. Themes on symptoms and concerns were clustered by domains in the World Health Organisation definition of paediatric palliative care.

Data sources: MEDLINE, EMBASE, PsychInfo, CINAHL, and grey literature. Inception-January 2015.

Results: 13567 articles were identified and 79 studies included. CYP self-reported in 44% of the studies. Themes on priority concerns and symptoms are presented by domain and an example.
1) Physical: e.g. physical symptoms, symptom distress,
2) psychological: e.g. Emotional, cognitive function,
3) social: e.g. relationships, social function
4) spiritual: e.g. worry about death, existential concerns,
5) other concerns: e.g. Communication and information, decision-making.

Conclusion: Data exist to inform face and content of a novel measure. Although half of CYP can self-report, methods of completion and proxy versions are needed. These priority outcomes should inform the development of PCOMs for paediatric palliative care and stimulate outcomes-based service development and research.
Care at the End of Life for Children and Adolescents with Cancer: A Study at a Brazilian and Spanish Pediatric Oncology Unit

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Background: What makes a patient be included in a palliative care program is the condition that, besides the modifying treatment of the disease, the curative treatment, there are other signs and symptoms that compromise his quality of life. Therefore, knowing these clients' needs is fundamental for the health services.

Aim: To describe the population of children and adolescents with cancer who died at palliative care units of two university hospitals in Brazil (between 2005–2015) and Spain (between 2010–2015).

Methods: Systematic review of the clinical history of children and adolescents with registered entrance in palliative care. To analyze the data, simple and relative frequencies were used. Approval for the study was obtained from Research Ethics Committees.

Results: Among the 18 Brazilian children and adolescents, 56% were female; the most frequent age was 1 to 10 years of age (56%); the most frequent cancer was acute lymphoblastic leukemia; 89% died at the ward and the most frequent symptoms were pain, vomiting and nausea; 39% had their pain registered, but no information was identified about assessment using scales or non-pharmacological control measures. Among the 50 Spanish children and adolescents, 54% were male; the most frequent age was 1 to 10 years (62%) at the moment of death; 46% suffered from central nervous system cancer; 20% used enteral tubes or gastrostomy and 44% a completely implanted vascular catheter; 14% died at the intensive care unit and the most frequent symptoms were neutropenia, fever and mucositis. With regard to pain, registers were found in 86% of the medical records, but no information was found about the use of assessment scales or non-pharmacological measures for pain control.

Conclusion: The results provided knowledge on this population’s profile, with a high degree of complexity. The systemization of actions based on their true needs will contribute to qualify clinical practice in palliative care. Funding by CAPES and CNPq.
"Problems Are Not Stop Signs, but Guidelines" The Intervention of the Social Worker in a Paediatric Palliative Care Unit


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Background: The National Association of Social Workers considers Social Work a broadly based profession that can meet families needs with end-of-life issues.

As the research suggests, to have a child in end-of-life situation is a distressing experience. This is why our unit offers a holistic approach which considers the assessment and support of the social worker.

However, families with socioeconomic hardships demand a more intensive intervention. The aim is reducing the negative aspects of caring for their children with a life-limiting illness.

Aim: To describe the intervention of the social worker with the families of non-oncological diseases patients during a year (Sep’2015 to Sep’2016) in a PPC. Furthermore, to identify the main reasons of it.

Method: Quantitative retrospective study, descriptive statistics of PPC unit register. Data base and scientific research.

Results: 22 families have been attended during the time of the study. The 27% received support and follow up. The 73% also received social treatment. The reasons that motivate intensive intervention were:

- Counsel: 68,2%
- Unfavorable socioeconomic conditions: 40,9%
- Hospital resources: 36,4%
- Community resources: 50%
- Housing problems: 27,3%
- Risk indicators: 9,1%
- Idiomatic, cultural barriers: 9,1%
- Crisis situation: 22,7%

Family vulnerability factors: 45,5%
The need of help for taking decisions: 18,2%

Usually, the intervention is based on 2 or more items. The intervention was only for 1 reason in 3 cases and it was related on getting information about community resources.

DISCUSSION: The social worker is able to treat broader effects of illness and to support families for taking decisions with and for children.

This professional profile can give support for empowering families and improving their abilities to give the best care. As the results show, social family aspects demand attention if we want to achieve a best quality of life for pediatric patients despite end-of-life illness limitations.
Scenario of Pediatric Palliative Care in Developing Countries: Experience of a Tertiary Care Hospital in India

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Objective: To evaluate the symptoms and approach to palliative care for cancer patients in the palliative ward of a tertiary hospital.

Methods: We did a retrospective, descriptive study after collecting the data from year Jan, 2007 to July, 2015 in a tertiary care hospital, India. This data was collected from the pediatric palliative care ward. Total number of children was 47. Age group was distributed as following:
1 – 5 years = 6 children
6 – 10 years = 13 children
11 – 15 years = 28 children

Almost every child complained of pain. 8 children complained of backache. Other complaints were burning micturition 1, proptosis 1, loss of vision 1, nasal obstruction 1, weakness in lower limb 1, swelling 1.

Data regarding prevalence of pain and other symptoms, multidisciplinary team approach, communication between staff and family and use of all medicine for the symptom relief were collected from medical records.

Results: Majority of children presented with Osteosarcoma (19.15%), PNET (14.89%), Ewing sarcoma (10.63%), rhabdomyosarcoma (10.63%), non-hodgkin lymphoma (10.63%), Neuroblastoma (6.3%). Median age of presentation was different for every cancer.

Pain was the most commonly reported symptom in this retrospective study at the end of life among almost every pediatric patient. Eight children out of 47 had complaints of breathlessness, cough, and sputum. Morphine was considered as first-line therapy for the relief of pain and dyspnea in our study. Ten children out of 47 presented with Gastrointestinal (GI) disturbances, including nausea, vomiting, decreased appetite, and constipation.

Patients were followed by palliative care physicians. Every child was followed by Non-governmental organisation like CANKIDS in Delhi, India.

Conclusion: In our tertiary care hospital where this study was conducted, does not have a specialized team in pediatric palliative care, but it meets all the requirement for pediatric patient.
Holistic Management of a Child with Acute Lymphoblastic Leukemia: A Case Study from Ocean Road Cancer Institute, Dar es Salaam – Tanzania

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Background: Palliative care as an approach that improves the quality of life for people with life threatening illness and their families, through the prevention, assessment and treatment of pain and other physical, psycho-social and spiritual problems or other challenges (WHO). It provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, offers a support system to help patients live as actively as possible until death and also uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated.

Patient description: This is a case study of the child TD 13 years old boy who was admitted at ocean road cancer institute. Upon admission he presented with neck swelling, difficulty in breathing, awareness of heart beat, severe loss of weight, neck pain and fever which was on and off. Both parents reported to be peasant with poor financial income. Their child had stopped school due to illness.

Method: Multidisciplinary approach was considered in addressing the problem of the child. Three unit of blood were transfused, haematenics, antibiotics, nutritional support were given. Pain assessment and management according to WHO analgesic ladder were provided. Chemotherapy were given as as spiritual leader took the charge to intervene the sense of loosing hope in a child.

Results: After four weeks in care, the condition of the child had significant improvement with well controlled physical and psychological pain.

Conclusion: The use of multidisciplinary approach where by health care workers, parents and the child (family centered care) were involved helped to improve the quality of life to the child. Palliative care plays a vital role in managing children with Acute Lymphoblastic Leukemia.
Clinical Mapping the Profile of Children and Adolescents in the Oncological Palliative Home Care

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Introduction: The World Health Organization defines pediatric palliative care as the pursuit of improving the quality of life, relief of pain and other physical symptoms, supporting the needs and spiritual and psychosocial expectations of the child and his family. Nursing professionals establish a supportive relationship with the child and family, through effective communication, relief measures from suffering and emotional support.

Objective: To describe the clinical and social demographic profile of children and adolescents with cancer in palliative care treated at home.

Method: A retrospective descriptive study of quantitative nature, through documentary analysis of medical records of children and adolescents by the pediatric team of home care in a public hospital of Federal specialized in oncology in Brazil from May 2011 to May 2015. The data collected was entered in Excel spreadsheet software, recorded and analyzed by simple descriptive statistics.

Results: We analyzed 44 medical records of pediatric patients in palliative care in home care. The period of palliative care in household ranged from two weeks to four years. stem tumor and osteosarcoma were identified diagnoses, not observed in the sample hematologic tumor. Ages ranged from 03–19 years, with an average of 11 years old. Patients residing in its entirety, in the State of Rio de Janeiro, Brazil. The average household income per capita was less than two minimum wages. This sample was identified symptoms: fatigue; ache; anxiety and sadness.

Conclusion: The findings allow characterizing the studied population, identifying the social situation and clinical status of children and adolescents with cancer, which will enable future adopt health actions to ease suffering and control the signs and symptoms.
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‘Not only of Drugs a Patient Lives: The Work of a Psychologist in a Paediatric Palliative Care Unit’

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Background: Research suggests that children often experience distress, worry, sadness, fear of being alone, loss of perspective, and loss of independence during end-of-life care.

In 2007 the European Association for Palliative Care published the standards of paediatric palliative care (PPC) where they established that the minimum skills and services provided should include a physician, nurse, social worker, child therapist or psychologist and spiritual adviser. In turn, the literature presents three defined areas for psychologist in a PPC: assessment, intervention, and research. However, in 2012 a survey of PPC programs showed that 94.6% of programs did not include a psychologist. Following these recommendations, our PPC unit includes a psychologist to improve the care of children and their families.

Aims: Describe the interventions made by a psychologist in a PPC unit in the period between June 2016 and February 2017.

Methods:
Design: longitudinal study.
Data collection: specific register about every intervention.
Analysis: descriptive statistics by IBM SPSS Statistics v. 24.

Results: Milies. The results about the first four months are:
SAMPLE
Number of children/families: 39
Mean age of children: 8,54
Gender of child: Male:62,7% Female:37,3%
Disease: Oncologic:68,7% No Oncologic:22,3%
VISITS
Number: 166
Priority: Scheduled:73,5% No scheduled:26,5%
Location: Inpatient:31,3% Outpatient:21,7% Home:30,1% Others:8,4%
INTERVENTION
How? Alone:59 % With team:41%
To whom? Child:43,4% Parents:33,7% Siblings:11,4%
Others:10,2 %
Purpose: Assessments:22,9% Follow-up:54,2%
Bereavement:16,8% Coordination: 4,8%

Conclusion and discussion: As reflected standards in PPC, the data shows the need to address the whole family. As literature states, paediatric oncology patients show a greatest complexity in the psychological care they need. Psychological care is necessary throughout the whole end-of-life process. It’s possible that the families choose where they want to be attended: hospital or home.
Perspectives and Challenges of Perinatal Hospice Care in Hungary

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Introduction: Losing a child in the perinatal period is highly demanding for families and health care professionals, too. While in 2015 the statistical number of perinatal death is relatively low (0.65%), the total number of babies lost in perinatal mortality was 553, the burden it conveys is all the bigger. Today no active perinatal hospice care is available in Hungary on institutional level, though there are attempts to implement it.

Objectives:
(1) Present the current healthcare services provided for the families facing child loss.
(2) Highlight the challenges of introducing perinatal hospice care.

Methods: Study of the applied protocol and practices in neonatology departments – 29 PICs nationwide, 36 in-depth interviews so far; 17 doctors, 7 mid-wives, 10 nurses, 2 psychologists – concerning infant death and support for the bereaved families.

Results: The comparison of the valid protocol and the actual practices, needs these events convey in the already visited 14 PICs reveals the lack of proper knowledge of the protocol in 9 institutions and its scarce application in 5. The professional and personal requirements of perinatal hospice care those working in neonatology may face show that while there is a growing need for this care, the mindset of the healthcare professionals can slowly be changed and specific trainings are also necessary in the formation processes.

Conclusions: For proper perinatal hospice care in Hungarian institutions a shift of attitude is needed in the competency fields of the professional as much as the established cooperation of a multidisciplinary group. It requires new protocols, trainings, supportive and psychological measures.
Analyses of the Psychological, Social and Spiritual Attention of the Families of Children Died in Pediatric Palliative Care

**Introduction:** The families that provide care to pediatric patients with incurable illnesses, present multiple and complex needs at psychological, social and spiritual level. It is necessary to have specific interdisciplinary teams.

**Aim:** To describe the psychological, social and spiritual needs presented by the families of children died in a program of pediatric palliative care (CPP) and to inventory the interventions realized.

**Method:** Study observational, descriptive, retrospective, through the analysis of the digital medical records of 50 dead patients, the program of CPP at Children’s Hospital in Seville 2011–2014. Descriptive analysis and inferential with statistical program SPSS 23.0. The study is approved by Research Ethics Committee.

**Results:** 50 children died. 31/50 children present oncological illness and 19/50 not oncological illnesses. The psychological needs were present in 5 (10%) families and they derived from situations of overflowing, physical and emotional surcharge, which need psychologist’s intervention for behavioural problem and pharmacological treatment. The social needs occurred in 33 families (66%) and the diagnoses were: Economic problems / extraordinary expenses for long hospitalization 82%(n=27); Changes in the familiar dynamics 60%(n=20); Problems dependence / disability 18%(n=6) and minder’s difficulty to combine work / care 12%(n=4). The intervention of a social worker provided advice and orientation. With regard to the spiritual needs, they were present in 14 families (28%) and they all needed the assistance for a Catholic chaplain.

**Discussion:** Not to have in the hospital of a team specializing in pediatric palliative care has been an important handicap for the attention to the families, because this attention has depended of professionals who do not devote themselves in exclusivity.

**Conclusions:** Important lagoons appear in the welfare, psychological and spiritual cost of the families with children with incurable illnesses.
Palliative Care Research in Scotland 2006–2015: A Scoping Review

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Background: The Scottish Government set out its 5 year vision to improve palliative care in its Strategic Framework for Action 2016–2021. This includes a commitment to evidence based knowledge exchange across Scotland. A comprehensive scoping review of Scottish palliative care research was considered an important first step.

Aims: (i) To identify all Scottish palliative care research published from 2006 to 2015; (ii) to map key thematic areas relevant to clinical practice, service development and policy.

Methods: Palliative care research involving at least one co-author from a Scottish institution was eligible for inclusion. Five databases were searched with relevant MeSH terms and keywords. Initially 1,953 papers were identified and screened; 460 underwent full text review; and 304 were retained in the final set.

Results: In terms of methodology, 35% were quantitative, 28% were qualitative, 15% were reviews and 10% were mixed method. Just over two thirds were descriptive studies, and 12% were interventions or feasibility studies. Fifteen RCTs were identified. 48 papers were concerned with palliative care for people with conditions other than cancer. Key areas of research focus were symptom management (22% of papers), services and settings (13%), methodology and assessment (13%), experiences or needs (11%), bereavement (7%), co-ordination (5%), and education and training (5%). 77 papers (25%) were focused on other areas including identification, quality of life and health economics.

Conclusion: The findings reveal a considerable increase in palliative care research output over the last decade when compared with 44 papers identified in a similar Scottish review in 2006 and the 151 papers identified in a review of Irish palliative care research in 2013. The new Scottish Research Forum in Palliative care will now disseminate key findings to clinicians, service managers and policy-makers to improve the reach and quality of palliative care.
Policy Measures to Support Palliative Care in the Home Setting: A Cross-country Case Comparison in 3 European Countries

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Background: Facilitating palliative care at home is increasingly identified as important by national health care policies. Many countries have created specific supportive policy measures to support palliative care at home. However, we lack insight into what policy measures exist in different countries.

Aim: To list and compare existing policy measures to support palliative care at home in Belgium, France and Germany.

Methods: A cross-country case comparison based on expert consultation, governmental policy documents and relevant scientific literature. We classified policy measures according to their aim (to whom is it directed?) and type (what kind of support does it offer?) as ‘allowances and cost-reductions’, ‘in-kind services’ and ‘employment and workplace-related measures’, either aimed towards the patient or the caregiver.

Results: All 3 countries have policy measures that allow informal caregivers to change their working time or take leave from work to provide care without losing employee rights. Belgium is the only country with an additional specific palliative care leave. All 3 countries offer various allowances to home-dwelling persons and their caregivers. Cost-reductions for out-of-pocket costs exist based on care dependency level in Germany and prognosis in Belgium, but not in France. Mobile home support teams exist in all 3 countries and are free of charge for patients and caregivers; only in Belgium and Germany this concerns specialist multidisciplinary palliative home care teams. Belgium and Germany organise respite care for palliative patients.

Conclusion: European countries with similar contextual characteristics offer comparable policy measures to support palliative care at home. However, important differences exist in the availability and extent of specific measures. This knowledge can help national health policy makers to further improve support for palliative care in the home setting.
Identification of Patients with Palliative Care Needs Is a Public Health Priority: The Implementation of a Screening Tool in Switzerland

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Palliative Care (PC) is characterized by interdisciplinary care of patients with life-limiting diseases. Too often PC is restricted to terminal care and to cancer patients. Many tools have been created to increase teams capacity of identification of patients with PC needs both in early phases of disease and in non-oncologic settings. In Southern Switzerland a Cantonal Strategy was initiated in 2014 and an urgent need for a screening tool emerged.

Aims of the work: To create a tool to:

a) early identify patients with PC needs.
b) identify the complexity of PC patients in need of specialist care.

Design and approach taken: A comprehensive literature review was performed. Screening tools from different international settings (Gold standard Framework, Supportive and Palliative Care Indicators Tool (SPICT), the NECesidades PALiativas tool NECPAL CCOMS-ICO©) informed the development of the initial draft of the tool. A consensus building procedure was used, involving stakeholders active in general and specialist PC. Three consensus conferences were established to reach consensus. The hospital mobile team then initially tested this tool.

Results: The tool consists of four steps, three of them to detect general PC patients and a fourth one to identify those in need of specialist care. The three steps consist of the “surprise question”, of general indicators of decline and disease specific criteria. The fourth one consists of 11 criteria to identify situations that need referral to specialist PC. In the first testing phase, conducted between January 2015 to December 2015, 961 patients referred to the mobile team were screened with this tool. Mean time for screening was 4 minutes. Of all cases 31% were identified as of general PC and 62% met the criteria for specialist level.

Discussion: The pilot test showed that the tool was easily integrated in daily practice and time for completion was reasonable. Future steps are to test the instrument in general PC settings.
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**Leaving No One Behind: Palliative Care and the Sustainable Development Goals (Agenda 2030)**

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**Background:** World leaders adopted 17 Sustainable Development Goals (SDGs) with the slogan “Leave No One Behind” in 2015. The 2030 reporting goal requires countries to develop policies to achieve these goals with help of major donor funding. The SDGs build on the success of the Millennium Development Goals and aim to end all forms of poverty. The majority of PC providers and policy makers are unaware of links between palliative care and key SDGs.

**Aims:** To show that policies integrating palliative care and capacity building are key to countries’ achievement of the SDGs.

**Method:** Examine each SDG to see how integrating palliative care supports it.

**Results:** PC supports: Goal 1 End Poverty by providing communicative and clinical mechanisms to help families avoid falling into poverty though inappropriate care, catastrophic out of pocket expenses, allowing primary income earners to return to work with appropriate pain management; Goal 3 Healthy Lives for All Target 3.8 Universal Health Coverage and Access to Medicines are essential for improving overall public health. Goals 4 and 5 Quality Education: PC, pain relief and home care allow women and girls, primary caregivers, to return to school and work; Goal 8, Decent Work and Economic Growth: integration of PC into healthcare systems will require training and licensing of tens of thousands of new providers; Goal 10 Reduced Inequalities: PC will narrow the “pain gap” within and between countries; Goal 16, “Peace Justice and Strong Institutions” Appropriate pain management can facilitate patients and families participation in local and community decision-making; PC exemplifies Goal 17 Partnership for the Goals, which requires governments, the private sector, and civil society to collaborate in realisation of the goals.

**Conclusion/discussion:** PC integration into national healthcare systems supports countries to reach key SDGs. National policymakers and PC providers must be educated and updated about synergies if no one is to be left behind.
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**Representation of ‘Palliative Care’ in Assisted Dying/Euthanasia Declarations**

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**Background:** The production of ‘declarations’ (formal, public statements to influence policy, raise awareness and invoke action) is increasing in the end-of-life care field. Several declarations have been issued on ‘assisted dying/euthanasia’ but have not yet been analysed systematically.

**Aim:** To map the emergence of assisted dying/euthanasia declarations in the international context and to establish the representation of palliative care in these declarations.

**Methods:** A two stage search strategy was used to identify assisted dying/euthanasia declarations:  
1) Systematic internet searches (Google search engine)  
2) Searches on websites of key organisations. Content analysis was employed to explore the characteristics of the identified declarations and to examine references to ‘palliative care’.

**Results:** 61 assisted dying/euthanasia declarations (1974 to 2016), 22 since 2011, were identified. Their geographic scope was global (18), international (2), national (38), regional (2). Two thirds of the declarations were against assisted dying/euthanasia. The issuing organisations were: healthcare (28), religious (16), lobbyist (12), political (3). Twelve declarations were issued by 14 palliative care organisations. 41 declarations made reference to palliative care. Palliative care references included: describing palliative care, clarifying it excludes assisted dying/euthanasia, demonstrating it can eliminate suffering, expressing concerns about the implications for palliative care of legalising assisted dying/euthanasia, and demanding access to and resources for palliative care.

**Conclusions:** Assisted dying/euthanasia declarations represent the views and demands of diverse communities. The value of palliative care in eliminating suffering at the end of life is recognised in the declarations, whether or not they support assisted dying/euthanasia. Despite divided opinions, ‘palliative care’ forms a significant part of the discussion on legalising assisted dying/euthanasia.
Developing Leadership for Palliative Care: An Evaluation of a Palliative Care Senior Nurse Network

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Background: There is a need to build nursing leadership capacity for palliative and end-of-life care. This is particularly relevant within a changing health care systems and expectations on service providers to deliver more within constrained budgets. A Palliative Care Senior Nurses Network (PCSNN), established by the All Ireland Institute of Hospice & Palliative Care (AIIHPC), sought to facilitate senior nurses working together to improve standards of palliative care practice and service provision in Ireland.

Aim: To evaluate the implementation, process and outcome of the PCSNN.

Methods: A multi-methods approach, comprised of three phases was undertaken. These included an online survey with nurse participants (n=30); key stakeholder interviews (n=9) and four focus group interviews with a purposive sample of PSCNN members (n=26). The interviews were transcribed verbatim. Thematic analysis was applied to identify core themes.

Results: Findings from the online survey indicated that the PCSNN members were generally positive about their experience of the programme and positive changes in leadership qualities were evidenced. The following six key themes emerged from qualitative data analysis: (1) recruitment and motivation, (2) role expectations, (3) professional experience and impact, (4) personal experience and impact, (5) Initiatives, role, experience and learning opportunities, (6) sessions, experience and learning opportunities and (7) strategic influence and the future role of the network.

Conclusions: The palliative care senior nurses network was viewed by its members as a personal and professional forum which enabled networking, leadership’s skills and personal development to be achieved. The development of such Networks have potential to not only enable personal and professional development but also to have an impact for practice, policy, education and research.
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The Use of QALYs in Cost-effectiveness Analyses in Palliative Care: Mapping the Debate

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Background: In cost-effectiveness analyses (CEAs) in healthcare, Quality Adjusted Life Years (QALYs) are often used as outcome measure of effectiveness. However, the appropriateness of its use in palliative care has been subject of debate.

Aim: The aim of this review was to systematically map arguments pro and con the use of QALYs in palliative care as brought forward in the debate, and to evaluate the QALYs' value for palliative care.

Design: The integrative review method of Whittemore and Knafl (2005) was followed. Theoretical arguments and empirical findings were mapped.

Data sources: A literature search was conducted in PubMed, EMBASE and CINAHL, in which MeSH terms were Palliative Care, Cost-Benefit Analysis, Quality of Life, and Quality Adjusted Life Years (QALYs).

Findings: Three core themes regarding the pros and cons of using QALYs in palliative care were identified.
1) restrictions in life years gained,
2) conceptualization of quality of life (QoL) and its measurement, including suggestions to adapt this, and
3) valuation and additivity of time, referring to changing perspectives on time.

Although the debate is recognized in empirical studies, alternatives are not yet applied.

Conclusions: The QALY is of value for palliative care, provided that specific adaptations are taken into account. Despite restrictions in life years gained, QALYs can be achieved in palliative care. However, in measuring QoL, we recommend to – additionally to the EQ5D – make use of QoL instruments specifically for palliative care. Also, we suggest to study how valuation of time might be integrated in the QALY framework in a non-linear way.
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Introduction of Patient Self-determination Act in Taiwan and its Application Problems with Foreign Laws

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Aim: To examine the newly passed Act (passed on 18th, December 2015 and valid on 6th, January 2019) under current clinical practice and raise the problems our government should manage.


Results: Limited clinical inclusion criteria and judge difficulties, complicated process and no punishment if doctors refuse to compliance are the three main problems of this act. These problems didn’t be seen in Germany or U.K. law. Such clauses restrict the patient’s autonomy.

Conclusions and lesson learned: We should union each medical association for its specific disease inclusion criteria development and carefully design the AD(advance directive) formed process according to patients’ disease stage to make the best possible “in-the-moment” decision-making and consider the special process if one has no family or is hard to reach witness. Besides, delicate the doctor-patient-family (or attorney) discussion method may also enhance the doctors and family’s confidence to perform the ADs exactly. How to make sure one patient makes the AD under patent capacity and AD reflect his/her exact preference and value are important. We shouldn’t assume everyone make medical decisions under calm, rational situation, sometimes they make it by feelings and preference.
Beating Crisis End-of-Life Care – Is Quality Proactive Care for People in the Last Years of Life in Primary Care Possible and Sustainable? Findings from the First GSF Accredited and Reaccredited Practices

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**Aim:** Crises are frightening especially near the end of life. Primary care teams are pivotal in caring for patients in the final years of life, enabling more to live well and die where they choose, and reduce inappropriate crises and hospitalisation. With increasing pressures from the ageing population, rising mortality and limited resources, a more proactive approach to meeting these challenges is required.

The Gold Standards Framework (GSF) Quality Improvement Programme has been influential in EOLC since 2000 with most UK General Practitioners using GSF foundation principles. We report on the findings of the first 17 GP practices undertaking GSF Going for Gold training and accreditation with some reaccredited 3 years later, demonstrating what is possible to achieve.

**Method:** Primary Care Teams undertake a practice-based distance-learning GSF Gold programme with optional interactive workshops over 6–12 months. Evaluations before and after in preparation for accreditation include key outcome ratios, on-line After Death Analysis plus submission of a portfolio of evidence and assessment interview.

**Results:** Cumulated findings for the accredited practices show significant improvements, including some reaccredited 3 years later demonstrating long-term sustainability. Practices demonstrate enhanced proactive end-of-life care, with earlier identification of over 60% of their patients who died, offering ACP discussions to over 65%, leading to more home deaths and improved outcomes for patients and carers.

**Conclusion:** Improving care for people in their last year of life in GP Practices with proactive person-centred care is pivotal to meeting the challenges of the ageing population, and making best use of limited resources. The GSF Gold programme reported here, is an example of a practical, well-received evidence-based quality improvement, leading to more proactive planned care in line with peoples’ preferences, meeting the increasing needs of the ageing population.
Trust in Physicians, Perceived Continuity and Coordination of Care, and Quality of Death in Patients with Advanced Cancer in Home Care (Japan Hospice and Palliative Care Evaluation Study 3: J-HOPE3)

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Background: When patients have advanced cancer, achieving a good quality of death (QOD) becomes an important issue for patients, family, and health care providers (HCPs). Although trust of patients in their HCPs, continuity of care, and coordination of care among HCPs are important aspects of end-of-life (EOL) care, it is unclear whether these factors affect the QOD.

Objectives: To explore whether trust of the patient and family in HCPs, perceived continuity and coordination of care among HCPs affected the QOD of cancer patients.

Methods: This study was a part of nationwide survey of bereaved family members of cancer patients evaluating the quality of EOL care in Japan. We investigated 702 family members of cancer patients who died at home. QOD was evaluated by the short version of the Good Death Inventory (GDI). We measured 5 factors on a Likert scale using original instruments: patient and family trust in HCPs (oncologist, home care physician, and home care nurses), perceived continuity of care by home care and hospital physicians, and perceived coordination of care among home care staff.

Results: A total of 538 responses (77%) were obtained and 486 responses were analyzed. The average GDI score was 50.6 ± 8.8 (maximum of 70 points). The majority of the bereaved family members reported that the home care physician (80.1%, n=347) and home care nurses (87.2%, n=344) had a comprehensive care approach, while only 54.7% (n=344) reported that the hospital physician had a comprehensive approach. Trust in HCPs showed a weak, but significant, positive correlation with the GDI score (r = 0.317–0.421). Perceived continuity and coordination of care had negligible correlations with the GDI score (r = 0.113–0.260), although it was significant for perceived coordination of care.

Conclusions: Trust of the patient and family in HCPs and coordination of care among home care staff have a positive influence on the QOD of advanced cancer patients in home care.
Cost, Effectiveness and Cost-effectiveness of Home-based Palliative Care: Integrative Literature Review

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Background: Early integration of palliative care is essential to ensure the quality of care for patients with advanced, incurable, life threatening diseases, and at the end of life. However, more evidence is needed about the cost, effectiveness and cost-effectiveness of an early introduction in the home care.

Aims: To analyse the literature on costs, effectiveness and cost-effectiveness of integrating palliative care in the care for patients with advanced illness and end of life at home.

Methods (design, data collection, analysis): Integrative Literature Review following Systematic PRISMA 2009 research in PubMed, Web of Science and EBSCO databases for the years 2000–2016. The keywords were: “palliative care”, “home care”, “cost (s)”, “cost-effectiveness” and “benefits”. The inclusion criteria were publications in English, full text and references available. Articles in intensive care, paediatrics and without relevance to the subject were excluded. Selected articles were independently reviewed by two investigators.

Results: Of the 87 articles meeting the inclusion criteria, 35 were selected for analysis. Findings show that the cost of institutionalized palliative care is 71% higher than home-based palliative care. The latter can reduce in 50% the number of patients requiring hospitalization. Palliative care units and hospital support teams achieved 57% cost savings through adequate and proportionate prescription of medication, treatments and diagnostic tests.

Conclusion / discussion: Home-based palliative care was associated with significant cost savings, fewer hospitalizations, proportionate care provision, increased likelihood of meeting patients’ wishes and preferences, including place of care and death at home. Early integration of home-based palliative care was also associated with lower symptom prevalence, reduction of caregiver burden and better quality of life.
Barriers to Recruitment for Implementation Research in Primary Palliative Care

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Background: Our research group investigated the implementation of a Care Pathway for Primary Palliative Care, aiming to improve GPs’ role in palliative care, in the action zones of five palliative care support teams (PCST) in Belgium. These PCSTs facilitated contact with GPs aiming for improved palliative care in primary care.

The project was rolled out sequentially as a stepped wedge cluster trial from January 2014 till March 2016. GPs had to (1) deliver data on the prevalence of positive surprise question (SQ) patients seen in 10 successive working days, and (2) include one SQ positive patient into the project, to fill questionnaires on quality of care.

Aims: We report on barriers to recruit GPs for this implementation project.

Methods: The recruitment process was logged step by step in an Excel-file. Per GP, the contact method (mail, phone, face-to-face, …) and a summary of the content were noted. Afterwards, barriers were analyzed per theme and linked to the 5-stage model for change in professional behavior (Orientation, Insight, Acceptance, Change, Maintenance). (Grol and Wensing, What drives change? Med J Aust 2004).

Results: 112 out of 4165 eligible GPs signed to participate. Only 65 GPs delivered SQ-list data. Only 12 GPs included patients.

The major themes discovered in the logbook were:
1) Difficulties to contact GPs irrespective of the used methods, probably linked to a low orientation towards (palliative) care innovations. (Orientation)
2) Some contacted GPs showed a lack of willingness to change their practice. (Insight)
3) Many initially interested GPs had many types of apologies, most often linked with low self-efficacy in dealing with perceived practical barriers (time, staffing). (Acceptance)
4) Of GPs having signed, 3 drew back because the practical barriers were more difficult than foreseen. (Change).

Conclusion: In the actual context, it proved to be extremely difficult to engage Belgian GPs in a primary palliative care research project.
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Implementing Basic Palliative Care for Cancer Patients in the Community

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Background: A draft Model of basic Palliative Care (MBPC) in community was developed based on mix method research, agreed through a Delphi process and subsequently piloted by 26 GPs on a sample of 271 cancer patients in 4 Romanian counties during July 2015–June 2016.

Aim: To describe the experiences of and impact on GPs involved in implementing the MBPC and to identify aspects that need to be refined in the model from GPs perspective.

Method: Qualitative research: focus groups (FG) were run in each county. Same interview guide and moderator in each location; verbatim transcription and semantic thematic analysis by 2 researchers.

Results: 18 GPs attended the 4 FG (Brasov4, Bucuresti5, Iasi4, Cluj5). Themes identified around the MBPC: Clinical interventions in the model of care are efficient in assuring symptom control for patients enrolled. Applying the MBPC is time consuming compared with routine care offered by GPs which might create resistance in applying at larger scale. The screening tool for PC needs is more appropriate for cancer patients with poorer performance status. Electronic patients’ records were a challenge as novelty and complexity of information required. Educational intervention need to include more practical training in specialized PC services; the theoretical case based training was useful in increasing knowledge and challenging own practices especially communication and pain prescribing. Local coordinator from specialized services was key to maintain commitment in the project if readily available as resource persons. Building a network of GPs, PC specialists and oncologist was a rewarding outcome of working in the project with immediate impact on patient trajectory in the health care system. GPs self growth in terms of confidence, self respect and satisfaction with care.

Conclusions: MBPC is efficient, needs adjustments in terms of documentation and education. GPs noted not just professional growth but also personal development.
Do General Practitioners, Patients and Caregivers Need an Additional Framework for Palliative Care in the Community?

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Background: In Italy, palliative care is provided by general practitioners who offer the first level of palliative care but many patients continue to have difficulty in accessing palliative care services, especially elderly patients or non oncological patients. An instrument like “Gold Standard Framework” with some adaptations for Community Palliative Care could improve access to palliative care services for neglected patients and help patients and caregiver orientate themselves in the palliative care service network easily. The aim of the project is recognize opinions from GPs, including doctors who work in out of hours services, and from caregivers and members of patients associations regarding a standard framework modified for local community palliative care services.

Method: Qualitative research through focus group methodology shall be used. Two different focus groups, one with GPs and out of hours M.Ds, with different ages and backgrounds, and the second with caregivers and members of patients associations will be conducted in to collect opinions, ideas and problems. Before the start of the focus group, the original Gold Standard Framework and some possible changes for the local palliative care network will be summarised.

Results: The goal is create and update a local charter of services regarding palliative care in the community, with the aim to guide GPs and Care Giver, to use the different resources to avoid patients discomfort, because the service and resources are rapidly changing. We expect positive feedback and a good participation on the discussion from GPs, also a good response from members of patients associations and care givers.

Conclusion: If the participants remark on the importance of a framework, we can continue to work to implement a charter of service and working to make it visible and accessible. At least it could be an additional encouragement for discussion and progress in the local community palliative care model.
Palliative Care and Public Health Mix: A Sustainable Model of Primary Prevention of Non-communicable Diseases in a Low Resource Settings

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Background: In 2008, 14 million premature deaths attributable to non-communicable diseases (NCDs) occurred globally, the number is projected to reach 52 million people by 2030. Tanzania is among the hardest hit nations by NCDs. Delayed diagnosis of NCDs in Tanzania is a common phenomenon that creates a huge demand for palliative care services while only a handful of facilities that offer palliative care services are available. The NCDs are major because of physical, psychological, social and spiritual pain and indeed suffering. Palliative care emphasis is on improving quality of life through prevention and relief of suffering in people with life threatening illness.

Aim: We aim to raise awareness on NCDs and set a stage for a continuum of palliative care services through a multi-sector engage.

Method: communities were invited through social media in a three day health camp on Sep 2016. Health education and screening services with a focus on cardiovascular related NCDs: diabetes, hypertension, and stroke and cancers of: breast, cervix and prostate were conducted.

Results: 
Managerial: Twelve institutions from the public and private sector participated, goal congruence were achieved by all institutions, top managers from local and central government attended, financial donations to support event came from families who were beneficiaries.

Clinical: A total of 452 people came of these 41% and 40% were pre-hypertensive and hypertensive, respectively and 13% knew of their status. 23% of people tested had diabetes. Breast and cervical cancer suspects were 3% and 5% respectively. 24% were suspects for prostate cancer.

Discussion: High prevalence of NCDs signifies the need for integrated continuum of palliative care. The approach attracted more actors from the public and private sector to meet our goal.

Conclusion: Palliative Care and Public Health mix is a sustainable approach to expedite our effort to meet the needs for palliative care services in low resource settings.
PalliArts, Where Guidelines Meet Care

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Context: In the Netherlands the aim is to provide palliative care at home as long as possible. This complex care at home is provided by the GP and often demands for acute actions.

Aim or goal of the work: Improve palliative care given by the general practitioner (GP) by giving quick access to all necessary (local and national) information about palliative care, on the spot, at any time, with the possibility to consult other disciplines.

Design, methods and approach taken: To obtain an inventory of needs to provide good quality palliative care at home, a broad consultation of all the partners was held (general practitioners, palliative care consultants, specialists in geriatric medicine, palliative networks). All the needs where grouped together. The app developing process from strategy to concept was an interactive process with the end-users.

Results: The content of the app is composed by 2 elements:
- **regional content** managed by the local network manager (medication, checklists, organizations, available beds, consultation, transmural appointments, patient education)
- **national content** managed by Netherlands Comprehensive Cancer Organisation (IKNL) (guidelines, medication, checklists, consultation, patient education)

This management structure of the content fits the existing structure of supporting palliative care in the Netherlands and facilitates the integration of the local and the national information. During the first 6 months 30 out of 66 regions have filled regional content and over 16,000 professionals downloaded PalliArts. An independent survey pointed out that PalliArts is an important source for nurses to find information: “easy to use, brief and to the point”

Conclusion / lessons learned:
- make use of existing organisational structures
- use an simple content management system
- the GP and other professionals appreciate this app because information about guidelines, checklists and the necessary consultant/ organisations is easily at hand.
Coordination with Primary Care System in Pediatric Palliative Patients: Our Experience

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Background: The role of primary care providers is essential when we look after a child with a life-threatening disease. They help to guarantee a 24 hours care, especially when our patients live far from the hospital. Many of them have long-standing relationships with children and their families, being useful in the detection of other problems, strengths and weaknesses and in situations where major decisions are made.

Aims: Optimize communication and relationship with the primary health centre (PHC) in order to improve our children’s attention.

Methods: Analysis through patients’ clinical history about contacts between our pediatric palliative care unit and the PHC from 1st January 2015 to 30th September 2016.


Conclusions:
- When we do often coordination with PHC, better home care in last days of life is provided.
- 85% of these patients died at home, but the results decrease when the contact es not made: 34% of patients.
- There is an important difference between non-oncological and oncological patients according to their relation with the PHC: only 3 of them were oncological patients (9.6% of the contacts), with a one-time contact with their pediatrician.
- Our results show non-optimal contact with our children’s PHC (22% of our patients). Due to this, we are working on a protocol to improve attention circuit and coordination with PCH.
Comparing Emotional, Relationship and Sexual Wellbeing of Gynecological Cancer Patients with a Matched Cohort

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Background: Gynecological oncology patients experience a high symptom burden of physical and emotional symptoms, from the time of diagnosis, through treatment, recurrences as well as during long-term survivorship. There is very little understanding of the nature of distress that these patients experience and whether the distress levels reported and significantly different from a matched cohort group.

Aim: The aim of the study was to compare levels of depression and anxiety symptoms, relationship distress, and sexual dysfunction in a sample of patients with gynecological cancer and a cohort group matched for race, age, and education level.

Method: A cross-sectional study was conducted and 106 gynecological cancer patients and 223 women with no history of gynecological cancer were recruited. 87 pairs of patient-controls were compared, using propensity score matching. We used Hospital Anxiety and Depression Scale (HADS) to look at the symptoms of anxiety and depression in patients, 4-item Dyadic Adjustment Scale to look at marital distress and Arizona Sexual Experience Scale (ASEX) to look at sexual dysfunction. We used independent sample t test to compare scores between patient and cohort group.

Results: Patients reported significantly higher levels of sexual dysfunction (M = 18.94 vs 14.54, p = .002) and reported significantly less belief that their romantic relationship is going well (M = 2.18 vs 2.77, p = .04). Depression and anxiety scores were not significantly different; however in examining women below the median age of the sample (45 years), patients reported higher scores of depression (M = 5.23 vs 3.79, p = .04).

Conclusions: Marital distress and sexual dysfunction may be targeted in future to improve the patient's wellbeing. Women who are younger are at higher risk of depression.
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Attachment Figures When Death Is Approaching: A Study Applying Attachment Theory to Adult Patients’ and Family Members’ Experiences during Palliative Home Care

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Background: Serious illness will routinely activate attachment behaviours in patients and family members, due to threats such as progressive physical disability, increasing dependency needs and threats of separation. There is, however, lack of studies with a specific focus on attachment figures in the end-of-life context. It seems important that palliative care teams are aware of what the repertoire of attachment figures may be, in order to facilitate patients’ and family members’ adaptation to such challenging situations.

Aims: To explore attachment figures (a central concept within attachment theory) during palliative care, using the experiences of patients and family members.

Methods: Twelve patients and 14 family members were interviewed during ongoing palliative home care. The interviews were analysed using qualitative content analysis.

Results: Four types of attachment figures were identified:
  i) family & friends;
  ii) health care practitioners;
  iii) pets;
  iv) God.

Both non-physical and physical contact with the attachment figures facilitated a sense of security. In addition, the patient/family members and their attachment figures were described by some as a “we”, and when one part of the “we” felt insecure, this made the other also feel insecure. The patients’ progressing illnesses constituted a threat to the patients’ and family members’ sense of security. The availability of the attachment figures made them feel secure, and they could then divert their attention from the patients’ illnesses to other things in everyday life, e.g. socialising with family. Some family members were also having to cope with the loss of their own attachment figure, when the patient, who had previously been a source of security for them, was no longer able to offer protection and comfort due to the progression of the illness.

Conclusion/discussion: Important aspects of attachment figures in the end-of-life context were identified, and their clinical implications will be discussed.
Dignity Therapy in Germany: Cultural Adaptation, Feasibility and Acceptability of a Short Term Psychotherapeutic Intervention in Palliative Medicine

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Background: Dignity Therapy (DT), developed by H.M. Chochinov, is an evidence-based intervention for patients nearing the end of life. It can reduce existential suffering and increase a sense of dignity. The basis of DT is a semi-structured question protocol. These questions have until now lacked a scientifically examined translation into German. Study Aim To test the feasibility of DT in Germany as well as acceptability and cultural adaptation of the question protocol. These issues are fundamental to the implementation of DT and further comparable research.

Method: In a clinical multicenter mixed methods study at two German palliative care units, university hospitals Mainz (M) and Wuerzburg (W), patients participated in semi-structured interviews after their DT interview; patients and relatives gave quantitative and qualitative feedback; and, to achieve 360° feedback, health care professionals (HCP) were interviewed in focus groups. The qualitative content of the HCP focus groups as well as of the semi-structured interviews with patients was analyzed in relation to the interview questions actually used in the DT interviews.

Results: Data collection ended in April 2016. Out of 410 patients (215 in M, 195 in W) 72 patients met the inclusion criteria. The most frequent exclusion criterion was a life expectancy less than two weeks. DT was conducted with 30 patients, 19 of these (and 25 relatives) provided feedback. Overall, comments from patients and relatives were extremely positive: 18 patients evaluated DT as helpful (“DT is a gift. It is more than I expected.”); 96% of the relatives would recommend DT. Data analysis of the patient interviews and the HCP focus groups yielded a validated German translation of the question protocol for DT (German consensus Würdezentrierte Therapie) following EORTC guidelines.

Outlook: The German DT question protocol has been proved ready for implementation and welcomes further research. DT is feasible at palliative care units in Germany.
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**Anxiety and Depression, Cognitive Coping Strategies and Mental Adjustment to Cancer in Cancer Patients during Anticancer Therapy**

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**Introduction:** Analyzing the factors that influence patients’ functioning help to identify the ways of coping with the disease that improve the healing process and the therapeutic relationship, slow the disease progression and facilitate the adaptation to difficult situation.

**Aim of the study:** The aim of the study was to assess the psychological functioning of cancer patients. The practical aim of the study was to develop guidelines for psychological care dedicated to cancer patients based on the results of the study.

**Material and methods:** 572 patients aged 19 to 91 (av. 54) with cancer treated in the Cancer Clinic in Institute of Oncology in Warsaw were examined. The study was based on single, voluntary and anonymous questionnaire consisting of HADS, MiniMAC and CERQ.

**Results:** The analysis showed that the intensity of anxiety and depression correlated positively with the intensity of cognitive strategies of self-blame (0.19 and 0.17), rumination (0.40 and 0.31), catastrophising (0.44 and 0.36) and blaming others (0.25 and 0.24) and correlated negatively with strategies of positive refocusing (-0.33 and -0.35). It also showed that positive coping strategies (fighting spirit and positive refocusing) correlated negatively with anxiety (-0.20 and -0.08) and depression (-0.18 and -0.03) while negative strategies (anxious preoccupation and helplessness/hopelessness) correlated positively with anxiety (0.45 and 0.47) and depression (0.56 and 0.50).

**Discussion:** The results provide guidance for psychological interventions in cancer patients. It is important to encourage patients to adopt an active attitude towards the disease – planning the next steps, finding out about the disease and treatment process, drawing of conclusions for the future and to look at current events in a broader context as a situation in which they are not helpless.
Performance of Three Diagnostic Approaches to Depression in Oncology

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Background: Depression is poorly managed in complicated clinical populations such as patients with advanced cancer. The primary source of this difficulty lies in the overlap between the DSM criteria for depression and the symptoms attributable to cancer and its treatment. The aim of the current study was to examine which of the major diagnostic approaches to depression (i.e., inclusive, exclusive, substitutive) appears optimal for use in oncology.

Method: Depressive symptoms were assessed using the PHQ-9 and Endicott substitutive criteria in 703 oncology outpatients. MDD was rated according to DSM criteria for the inclusive approach. The exclusive approach eliminated appetite disturbances and fatigue (7 symptoms) and the substitutive approach replaced 4 somatic items with Endicott criteria (tearfulness/depressed appearance, cannot be cheered up/no response to good news, socially withdrawn, brooding/self-pity). Chi-square tests and kappa coefficients were calculated to compare approaches.

Results: The inclusive approach identified the largest number of participants as having MDD (n=65; 9.2%), followed by substitutive (n=43; 6.1%) and exclusive (n=31; 4.4%). The inclusive and substitutive approaches identified significantly more patients as having MDD than the exclusive ($\chi^2$ (1,N=619)=293.7, p<.001; $\chi^2$ (1,N=615)=380.7, p<.001). The substitutive approach classified far fewer participants as depressed than the inclusive approach, $\chi^2$ (1,N=615)=363.6, p<.001. Despite differences, kappa coefficients indicated substantial overlap between approaches (k=.62–.77).

Conclusion: These results underscore the necessity of considering alternative diagnostic approaches to depression in oncology. The substitutive approach may be a reasonable compromise for the cancer setting as it appears to balance sensitivity and specificity. Future studies should determine the reliability of the substitutive approach in order to inform development of assessment strategies in the cancer setting.
Contribution of the Thanatology in the Psychologist’s Training: The Academic’s Perception

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Background: The Psychology contributes to reduce the psychological distress in the palliative care by modifying the meaning of the illness process to the patient and their family. For that, training in this area is essential for the professional and personal experience.

Aims: To evaluate the contributions of the Thanatology in the Psychologist’s training.

Methods: An empirical study with 30 participants from the second year of the Psychology course, in which 43% are 18 years old. Also, 84% of them are female and 70% have a religion, yet 26% are non-practicing. 96% are single. A questionnaire with ten questions was applied collectively and the collected data was analyzed according to the Discourse of Collective Subject.

Results: It was found that 93% of the participants considered the subject very important for their professional training. 22 students considered the discipline excellent and 7 considered it very good. The most mentioned themes were palliative care and death, but also mourning and suicide. Kübler-Ross and Kovács were the most cited authors. The Discourse of Collective Subject about the perceptions of the discipline were:
1) Demystify the taboo of death through the construction of new views of the dying process as a natural phenomenon, a phase of life;
2) Reframe life and death;
3) Enable the professional training for a humanized management of mourning and dying process, developing a suitable repertoire for intervention in palliative care.

Conclusion: The perceptions were positive; the participants recognized the studied themes and the relevant authors of the area. Emphasis was given to a new vision of the mourning and dying process and the contribution for the professional training, offering a support system to help the family to deal with illnesses and bereavement.
System Theory in Psychosocial Support – Family Therapy in Hospice/Palliative Care

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Background: Regarding psychosocial support in hospice/palliative care in Hungary, we often see that carers deal separately with patients and family. The main causes of this situation are the lack of open communication and the lack of system theory in psychosocial care.

Aims: We would like to show that the application of the system theory – particularly in hospice home care – seems to be a very effective approach, as the pressure of suffering is often accentuated as part of conflicts within the family or relationships.

Methods: For two years, the author has been applying family therapy as an end-of-life psychosocial support and attempts now to show the first experiences – the benefits and difficulties of this special methodological tool – through the reported cases. The most interesting questions are:

- Is there any real benefit in the short-term intervention?
- Is it possible to conclude a therapy contract?
- Is there a real hypothesis?
- How are therapeutic frames shaped by the characteristics of the situation?

Results: Family therapy sometimes effectively helps to deal with dysfunctional families, solve generation conflicts, role conflicts and deal with coalitions within the family, and most of all to support open communication.

Conclusion: Family therapy is a special and very useful resource in psychosocial care; it is more than family consultation. We would like to train professionals: psychologists and mental health supporters to apply the system theory in care.
Determinants of Psychological Well-being in Patients with Advanced Chronic Somatic Disease

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Background: The World Health Organization defines chronic illness as diseases of long duration and generally slow progression. Psychological well-being is usually conceptualized as some combination of positive affective states such as happiness and functioning with optimal effectiveness in individual and social life.

Aims: The purpose of the study was to assess the intensity and determinants of psychological well-being in patients with advanced chronic somatic disease.

Material and methods: The study involved 71 subjects, aged between 24 and 84 (37 women). The studied persons were classified into two groups: the first group (I) patients with advanced cancer (n=36); the second group (II) consisted of patients with end-stage renal disease (ESRD) (n=35). We used: Positive and Negative Affect Schedule (PANAS), Satisfaction with Life Scale (SWLS), Visual Analogue Score, The Values Scale (VS), The Purpose-in-Life Test (PIL), Scale of Personal Religiousness (SPR), The Hospital Anxiety and Depression Scale (HADS), The Cantril’s Ladder, sociodemographic questionnaire. The correlation level between variables was determined by the Pearson’s coefficient.

Results: Analysis of the results showed that:
1) Patients received an average score on The Satisfaction with Life Scale and the Positive Affect Schedule and low level on Negative Affect Schedule
2) there was a statistically significant correlation between psychological well-being and:
   a) quality of life assessment;
   b) meaning in life;
   c) values system;
   d) intrinsic religiosity;
3) ESRD patients presented higher level of anxiety and depression than cancer patients.

Conclusion: In patients with advanced somatic disease (ESRD and end-stage cancer) presented an average level of psychological well-being and low level of negative affect. Intrinsic religiosity, meaning of life, values system and quality of life are factors determining psychological well-being in patients with advanced chronic somatic disease.
Acceptance and Commitment Therapy for Adults with Advanced Cancer (CanACT) Randomised Controlled Trial: Baseline Characteristics

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Background: Many people with cancer experience psychological distress. Acceptance and Commitment Therapy (ACT), third wave behavioural therapy, may be suitable in advanced cancer where physical and psychological difficulties are complex with no simple solutions. Evidence of effectiveness in ACT is limited in this population.

Aims: This feasibility study aims to assess delivery of intervention and patient recruitment. This work presents baseline characteristics from this trial and compare these with other studies of ACT in cancer populations.

Methods: Participants with advanced cancer were randomly allocated to receive either ACT or a talking control. Participants were recruited from 3 specialist palliative care centres in London, UK. Participants were assessed at baseline, 3 and 6 months; the primary outcome is functioning assessed using Functional Assessment of Cancer Therapies – General (FACT-G) at 3 months; secondary outcomes include (i) Acceptance and Action Questionnaire (AAQ) II; (ii) Kessler Psychological Distress Scale (K-10); (iii) quality of life using Euroqol-5D and ICE-CAP SCM.

Recruitment ends in November 2016.

Results: To date 34 participants have been recruited out of a target of 54 over 11 months. They were predominately white (79%), female (76%) with a mean age of 62 (SD = 11) years. Our sample had median FACT-G score of 59 (IQR 43–69), median AAQ-II score of 30 (IQR 24–39), median K-10 of 23 (IQR 18–30), median EQ-5D score of 0.694 (IQR 0.450–0.785) and median ICE-CAP of 23 (IQR 21–24). Our sample had similar baseline demographic and clinical outcomes in terms of gender, level of functioning and acceptance to a comparable study.

Conclusion: It is feasible to recruit patients with advanced cancer and they are willing to complete the main outcomes. FACT-G scores showed low level of functioning. The characteristics of our sample are similar to those reported in a previous study.

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Self-medication, Distress and Palliative Care

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This study aims to understand the interest of self-medication during end of life. We think that self-medication may limit distress consecutive to pain. According to Van Lander (2012) distress begets identity crisis when pain is significant. 801 interviews conducted among 237 patients demonstrated that the correlation between distress and pain is significant. Self-medication for pain purpose may also offers an opportunity to limit distress. Patients yet have a possibility of action and also have the feeling of being less dependent on medicine. It offers the same interest as anticipated requirements but on the other hand an hazard to make medical errors. The study verifies if self-medication in palliative care reduces distress. It is new to involve pharmacists. The interest of their contribution has been demonstrated (IPADAM, 2015). We want to evaluate if pharmacist’s interventions are a condition in palliative care for correlation between distress and self-medication.

Method: 150 communitys pharmacys and a palliative care hospital unit both participate. They use a distress thermometer (Holland, 1999). Pharmacists use a grid to indicate their intervention (IP) during three weeks. 300 patients at home and 50 palliative patients in hospital are taking part. Patients at home have various pathologies. 20 Patients in palliative care with distress and self-medication comportment are interviewed by a psychologist. Statistical analysis is performed with STATA 10.0 and Alceste software.

Results: we present the grid and results of psychological interviews.

Conclusion: self-medication is an opportunity in palliative care in patient’s representation.


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Predictors of Well-being among Women Working in Hospice Care

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Background: According to the national hospice database approximately 1600 people work in hospice care (the population is 9.9 million). The physical and mental burden of the workers is increasing, yet most of them are still satisfied with their work.

Aims: The aim was to explore the predictors of psychological well-being among female hospice workers, and identify the protective and risk factors.

Methods: The response rate in this national cross-sectional survey was 14%, 91.8% of the respondents (N=179) are women, 71.9% are employees, and 28.1% are volunteers. Nearly half of the respondents are nurses. The mean age is 45.8 years (SD=10.46 years, range: 23–73 years). Besides socio-demographic data the following questionnaires were used: the shortened versions of WHO Well-Being Index, Effort-Reward Imbalance Questionnaire, Beck Depression Inventory, Maastricht Vital Exhaustion Questionnaire, Athens Insomnia Scale, and Sense of Coherence Scale.

Results: According to the results of the path analysis work overload contributes to decreased psychological well-being through increased perceived stress, sleep difficulties and vital exhaustion. Sense of coherence enhances well-being through lower perceived stress, less sleep problems, and reduced vital exhaustion. Sense of coherence is stronger among older workers, and among those who enjoy better financial situation. Sense of coherence negatively correlates with work overload. The model explains 53.1% of the variance in well-being ($\chi^2$(10)=15.1, $p=0.128$, CFI=0.987, TLI=0.961; RMSEA=0.053, SRMR=0.047).

Conclusions: Work overload is a risk factor for worse psychological well-being, while sense of coherence as a protective factor mitigates the levels and negative impact of perceived stress. This ultimately facilitates the maintenance of well-being. A deeper analysis of associations points out the strategies of effective coping that can be helpful in the prevention of burnout.
**Life Changing Disease – A Qualitative Study**

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**Background:** When a person is diagnosed with a severe disease, life can be influenced by physical, psychological, social and existential matters. The person must cope with the new way life is taken according to that ordinary life is changing and that the disease shortens life. Not many studies focus on how the patient’s feelings look like and what support is needed.

**Aim:** To investigate how patients with a life changing disease cope with the life situation.

**Method:** The study use a qualitative approach with in-depth interviews which are analyzed with a content analysis with themes and categories.

The patients were introduced by an information paper in the hospital waiting room. Those who wanted to participate sent a consent to the researcher. The interview was recorded and transcribed into paper.

**Result:** 41 patients were interviewed. All patients experienced that the disease influence their ordinary life, more or less depending on how the symptoms looked like and if they must change a lot in their daily life.

Support was important and most support was given by family and friends and was a help to cope with the new situation. Another theme was about turning points that give them a better or a worse life. Example of a positive turning point could be when the patient learned how to cope with the symptoms. A negative turning point was when the patient got a message of progress.

Access to information from different ways and how it was given, influence their way of coping with the new life situation. Information is a crucial point and all patients had both positive and negative experience about this subject.

**Conclusion:** The study shows some areas that is important in order to facilitate the patients own possibility to cope with their disease. Through increasing knowledge, the health care professionals can give better support and information to the patient throughout the disease.
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Putting a Smile on their Face – Effects of Humour Interventions on Palliative Care Patients

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The effects of humour on patients receiving palliative care have not been investigated in a structured clinical trial. This three-year interdisciplinary study seeks to investigate this issue using a multi-stage humour intervention on psychological as well as physiological outcome parameters. In the pilot study 7 patients have been included. The main study will investigate 120 patients using a randomized control trial. Each patient received two humour interventions, which were developed using a humour training for psychiatric patients based on Paul McGhee. The effects were evaluated by the degree of change in cheerfulness, life satisfaction, burden of symptoms, pain threshold and the level of oxytocin in saliva, measured with standardised instruments and questionnaires. The research team consists of experts from palliative care, positive psychology and humour interventions. The feasibility of the study setting has already been evaluated during the pilot stage and adaptions were necessary, reducing the burden on the patient with a lower number of questionnaire items and physiological tests and shortening the duration of the study from three to two interventions. The pilot stage also showed that the humour intervention represents an added value to the existing therapy options at the palliative care unit.
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The Electronic Patient Record and the Patient Record, how to Close an Information Gap?

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Since 2011 specialist palliative care in Wales has adopted a single electronic clinical record, Canisc, designed to support activity and quality data collection and a live clinical record. The information issues in England and Scotland have been approached differently. There has been no single IT system. In relation to advance care planning and information sharing is EPaPPCs and in London, ‘Coordinate my Care’, both rely on existing primary care IT systems.

As a team we began to feel, that our narrative templated holistic palliative assessment needed particular consideration. This project was developed as a response to how to support our team in their use of an electronic record with the specific angle of psychological care. 

Method: Initially a small baseline appraisal of clinical face to face assessments. 2 month of referrals to the palliative care team = 95. Referrals where psychological dependency was the only reason for referral were given more detailed review by looking on the Canisc system=10 notes reviewed. A staff questionnaire conducted to assess the absolute level of support our permanent staff felt they required in relation the delivering psychological care of our clinical population.

Results: The holistic palliative care narrative assessment as held in electronic form does not provide an adequate template for the assessment and care planning of the patient with psychological needs. It may be an adequate screening tool for a new patient, but once concerns or problems are elucidated there is no evidence of consistent language of symptoms, severity and care planning.

Discussion: Formal engagement with the primary care and psychiatry to share local evidence based screening and assessment tools for consistency of assessment and communication. We will compare specialist assessment tools with generic tools to provide the shared language we need. A team based plan of supporting educational needs will be planned and evaluated using the same methodology.
Early Psychological Care: Who, How and When

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Background: International palliative care guidelines (White Paper on standards and norms for hospice and palliative care in Europe: part 1. European Journal Of Palliative Care, 2009; 16(6)) highlight the importance of a comprehensive and multi-professional palliative care for patients and their relatives. Psychologists are considered an essential part of PC team. So far scientific publications don’t define clearly how psychological interventions have to be planned and which kind of psychological support is requested in the different clinical situations.

Aims: This study investigated the timing of psychological support activation in a sample of advanced cancer patients assisted at home and their relatives. The goal was to examine the potential relation among an early psychologist’s involvement and some characteristics of the psychological intervention itself (e.g. type and frequency of intervention).

Methods: The observational retrospective study has involved 1,169 patients (58.3% F; mean age 65.4), 987 caregivers (61.8% F; mean age 52.1). Clinical, social and personal data were statistically processed (SPSS V22). Descriptive analyses and c² test were run.

Results: Most of patients (43%) received psychological support within the first week of home care, 31% within a month and 25% after the first month. Caregiver sample showed similar rates. Psychotherapy and weekly sessions were significantly more frequent among patients who had required support early (p< .005). In the caregivers sample, frequency of sessions was significantly related to an early psychological care (p=.000).

Conclusions: Results confirm the need of specialized and tailored psychological approach. Although most of patients take relief from psychological support, it is essential to identify those who need an early and intensive psychotherapy. For this reason a multidimensional assessment is necessary in order to plan the most effective treatment.
The Phenomenology of the Desire of Death. A Feasibility Study in Advanced Cancer Patients

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**Background:** The Wish to Hasten Death is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death (Balaguer, 2016). We have designed a study aimed to explore the phenomenology of desire of death (DD) testing potential mediators and re-testing after 2–3 days. We present here the feasibility study to determine recruitment, patient retention rates and the acceptability of the assessment tools.

**Method:** Prospective study of advanced cancer patients approached by a attending professional using first psychoexistential tools and then exploring DD. Questionnaires day 0: consent, ESAS, Patient Dignity Inventory (PDI), HADS and the Interview of the Desire of Death Rating Scale (DDRS); day 2–3: Kissane Demoralization Scale and DDRS.

**Results:** 25 patients were recruited in four months (mean of 56 years, 16 male, 10 postgraduated, 10 religious in practice, 4 non-religious; ESAS: pain 2.3 -DE:2.8-, asthenia 5.4 -DE:2.8-), one patient refused consent and other two preferred don’t follow after consent. Patients completed all the questions explored and the DDRS interviews twice. DD was presented in six patients the day 0 and in five patients, consistently, the day 2–3. Of the five, one had DD with high level of demoralization, anxiety and depression; another had DD with high demoralization and the other three had consistent DD alone.

**Conclusion:** The approach to maintain the DDRS interview after progressive psychoexistential questionnaires was positive, recruiting and retaining significative number of patients in the feasibility period. In the group explored, one of five patient expressed consistent DD with different metiators involved.
Coping Strategies in Advanced Cancer Patients Referred to Palliative Care Clinic in a Tertiary Care Cancer Hospital: A Retrospective Observational Study

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Aim: For people with advanced cancer, the months preceding death can be very stressful and to deal with stressors, they use a range of coping strategies, which refer to behavioural and psychological efforts to tolerate or reduce stressful events. There is a dearth of studies documenting coping strategies in patients with advanced cancer in a developing country context. We conducted a retrospective observational study to note types of coping strategies and their relation to the patient’s awareness of the disease status.

Methods: Patient assessment records of the first visit of advanced cancer patients referred to palliative care services over a 1-month period with complete psychological assessment were included and retrospectively analysed. Data on demographic variables, types of coping strategies, and patients’ awareness of disease status was collected. Descriptive statistics and Chi-square tests were used to note types of coping strategies and its association with patients’ awareness of disease status.

Results: Out of 185 patients, 96(52%) patients were males and 93(50%) patients were within 40–59 years age group. The three most common coping strategies used were acceptance (43.2%), seeking support (23.2%) and problem solving (12.4%). 59(77.6%) patients who knew both diagnosis and prognosis and 77(70.6%) patients who knew only diagnosis used these three common coping strategies rather than distancing and denial. However, this difference was not statistically significant.

Conclusion: In this study, the most common coping strategies used by patients was acceptance, seeking support and problem solving. Patients who knew only diagnosis or diagnosis and prognosis both used these strategies more commonly. It would be important to understand the sociocultural factors which might influence patient’s coping strategies despite facing an adversity of a life limiting illness like advanced cancer. Future studies are required to address this concern in our setting.
Body Image Perception in Gastrointestinal Cancer Patients: Accuracy and Satisfaction

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Background: Little is known about the perception and satisfaction with body image in patients with gastrointestinal cancer.

Aims: To identify the prevalence of accuracy of body size and the satisfaction with body size; and to know independent predictors of perception accuracy and satisfaction with body image in gastrointestinal cancer patients, with and without cachexia.

Methods: 378 adults patients were classified in No-Cachexia (No-SAC, n=203, 53.7%), Pre-cachexia (Pre-SAC, n=53, 14%) and Cachexia (SAC, n=122, 32.3%) and assessed for sociodemographic, clinical and nutritional characteristics and presence of symptoms. Body image was assessed by Silhouette Scale and logistic regressions analysis identified factors associated with accuracy and satisfaction with body image in the Groups.

Results: The inaccuracy of body size occurred in 75.8% of patients and dissatisfaction with body size was 78.8%. In the Pre-SAC/SAC Group, the risk factors for inaccuracy were: being male, to have metastasis and moderate/severe depression; advanced age was a protective factor. As for dissatisfaction, to have tumor colon / sigmoid and delayed diagnosis were protective of the desire to increase body size. In the No-SAC Group, have a partner and mild depression increased the risk of overestimation of body size (inaccuracy) and higher KPS was protective. As for dissatisfaction, being male was protective for the desire to be slimmer and to have tumor colon/sigmoid protected of the desire to be fatter.

Conclusion: inaccuracy and dissatisfaction with body image occurred in 2/3 of the patients and can bring unnecessary suffering to them and compromise nutritional treatments; to be aware of risk and protective factors permits to identify risk groups and to plan actions to adjust expectations.
Frequency, Characteristics and Impact of Delirium on the Short Term Survival of Cancer Patients in Mexican Palliative Care Setting

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Introduction: Delirium is a neuropsychiatric syndrome characterized by acute and fluctuating course. The prevalence among palliative care patients, ranges from 26–62% at admission, and up to 58–90% at the later stages. The hypoactive subtype is the most frequent, followed by mixed and hyperactive. Regardless of the high prevalence reported, delirium is still underdiagnosed and/or mistreated in patients suffering from cancer. Delirium augments morbidity, causes distress to patient, family members and health care professionals, and increases health expenditures. Moreover, the presence of delirium diminishes short term survival in palliative care patients. It is necessary to study the presence and impact of delirium in the palliative care area, in order to develop strategies to prevent, diagnose and provide opportunely treatment, lowering health costs, and improving the well-being of these patients.

Methods: We include patients referred to the Palliative Care Center of the National Institute of Oncology in Mexico City, from August, 2014 to March, 2015. We applied the Spanish version of the CAM. Those patients diagnosed with delirium, were classified subtypes according to DSM 5 criteria. In June, 2015 we reevaluate all patients in order to know their survival status (live/death).

Results: We include 174 patients with an average age of 50.91 years, 63.2% were female. 70 patients met criteria for delirium. We found hypoactive 45.7%, mixed 42.9% and hyperactive 11.4%. The average survival of patients with delirium was 11 days, while those without delirium was 21 days.

Discussion: In our study there was a high frequency of delirium to admission than in previous reports, the persistence of delirium decreases 50% in short-term survival. The most common subtype is hypoactive, this would be the reason for the unfrequent diagnostic in oncological areas. One limitation of this study is the relatively small population.
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Psychological Counselling Curriculum in Palliative Care

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Background: In Romania there is no psychological counseling curriculum in palliative care. When medical specialists are trained, there are clear medical protocols on interventions in palliative care, training courses and experienced trainers. However, in psychological counseling, we do not have the same level of development even though psychological counseling is vital in this area. We all know that drugs cannot take effect if the patient is not treated properly, from a holistic point of view. Psychologists working in palliative care need a curriculum.

Objectives: Obtaining models of psychological curricula in palliative care from experienced specialists to be adapted to the specificities of Romania. Identify the needs of professionals working in palliative care in psychological terms to be included in the new psychological Curricula.

Methods: quantitative and qualitative methods research were used.  
1. To fulfill the first objective, a survey via e-mail to the National Association for Palliative Care from 7 countries on the existence of a psychological curriculum in palliative care was conducted. Materials about the psychological curricula in palliative care have been received from the European Academy of Palliative Care. Project team members (7 persons) analyzed data obtained and selected materials for writing a psychological curriculum in Romanian.  
2. For the second goal we organized a focus group of 10 specialists working in palliative care at the Center for Palliative Care St. Nektarios in Bucharest (doctors (2), priest (1), social worker (1), nurses medical (3) and nurses (3) who aimed to identify the needs of staff working in palliative care who may need to be helped psychologically in their work.

Results: On an international level, there is a need that this activity be improved by involving specialists from each country. Not all countries have psychological curricula in palliative care.
Desire for Death in Patients Receiving Palliative Care for Cancer. An Expression of Despair

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Introduction: Depression, anxiety, and delirium are common psychiatric syndromes in palliative care setting; although these contribute to a substantial burden of suffering for patients and families, frequently are under-recognized or underappreciated, and often are difficult to differentiate in the setting of serious illness, due to symptom overlap with medical conditions. Palliative care psychiatry is an emerging subspecialty field, with a role yet to be defined; one of the main opportunities to be involved it’s the specialized view of one of the central tenets of modern palliative care, the concept of “Total Pain”, and the patient’s desire to hasten their death. However, far more common for terminal cancer patients is the desire to die as a consequence of poor symptomatic control. The purpose of this investigation was to explore the relationships between desire to die and depression, anxiety, and poor symptomatic control.

Methods: Patients’ referred for psychiatric evaluation (PE) between January to December 2015 at the Palliative Care Service of the Instituto Nacional de Cancerología, with life expectancy of less than 6 months, cognitively intact.

Results: 182 patients were referred for PE, 7.1%, were send because desires to hasten death and 64.3% because of clinically major depressive syndrome; average age 49.9 y/o; 71.4% females. During the PE 43.8% expressed DOD; 92.9% of these were diagnosed with major depression, 21.4% anxiety and 10.7% substance abuse. A statistical significant correlation was found between DOD and major depression (p=>0.000).

Discussion: The patients in this sample had a higher rate of major depression that those reported by other authors. A general consensus that major depression can be effectively treated in the context of terminal illness requires further research. A major limitation of the study is that no instrument was used for the evaluation of the DOD.
"My Memorial Book – Especially for you” A Case Study on How to Manifest Connection between the Dying Palliative Patient and their Child

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The casestudy is an aspect of psychological and existential palliative care; patients with life-threatening and incurable cancer disease, with the support from a psychologist, create a personal memorial book, to be given to the patients children.

Background: Parents having to die from their young children is heavily strained likewise the children will be psychologically and existentially affected by the loss.

Aims: The aim is two-folded; that palliative patients with children living at home is supported in parting from their children and the children is supported in the proces, by keeping the relationship between parent and child present and alive.

Methods (design, data collection, analysis): The study is an independent casestudy with 10 patients creating a memorial book for their children, while they were in hospital for palliative care. The patient is offered 4–8 conversations, structured by the psychologist, and based on a semi-structured guide with different themes, i.e.;

- experiences and tales from the patient’s life
- likes and dislikes/values
- the disease
- the patients love and appreciation for the child

The proces has been evaluated through qualitative semistructured interviews with patients, partners and children focusing on the proces of making/recieving the book.

Results: The study has shown

- that the proces have therapeutic and existential value including relief for the patient
- to increase the childs capacity to handle the loss
- value for the surviving parent

“The value of creating this book is crucial. To be able to give this to my daughter, is to be able to stay with her. In some way I will never leave her”.

Conclusion and discussion: The next steps is to do quantitative research on a bigger sample of patients and children.

And discuss how the Memorial book can be supplied with other rituals.
The Use of Health Behavior Theories in End-of-Life Care Research: A Systematic Review

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Background: Health behavior theories are highly useful in evidence-informed health promotion. Understanding relevant behaviors is also crucial in order to improve quality end-of-life care (EoLC). However, hitherto little is known about the extent and manner in which these theories are used in an EoLC context.

Aim: To assess the number of studies using health behavior theories with the aim of understanding, predicting or changing EoLC behaviors, which theories have been used, to what extent essential constructs were measured and what behavioral outcomes were aimed at.

Methods: A systematic review in MEDLINE (PubMed), PSYcInfo, EMBASE, Web of Science & CINAHL was performed on February 2016 followed by data extraction and quality assessment using a self-developed data extraction tool and the QualSyst quality rating tool. Only articles aimed at understanding, predicting or changing EoLC behaviors and that were explicitly referring to individual health behavior theories were included in the analyses.

Results: We screened 1921 records by title and abstract, retrieved 49 full text articles, and eventually included 27 (23 quantitative, 4 qualitative) studies for data extraction. Four studies used Theory of Reasoned Action, 7 Theory of Planned Behavior, 7 the Transtheoretical Model, 3 the Health Belief Model, 3 Social Learning theories, 1 Self-determination Theory and 1 Protection Motivation Theory. Only in nine studies the theory was fully applied. Regarding the EoLC behaviors, 14 studies focused on behaviors in advance care planning.

Conclusion: In EoLC research the application of behavioral theories is limited, and in those studies where a behavioral theory was applied, the application was often incomplete. As a multitude of behaviors at the EoL will determine the quality of care, our study suggests that there may be a need for a more extensive use of these theories if we want to better understand and eventually influence these behaviors.
Study of Urine Cultures in Palliative and/or Chronic Patients Admitted in a Palliative Care Unit

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In patients with advanced disease, infections are a destabilizing factor in the way to control symptoms. Urinary tract infections (UTI) are often among the main causes. The growing emergence of multidrug resistant bacteria in hospitals, determines the need for isolation and the use of iv antibiotic therapy. The controlling of the entry of these microorganisms in our hospitals is as important as avoiding the spread of disease between patients already admitted. To analyse the results of urine cultures performed to identify the main microbiological agents which cause UTI in patients admitted in the palliative care unit (PCU); to study their antibiotic resistance pattern to adapt the antimicrobial treatment. To detect possible transmission infections among hospitalized patients and, if need be, strengthen hygienic measures and microbiological prevention. All the urine cultures done in a PCU between 1st September 2015 to 31st August 2016 were studied retrospectively. The data was collected in a Microsoft Access® database: data patient, microbiological culture, pathogens isolated and antibiograms. Afterwards, descriptive statistical analysis was done through Microsoft Excel® and Statgraphics®. 79 patients. 42 women. Age 78.7 ± 12 years. Oncologic 57 (29.8% digestive, urinary 19.3%, 17.5% pulmonary). Non oncologic 22 (72.7% neurological, cardiovascular 13.6%). Urinary catheter 25. Urine cultures (UC)127 (48 repeated). Positive 67. Multidrug-resistant bacteria (MRB) 61. Multiple bacteria 16. More common: E. coli 17, E. faecalis 16 (12 UC same antibiotic resistance pattern), P. aeruginosa 14 (2 UC). The main bacteria isolated in a PCU are E. coli, E. faecalis and P. aeruginosa. Virtually all of them are MRB. The UC allows us to target the antibiotic treatment and prevent nosocomial infections among patients. It seems that the preventive isolation measures of our hospital are appropriate; the study showed a low level of spread of infection between the admitted patients.
**Care Homes and End-of-Life Care in England**

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**Background:** There are over 450,000 places in care homes in England, caring for many of the most vulnerable in society. Recent years have seen an increasing proportion of deaths occurring in care homes during a period of population ageing and reducing health and social care budgets.

**Aims:** To explore national data sources to explore the recent trends of death in care homes and of care home residents who die elsewhere.

**Methods:** The primary data source was routinely collected mortality data, in particular age, sex, causes of death, place of death and address of residence. For people who died in a care home, temporary residence was inferred if the recorded residential address was not a care home.

**Results:** 101,203 people died in care homes in 2014 (22% of all deaths) up from 76,977 (16%) in 2005. 70% of care home residents die in a care home (58% in 2005). The number of temporary residents dying in a care home rose 26,362 (2005) to 34,638 (2014); a constant third of deaths in care homes. Cancer is the most common cause of death for temporary residents (33% in 2014). Over 60% of deaths in care homes have dementia, Alzheimer’s disease or senility either as an underlying or contributory cause of death (2014) compared to 23% of all deaths.

**Conclusion and discussion:** Care homes are an important provider of end of life care. The policy of enabling people to die away from hospital is increasing the demands on them in this regard. Not only are care home residents increasingly likely to die in a care home, but an increasing number of people are dying in a care home after a short stay, either after discharge from hospital or having been admitted after their care in their own home became impossible.
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Dying at Home? Preferences of Older People in the City of Belo Horizonte, MG, Brazil

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Background: Brazil is facing an accelerated process of population ageing, with important consequences for end-of-life care provision. It is important that care preferences are known and respected, including people’s preferences for place of death. International studies often show that most people would prefer to die at home, but evidence for the Brazilian population is scarce.

Aims: To investigate preferences for place of death among older people (≥60 years) and identify factors associated with a home death preference.

Methods: The Brazilian version of the PRISMA questionnaire was administered face-to-face to a representative sample (N=400) of older people living in the city of Belo Horizonte, Brazil. Data were analysed using descriptive statistics and binomial logistic regression.

Results: Over half (52.2%) of the participants chose home as their preferred place of death, while 21.5% chose hospital, 17.8% a setting providing palliative care and 8.5% chose a care home. Five factors were associated with a home death preference: those living with one child (OR0.41: 95%CI:0.18–0.92; ref: without children); or having attained primary education only (OR0.42; 95%CI:0.20–0.89; ref: higher education) were less likely to choose home. In contrast, those finding it difficult to live with the present income (OR3.18; 95%CI:1.53–6.62; ref: living comfortably); with fair overall health (OR2.07; 95%CI:1.06–4.03; ref: very good health) and selecting “choosing who makes decisions about your care” as the care factor that would matter to them the most (OR2.43; 95%CI:1.34–4.40; ref: dying in the preferred place) were more likely to choose home.

Conclusions: Our results indicate that place of death preferences in Brazil are in line with those reported in other countries, with most people preferring to die at home. Furthermore, in a country where over 70% of the population die in a hospital, our results indicate a possible discrepancy between preferred and actual place of death.
“I Want to Stay Home and Die on the Farm.” The Actual Place of Death in a Rural Setting

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Background: The preferred place of death (PoD) for most people is home; however, there are unique challenges faced by rural residents wanting to die at home. Studies reporting PoD in rural settings for cancer and non-cancer palliative deaths are limited.

Aims: To describe the actual PoD of residents with a palliative related illness living in a rural setting and to explore factors associated with dying in one’s usual place of residence (UPoR).

Methods: Cross-sectional study using death records for all deaths between 1st February 2015 and 31st May 2016 in a rural region of New South Wales (Australia). UPoR included private residence and long term (≥3 months) residential aged care facilities (RACF). The association between PoD and patient demographics was assessed using logistic regression and reported as odds ratios.

Results: Out of 223 deaths recorded in the region 139 (62%) were due to a palliative related illness, and of these 52 (37.4%) occurred in UPoR (32.7% in a private residence; 67.3% in a RACF). There was no association between PoD and gender, age or marital status. Residents with dementia were more likely to live in a RACF and therefore die in their UPoR compared to cancer patients (OR 11.3, 95%CI 3.7–34.8). Residents living on farms or small towns with limited or no medical services were less likely to die in their UPoR than those living in towns with general practitioners and rural hospitals (OR 0.32, 95%CI 0.11–0.93 and OR 0.14, 95%CI 0.02–1.19, respectively).

Conclusion: PoD can partly be explained by the availability of and distance to health services. Most dementia deaths occurred in aged care which could be considered ‘home’. Rural hospitals act as substitute hospice and play an important role in rural end-of-life care. While encouraging efforts to increase the rate of home deaths one must not overlook increasing end-of-life resources in rural hospitals and aged care facilities.
Predictors of Length of Stay before Death in Nursing Homes – A Systematic Review

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Background: As the population ages, it is likely that the number of older adults admitted to nursing homes (NHs) will increase. NH residents are more likely to have multiple co-morbidities and have a greater use of healthcare services than older adults living in the community. It is unclear how length of stay in a NH varies between residents and across NH facilities.

Aims: This study aims to provide a comprehensive, up to date summary of published research exploring factors associated with the length of stay of older adult’s residing in NHs.

Methods: A systematic review of published, peer-reviewed and grey literature. Electronic searches were conducted using MEDLINE, EMBASE, PsycINFO, CINAHL, Proquest, the Cochrane Library, Web of Science, the Campbell Library, SCOPUS and Social Care Online. Papers were included if they were observational, epidemiological studies exploring the influence of at least two predictive variables on either length of stay before death or mortality in adults aged over 65 years residing in NHs.

Results: The electronic searches identified over 11,000 papers, of which 56 met the initial inclusion criteria. The findings suggest that increased age, being male, functional dependence in ADLs, cognitive impairment and urinary incontinence may be related to increased mortality. Contact with primary care services, hospital admissions, medication use, placement from hospitals and residence in facilities with nursing may also be associated with decreased survival.

Conclusions: The predictive characteristics identified could facilitate recognition of residents approaching end of life and inform treatment choices. Although the value of using length of stay as an indicator of quality of care is debatable, variation within and across NHs warrants further attention. Internationally comparable data collected by studies such as the PACE study could be used to further research in this area.
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Abstract type: Poster Exhibition

Atlas of Variation in End-of-Life Care for England – Largest of its Kind in the World

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Background: The first Compendium NHS Atlas of Healthcare Variation in England published in 2010 and updated with 101 indicators in 2015 showed wide variation in healthcare indicators. Specialist Atlases for example Liver Disease (2013, 2016) are available. The National End of Life Care Intelligence Network in England has published since 2010 National End of Life Care Profiles for Health and Local Government Administrative Districts showing wide geographical variation in every indicator. Almost half a million people die each year and one third of National Health Service costs are spent on care in the last year of life, so an Atlas of Variation in End of Life Care was considered to be a National Priority.

Methods: 30 indicators were selected for face validity, importance for patients, government, health services providers and commissioners of health and social care. Each indicator was compiled for the 209 local health (Clinical Commissioning Group (CCG)) areas where possible and alternative geographies otherwise, together with England as a whole. Statistical differences between local area and England values were calculated. Maps of England show statistical and absolute variation in indicators. Column charts show magnitude of variation across localities and box and whisker charts show trends in the England median value and extent of variation.

Results: Every one of the 30 indicators shows marked geographical variation: demographic characteristics, place and causes of death or median length of final admission to hospital. Trend data shows deaths in hospital reducing and the community increasing, age at death increasing and dementia related conditions as a cause of death increasing. Widening and narrowing of variation with time is seen across the indicators.

Conclusions: This is the biggest Atlas of its kind in the world. It will have a radical impact on National and Local policy maker’s ability to plan for and assess the quality of End of Life Care in England.
Variation in Numbers and Lengths of Hospital Admissions in the Last Months of Life by Local Health Administrations across England

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Background: The proportion of deaths which occur in Hospital in England has dropped from 57.9% in 2004 to 46.7% in 2015. However, hospital still remains an important place of death for almost half of all patients and of care in the last few months of life for at least 70%.

Aim: To examine the extent of variation in patterns of hospitalisation between health administrative areas across England in the last days of life.

Methods: Information on all deaths in England (2015) was extracted from a linked Hospital Episode Statistics (HES)–ONS Mortality database with their admission data. The England mean and median for each of 209 Clinical Commissioning Groups (CCG) – health administrations – in England were calculated as outcome measures:

a) % deaths with a hospital admission in final 90 days (F90D)
b) median length of hospital admissions ending in death – admitted during F90D,
c) % of hospital admissions ending in death of duration ≥8 days and
d) median number of days (nights) spent in hospital during final 180 day (F180D) of life.

Results: Each indicator showed substantial variation across CCGs.
a) On average 69.1% of decedents in England had a hospital admission in F90D but the CCG median varied from 44.2 to 76.4%:
b) Average number of days hospital admissions ending in death (F90D) for England 7.3, variation in CCG median 5.0–11.0 days;
c) England average for % final hospital admissions ≥8 days ending in death was 50.5%, variation in CCG median 36.3 to 63.4%;
d) The average number of days spent in hospital in F180D in England was 14.1 with variation in CCG median 8 to 20 days.

Conclusions: Most patients would prefer to spend less time in hospital and there may also be opportunities for cost savings. Large geographical differences in hospital use in the last days of life are found and may reflect demographics and/or quality and level of community end-of-life care provision. Comparisons of services and funding in ‘outlier’ areas could reveal models of high-quality care.
Determinants in the Place of Death for People with Different Cancer Types: A National Population-based study

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Abstract number: P01-413
Abstract type: Poster Exhibition

Background: Variations in place of cancer deaths have previously been reported in the context of country-specific health care organisation, but without differentiating between cancer types and national regional variations.

Aim: To examine, at a population level, where people with cancer diseases die, and to investigate associations of place of death and cancer type with individual, socioeconomic and geographical characteristics of the deceased.

Methods: The study is based on death certificate data and population register data (area of residence, degree of urbanisation, and health care region) of all 2012 cancer deaths in Sweden, with a registered place of death (hospital, nursing home, home, other). Descriptive analysis and multivariable logistic regression analyses were performed to analyse for associations between place of death and cancer types, and individual and environmental characteristics.

Results: Place of death varied among cancer types. Regional variations in cancer deaths occurring at home ranged from 17.1% to 28.4%. Factors associated with place of death by cancer type were age, educational attainment, marital status, health care regions and degree of urbanisation.

Conclusion: Large health care regional variations in place of death among different cancer types were found. Potential explanations might be week national palliative care policy, and absence of palliative care policy in cancer type specific guidelines.

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<th>Cancer Type</th>
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<th>Home %</th>
<th>Nursing home %</th>
<th>Other %</th>
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<td>20.8</td>
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[Place of death by cancer types]
Abstract number: P01-414
Abstract type: Poster Exhibition

**Palliative Care in Primary Care for People with Intellectual Disabilities in England – How Much Happens and how Much is Needed?**

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**Background:** It is estimated from school records that 2% of adults may have an Intellectual Disability (ID) but only 0.5% are flagged by Family doctors (GPs). People with IDs often die prematurely. They are often excluded from decision-making by misguided medical paternalism.

**Aims:** To compare provision of palliative care in primary care in England using data from Primary Care Electronic Record Systems for people with and without ID.

**Methods:** Data was obtained from general practice systems covering 28.9 million patients. 127,351 of these, (0.44%) were recorded as having ID. This represents just over 50% of the GP registered population in England. Records were searched for a ‘flag’ on the record for ID and for palliative care (PC) and causes of death.

**Results:** The crude rates for PC flags were almost double for people with a flag for ID 5.51 per 100k (95% CI 5.11–5.94) than for those without 2.99 (95% CI 2.97–3.01). People with ID receive GP PC at younger age: 40x more likely < 18 years, but even ≥75 people with ID are 1.6x more likely to have a PC flag. Rates of GP PC flags across England vary significantly and more for ID – directly standardised rate per 100k population – ID interquartile range 23–810 and Non-ID 140–242. 29% local health areas report nobody with ID with PC flag. Cancer is a less frequent cause of death for people with ID but congenital anomalies, neurological conditions, respiratory conditions and epilepsy are important.

**Conclusions:** This is the first national study providing direct comparison of GP PC provision to people with and without ID covering 50% of the population of England. People with ID are more likely to receive GP PC than those without. The GP system ID flag may be important to signal potential need for PC. The practical considerations in providing PC for people with ID and different causes of death mean GPs must plan specifically for this group. It is worrying that there is such a wide variation in GP PC provision across the country.
Variation in Place of Death for Leading Causes of Death, England 2015

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Background: Place of death is considered an important proxy quality marker of patient choice and quality of care. In England the proportion of deaths which are in hospital has reduced with corresponding increases in deaths at home or in care homes.

Aims: To highlight variation between leading causes and place of death, so that implications for end-of-life care can be considered in more detail.

Methods: Underlying cause of death was categorised using Office for National Statistics (ONS) leading causes of death. The proportion of deaths was calculated as a percentage by cause and place of death (Hospital, home, care home, hospice. elsewhere), for deaths registered in 2015.

Results: Hospital was the most common place of death for most (38 out of 50) leading causes of death. 21 cause groups had more than half of deaths in hospital. The highest proportions of hospital deaths included septicaemia (91%), accidental falls (81%), meningitis (80%), musculoskeletal diseases (74%), liver disease (70%), flu/pneumonia (69%), pulmonary oedema (65%), and urinary disease (65%). Lymphoid cancer (56%) had the highest proportion among cancers. Causes with the lowest proportions of hospital deaths included brain cancer (22%), dementia and Alzheimer’s (25%), Parkinson’s disease (31%), high blood pressure (36%), and systemic atrophies (central nervous system, 37%).

For some conditions amenable to end-of-life care, places other than hospital were most common. Care homes: dementia and Alzheimer’s (65%), Parkinson’s disease (52%), acute respiratory diseases (excluding flu/pneumonia; 45%). Home: high blood pressure (38%), pancreatic cancer (35%), brain cancer (34%) and bowel cancer (32%). 14 causes had more than 32% of deaths at home.

Conclusion and discussion: Planning for palliative and end-of-life care needs to take account of the variations by place and cause of death and take account of good practice across a range of specialisms.
**Abstract number:** P01-416  
**Abstract type:** Poster Exhibition

# Place of Death – Among Patients Dying from Chronic, Progressive Diseases. A Danish National Cohort Study

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**Background:** The proportion of deaths caused by progressing diseases is high in western countries. Knowledge of both causes and place of death are among the premises to optimize the organization of palliative care in the countries. Place of death, focusing on patients dying from chronic progressive diseases, at the national level, has to our knowledge not been presented previously.

**Aims:** To investigate how place of death is distributed among persons dying from chronic progressive diseases – and to analyze which factors may play a role for place of death.

**Methods:** A population based cohort study using the Danish national registry for causes of death during the period 2007–2011. All natural causes of death among persons aged 19+ were included (N=257,266) and categorized. Deaths, caused by non-malignant chronic progressive (progr) diseases (N=77,681) were analyzed and presented as adjusted odds-ratios (ORs) for deaths in hospital (DIH) with 95% confidence intervals.

**Results:** Among all deaths, 48% died in hospital. And 30% died from non-malignant chronic progr diseases, of whom 36% died in hospital. Using chronic heart disease (N=28,517) as reference, the ORs for DIH among chronic progr diseases ranged from 0.14[0.13;0.15] for dementia to 3.47[3.21;3.75] for chron.hepatic diseases. The OR for COPD (N=16,325) was 2.00[1.92;2.08] for DIH. Men had higher odds ratios for DIH, 1.21[1.18;1.26], and factors like geographical region and age also influenced the odds of dying.

**Conclusion and discussion:** Most patients dying from non-malignant chronic progressive diseases died outside the hospital. However, several factors significantly influenced place of death. Differences in the distribution of diseases, age and comorbidity entail different patient trajectories, among patients dying in hospital or outside. For the health care persons in the primary or secondary health care sectors, who must foresee and offer palliative care, this is likely to imply a need for different competencies.
Prevalence of Patients with Palliative Needs in the Wards of Portuguese Public Hospitals

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Introduction: The early referral to palliative care is one of the keys to the success of this care, to promote the best quality of life possible of patient and his family and to achieve the most important outcomes.

Aim: To determine the prevalence of patients with palliative need in the Portuguese public hospitals, from which how many are referenced to palliative care and if not what are the main reasons.

Methods: 32 physicians from 11 hospitals were asked about 1273 patients (≥18 years old) using the surprised question (Would you be surprised if your patient dead within the next year, 6 months, 30 and 15 days?); when the answer in at least one period was no, they were asked if the patient was referenced to palliative care and if not, they were invited to indicate 5 main reason from a list of 19. Exclusion criteria: patients in wards of pediatric, obstetrics, psychiatry, palliative care units and ER.

Results: The dead was expected within 1 year for 51.4% (prevalence of patients with palliative care needs), within 6 months for 38.3%, within 30 days for 22.3% and within 15 days for 16.1%. 67.2% of cancer patients, 48.7% of non-cancer patients and 45.5% of mixed disease have palliative care needs. Only 6.8% of the patients whose dead was expected within 1 year, 7.5%, 9.9% and 9.8% of those dead was expected within 6 months, 30 days and 15 days, were referred to palliative care. The 5 main reasons for not referral were: the patient is still actively treated to the disease, we still can treat (cure) the patient, the symptom control was achieved, the patient is not dying and the palliative care was not the best for the patient.

Conclusions: The general hospitals wards have a high prevalence of patients with palliative care needs but only a very few of them are referred to palliative care. More education of the physician in palliative care is needed to increase the proportion of patients referred ant to increase the early referral as one of the keys to success of health care.
Challenges in Integrating Supportive and Palliative Care in the Management of End-stage Liver Disease. A Mixed Methods Study of UK Hepatologists

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Introduction: Data from the England National VOICES study of bereaved relatives suggest that liver disease patients receive worse care compared to similar conditions at the end of life.

Aim: To assess current practices, attitudes, service provision, and barriers in the use of specialist palliative and supportive care (SPC) in the management of end stage liver disease in England.

Method: An online questionnaire to members of the British Association for the Study of the Liver and the British Society of Gastroenterology.

10 respondents were purposively selected for in depth qualitative interview based on their questionnaire responses to encompass a range of clinical settings, experience and attitudes. Transcripts were coded (open, axial, selective) and analysed using principles of grounded theory.

Results: 305 responses were analysed (33.6% response rate).

91.7% thought SPC interventions appropriate in severe decompensation and 90.4% in liver cancer. SPC referral was significantly more common for liver cancer compared to decompensated disease alone (75.9% vs 46.9% p < 0.05). In uncertain trajectory (e.g. recurrent severe alcoholic hepatitis), opinion was divided on concurrent SPC interventions. Only 26.8% believed integrated SPC to be suitable at the point of listing for transplantation. Lack of routine consideration, absence of evidence based models, uncertain trajectory of liver disease, and misperceptions regarding role of SPC were cited barriers for improvement. Different opinions between transplant and non-transplant centres were found. Qualitative analysis highlighted: importance of parallel palliative and active care; difficulties with the term “palliative”, importance of integrated services (hepatology, community, SPC); need for evidence based models; resource limitations.

Conclusion: Broader use of SPC in liver disease is limited by difficulties in managing an uncertain trajectory, a paucity of evidence based models of care, and misperceptions of SPC.
The Use of Subcutaneous Acetaminophen in the Palliative Care Units in France

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Background: The pain relief is one of the main missions of physicians, mainly in palliative care. The subcutaneous (SC) route allows the administration of painkillers when the other routes are not reliable, not available or not acceptable for the patient. Among the painkillers we can use by SC route, acetaminophen can’t be recommended because of the lack of validated reference, “even if some teams use it”. To know the reality of this practice, we have made a study about the use of SC acetaminophen in palliative care units (PCU) in France.

Aims: Main objective: knowing the prevalence of SC acetaminophen in the PCU in France.

Secondary objectives: knowing the feeling of practitioners about the effectiveness and side effects of SC acetaminophen; finding the determinants of its non-use.

Methods: A questionnaire was send to 131 physicians in charge of a PCU in France.

Results: We received 78 responses (60%).

Among the responders, 31 (40%) use SC acetaminophen, 28 (77%) using it several times a week.

Acetaminophen is used for analgesic and antipyretic effects, respectively by 29 (93%) and 25 (80%) of the responders. Almost 90% of them think that it is effective on these symptoms.

Eleven physicians (35%) say they have observed side effects, which occur rarely (less than once a week). These effects are: erythema, pain, swelling, warmth and itching.

Forty-seven physicians (60%) don’t use SC acetaminophen because of the lack of recommendation for 39 practitioners (80%) and fear of side effects for 24 (50%). But 41 physicians (85%) would be willing to use it if there was evidence of its effectiveness.

Conclusion: This study shows frequent use of SC acetaminophen in the PCU in France. Barriers to the use of SC acetaminophen are the fear of side effects, which seem infrequently reported, and the absence of recommendation because of the absence of literature to support this practice. Further studies are needed to document the efficacy and safety of SC acetaminophen.
Abstract number: P01-420
Abstract type: Poster Exhibition

Older People’s Preferences and Priorities for End-of-Life Care in the City of Belo Horizonte, MG, Brazil

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Background: Respect for personal preferences and priorities is a fundamental end-of-life care issue. This is especially important in a context of an ageing population dying with chronic life-limiting conditions.

Aims: To explore preferences and priorities for end-of-life care, within a scenario of serious illness with less than a year to live, among older people (≥ 60 years).

Methods: The Brazilian version of the PRISMA questionnaire was administered face-to-face to 400 older people living in the city of Belo Horizonte, MG, Brazil. Participants were recruited from 10 locations in order to include all regions in this city. Data were analysed using descriptive statistics.

Results: 74.0% of the participants reported that they would always want to know if they had limited time left. The three problems that concerned them the most were: being a burden to others (44.3%), being unable to get their breath (20.5%), and being in pain (20.0%). Most respondents preferred self-involvement in end-of-life decision-making when capable (95.3%) and self-involvement when incapable through, for example, a living will (64.5%). Keeping a positive attitude was the most important priority for participants (53.0%). When asked about what would matter most to them in the care available, 65.3% chose ‘improve quality of life for the time they had left’, while 46.0% selected “having as much information as you want”.

Conclusion: To our best knowledge, this is the first study investigating end-of-life preferences and priorities in Brazil. Results show that obtaining information, being involved in decision-making, keeping a positive attitude and improving quality of life are valued amongst this population, and that concerns about being a burden to others are common. We hope that the study results can help to inform new policies emphasising the need to respect end-of-life care preferences and priorities for the Brazilian population.
**Abstract number:** P01-421  
**Abstract type:** Poster Exhibition

### Analysis and Description of Procedures Applied to Advanced Chronic Patients in Need of Palliative Care, and Related Cost in a General Hospital

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**Aims:** General: To estimate the potential palliative care PC need during the last month of life for patients died in a general hospital. Specifics: 1) To quantify diagnostic and therapeutic procedures during hospital staying, 2) To estimate the cost of the procedures performed.

**Method:** Retrospective observational study. Patients died between January-April/15 with positive McNamara criteria were included. Medical recordings were reviewed collecting more than 35 variables related to the last month of life. The sample size required was 95 subjects (α = 0.05, β = 0.2). To estimate costs related diagnosis groups (RDG) were used relating directly to average prices.

**Outcomes:** 134 patients were identified and 119 met the inclusion criteria. Prevalence of PC need was 88.81%. Cancer diagnosis was the most frequent (141, 118.49%). 6.7% had been identified as a palliative patient and 26.1% were under “therapeutic effort limitation”. In general, we identified: 165 emergency room visits, 73 outpatient visits, and 23 surgeries. Globally, 147 admissions were performed, meaning 1007 days of hospitalization plus 61 days in intensive care unit. The average RGD ‘weight’ was 2,779 ± 1,599, assuming an average cost of 4570,072 €

**Conclusions:** This study shows a high prevalence of PC needs in a general hospital. Which means that a large majority of patients with PC needs are not identified and treated as such. Procedures performed to these patients follow the same pattern that those we use for acute illnesses, which drives to a high cost for the healthcare system. Deep changes in organizational culture regarding the adequacy of interventions is an imperative task to do.
Abstract number: P01-422
Abstract type: Poster Exhibition

**Place of Death is Associated with Socioeconomic Status for Patients Known to Hospice Services**

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**Background:** Place of death is a priority to patients and relatives at the end of life with most choosing to be cared for at home. Despite this, 58% of Scottish deaths in 2015 occurred in hospital. Studies of people with cancer suggest that those living in deprivation are less likely to die at home.

**Aim:** To describe the relationship between place of death and socioeconomic status for all patients (cancer and non-cancer) known to a hospice over a 5-year period.

**Method:** Scottish Index of Multiple Deprivation (SIMD, 2016) was used to group patients according to socioeconomic status. Place of death was examined for each SIMD deprivation quintile (DQ). Deaths where location was unknown or in a nursing home were excluded.

**Results:** Of 4585 patient deaths 41% died at home, 40% in the hospice and 19% in hospital. Over half the patients (54%) were from SIMD 1 (most deprived) compared with 18% from SIMD 5 (least deprived). Deaths at home were lowest in the most affluent group (33%) compared with 41% in SIMD 1. Hospital deaths accounted for 21% of all deaths in SIMD 1 compared with 16% in SIMD 5. There was a highly significant direct relationship between DQ and the proportion of patients dying in the hospice. There was an inverse correlation between DQ and the proportion dying in hospital (P=0.0002, Chi squared test for trend).

**Conclusion:** Overall, this study demonstrates that patients from more deprived areas, who are known to the hospice, are still more likely to die in hospital than their more affluent counterparts, who are more likely to die in the hospice. This is potentially inequitable, does not necessarily reflect need and has resource implications. There were also fewer home deaths in the most affluent group which could suggest less family support. Further investigation is required to explore reasons for admission, anticipatory care planning in SIMD groups and characteristics of, and reasons for, families achieving home death.
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Abstract type: Poster Exhibition

End-of-Life Care for Problem Substance Users: A Hidden Exclusion?

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People with non-cancer diagnoses, mental illness and social exclusion face substantial barriers in accessing palliative care. With alcohol-related deaths at 5% of all deaths and drug-related deaths at their highest level, reliable data on these populations are needed for effective palliative care development.

As part of a larger UK Big Lottery Fund project, this research explores prevalence and incidence of palliative care among people using alcohol or drugs. By examining existing data, this research explores the associations between substance use and premature mortality, and identifies crucial gaps in the knowledge base.

The study comprised two main strands. First: a review of accessible databases relating to palliative care and alcohol/drug use. Second: investigation of how current data could be enhanced to improve knowledge of palliative care and substance use; making recommendations for future database development to better inform policy and service development.

The study identifies that ICD10 diagnostic criteria do not facilitate identification of substance-using patients. Whilst alcohol-related deaths are visible, drug users are ‘hidden’ in the data. End of life care and causes of death data suggest that palliative care exclusion has more clinical than social reasons, although an exception to this may be end-stage liver failure which is mostly managed in hospital.

This is the first known UK report exploring existing data on end-of-life care for people using alcohol and drugs. Without robust prevalence and incidence data, it is impossible to plan effective service development, yet our findings suggest that poor data availability, over-reliance on medical diagnoses and poor reporting prevent identification of cases in UK health surveillance sources. However, there are clear options for improving surveillance of end-of-life care provision for disadvantaged groups.
Building Research Leadership and Capacity to Address the Public Health Need for Palliative Care

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**Background:** The growing demand for evidence to address significant public health issues including ageing populations, changing patterns in chronic diseases, and individuals living longer with life-limiting conditions requires the availability of high quality and clinically relevant research and a critical mass of experienced researchers and leaders. The Palliative Care Research Network, which is led by the All Ireland Institute of Hospice and Palliative Care (AIIHPC), represents a significant investment by the Irish Health Research Board and Northern Ireland’s Public Health Agency (Research & Development Division) to develop and support research leadership and capacity building in palliative care on the island of Ireland.

**Aim:** Capacity building is a major component of large national and international funding schemes that seek to enhance and develop research expertise and leadership in specific health areas, for example, Horizon 2020 and the Canadian Institute of Health Research. The current paper sets out to describe some of the highlights and challenges in supporting research leadership and capacity building in palliative care, drawing on examples from the Palliative Care Research Network in addition to the international literature.

**Method:** This paper is based on a review of the research leadership and capacity building activities and experiences in palliative care on the island of Ireland, situating it within an international context.

**Conclusion:** AIIHPC’s Palliative Care Research Network is taking forward a multi-tiered approach to research capacity building and leadership which is in line with international models of best practice that seek to make substantial progress in the quality of palliative care research.
Survey of End-of-Life and Terminal Care in Nursing Facilities in Rural Area in Japan

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**Background:** Although more end-of-life care will need to be provided in nursing facilities in the future, no surveys of end-of-life and terminal care in those facilities in Tagawa county, which is a rural area, have been conducted yet.

**Purpose:** Conduct a field study on end-of-life and terminal care in nursing facilities in Tagawa county so that we, as a regional hub hospital, can evaluate what should be done to increase terminal care in these facilities.

**Method:** The questionnaire sent to nursing facilities included yes-no questions about whether the facility was willing to commit to end-of-life and terminal care, if it provides training for such care, if drip infusions and medical narcotics are available in the facility, as well as questions to identify areas of concern if terminal care were to be provided in the facility. Analysis: The results were divided into two groups depending on whether or not terminal care was provided in the facility, and the chi-square test was performed to compare the two groups in terms of availability of

1) Drip infusion availability in the facility
2) Medical narcotics in the facility
3) Willingness to provide end-of-life and terminal care
4) Availability of education and training for end-of-life care.

**Result:**
1) Availability of drip infusion in the facility and willingness to actively promote end-of-life and terminal care were significantly associated with the provision of end-of-life care in the facility.
2) Care takers in these facilities have limited knowledge or experience regarding terminal care.

They have few opportunities to study such care. However, they are willing and eager to participate in educational training on end-of-life and terminal care.

**Conclusion:** The nursing care facilities have a strong desire to actively participate in educational training on end-of-life and terminal care, and we, as the regional hub hospital, should consider conducting regular educational training on terminal care for caregivers in Tagawa county.

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Aims: To determine the extent to which members of the general population have talked to their physician about their wishes regarding medical treatment at the end of life, to describe the prevalence of advance directives on euthanasia, and to identify associated factors.

Method: This study used data from the cross-sectional Health Interview Study (HIS) 2008 that collected data from a representative sample (N = 9651) of the Belgian population.

Results: Of all respondents, 4.4 % had spoken to their physician about their wishes regarding medical treatment at the end of life, while 1.8 % had an advance directive on euthanasia. Factors positively associated with discussions regarding wishes for medical treatment at the end of life were being female, being older in age, having poorer health status and having more GP contacts. People older than 55 years and living in Flanders or Brussels were more likely than the youngest age categories to have an advance directive on euthanasia.

Conclusion: Younger people, men, people living in the Walloon region of Belgium, people without a longstanding illness, chronic condition or disability and people with few GP contacts could represent a target group for education regarding advance care planning. Public information campaigns and education of physicians may help to enable the public and physicians to engage more in advance care planning.
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**Abstract type:** Poster Exhibition

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## Life Sustaining Treatments Preferences of Healthy Adults in Slovenia

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### Background:  
Research has shown that living will for non/treatment of advance chronic disease at the end of life can improve the care of patients, when they can no longer make decisions.

### Aims:  
The purpose of research is to find out the preferences of healthy adults about life-sustaining treatments in Slovenia.

### Methods:  
A quantitative research with interviews has been completed. The paper presents the levels of agreement/disagreement with six life-sustaining treatments in current and three poor-health hypothetical states. Correlation of interviewees preferences was determined with a t-test, at confidence level of 5 % ($p < 0.05$).

### Results:  
The 695 interviewees come from all regions of Slovenia. 59 % are women, 56 % are 18 to 59 years old, 44 % are older than 60. On average the interviewees agree with all life-sustaining treatments, particularly with resuscitation and dialysis. For all uncertain cases public agrees on less invasive antibiotic treatment and short term mechanical ventilation. Statistically, the most important treatment with all uncertain cases is resuscitation, which is preferred mostly among men, younger than 59 and without children. In the current medical state, short and long term mechanical ventilation is preferred by more educated interviewees, while resuscitation and long term mechanical ventilation is preferred by those who are more familiar with palliative care.

### Discussion:  
Decisions for life-sustaining treatments at the end of life are frequent in healthy adult population of Slovenia. This may be attributed to not being familiar with palliative care, practice and prognosis at the end of life treatments. Discussions about advance decisions or living wills should be part of the routine health care.

### Keywords:  
Living will, care at the end of life, decision-making
Use of Antibiotics in the Last Week of Life in a Palliative Care Unit: Retrospective Study of 6 Months of Activity

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Introduction: Palliative care (PC) patients have higher infection risk causing symptom decontrol, due to immunosuppression, dependency and lower performance status.

Aim: Analyse antibiotics (ATB) use in the last week of life in a PC unit.

Methods: Retrospective study of all deceased patients in a PC unit from January 15 to June 15. Data of all patients to whom ATB was prescribed in the last week of life was collected from the file and analysed.

Results: 106 patients were analysed, 31 received ATB in the last week of life (29.2%). There was male predominance (54.8%), mean age of 80.2 years and 54.8% were oncologic. Mean hospital stay of 11 days, mainly admitted from home (77.4%) with high dependency index (Barthel< 30: 41.9%) and low performance status (Karnofsky< 50: 52.9%). Symptom control was the most common admission motive (71.0%), with infection assumed as direct cause (61.29%). 24.8% patients were on ATB on admission. Respiratory (51.6%) and urinary (22.6%) infections were more frequent. Cephalosporins (54.8%) and quinolones (25.8%) were more commonly used. Subcutaneous route was the most frequent. Mean time of ATB course was 6.4 days, mostly empirical (93.5%). Microbiology tests were undertaken in 11 patients (35.5%) with 6 testing positive (54.6%). ATB was suspended in 2 patients. Patients who died in the first 3 days after admission in 81.5% weren’t prescribed ATB. In the last 24 hours of life 17 patients (54.8%) were given ATB subcutaneously.

Conclusion: The decision to start, suspend or not initiate ATB is difficult, with no guidelines in PC to help guide this decision. Infections are one of the most common causes of symptom decontrol with widespread prescription of ATB, despite the risk of adverse effects and increased antimicrobial resistance. Hence, there is an obvious need to adjust measures in end-of-life care. Therefore we aim to analyse a larger period of data, to design an ATB prescription protocol for our PC unit as a measure of symptom control.
The Meaning of Death & Dying for Spanish Firemen: A Curriculum Development Study

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Background: Little is known about the needs and resources firemen to face when they confront death and dying (D&D) in their daily work. Few suggestions are reported to educate firemen for coping with D&D.

Aim: The aim of this study was to develop a curriculum to support D&D issues for firemen.

Methodology: A qualitative methodology involving focus groups was conducted in two fire stations in Spain. All participants were male. The total sample was 38 with a median age of 46.5 y.o (range: 30–59 years) with a median tenure of employment of 17.5 years (range: 6–35 years). Data were subjected to a thematic analysis. Analysis was enhanced by dual coding of the transcripts in addition to member checking.

Results: 9 themes were emerged:
1) Witnessing D&D;
2) Memories about D&D;
3) Impact on firemen’s family;
4) Decision-making process under stress;
5) Teamwork;
6) Inadequate D&D preparation and training;
7) Adequate technical & training preparation;
8) Relationship between equipment, legal-moral obligation and victim’s consequence;
9) Communication issues: to the victim and/or relative’s victim. Those themes were framed in three basic domains: 1) Personal impact of D&D;
2) Team impact of D&D;
3) Victim impact. Each domain, in its turn, is covered by 3 topics.

The curriculum’s pedagogy is mostly based on experimental and reflective activities during 16 study hours.

Conclusion: We identify that a substantial need for education regarding death and dying issues for firemen. To this end, a broad outline of a curriculum is suggested based upon the needs experienced and described by the firemen participating in this study.
How Acceptable and Appropriate are the Hospital Anxiety and Depression Scale and the Quality of Communication Questionnaire to Palliative Care Patients and Caregivers in the UK? Cautions from a Cognitive Interview Study

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Background: Few evaluations of palliative and end-of-life care (PEoLC) communication skills training examine the impact on patients and informal caregivers. Those doing so often use diverse measures which although psychometrically validated have not been explored in depth in the target population. Critical examination of measurement tools is essential to inform future studies aimed at improving care.

Aims: To explore the acceptability and appropriateness of patient- and family-completed questionnaires used to test the impact of PEoLC communication skills training.

Methods: Cognitive interviews explored two questionnaires: the UK-developed Hospital Anxiety and Depression Scale (HADS) and US-developed Quality of Communication Questionnaire (QoCQ). These tools have previously been identified as relevant to PEoLC communication skills training via a systematic review, but have not been explored with UK palliative care patients and caregivers. Acceptability and appropriateness was assessed across four areas of processing: comprehension, retrieval, judgement, and response; plus potential for distress and user-friendliness. Framework Analysis was used, with attention to non-confirmatory cases.

Results: Participants comprised 8 patients with advanced disease, 9 caregivers of patients with advanced disease, and 2 bereaved caregivers. Although generally acceptable, some HADS items were deemed particularly sensitive in the context of advanced disease (eg. “I get a sort of frightened feeling as if something awful is about to happen”). When completing the QoCQ, some items were conflated with one another. Crucially, assigning the lowest possible score to ‘the clinician didn’t do this’ on the QoCQ did not account for individual preferences to not discuss some topics.

Conclusion: Researchers and clinicians must be aware of specific sensitivities if using the HADS, and the need for substantial revisions to the QoCQ questionnaire for this purpose.

Funding: Health Education South London
Recruitment to Palliative Care Studies – How Many Are Approached and how Many Consent?

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Background: Recruitment to palliative care studies is challenging. Eligible patients may not be invited due to ‘gatekeeping’, and even if invited, may decline if concerned about high research burden.

Aim: To compare screening and recruitment rates across three palliative care studies with varying amounts of participant research activity.

Methods: Analysis of the research study screening and recruitment logs for three studies conducted in the hospital setting who were receiving palliative care. Variables included numbers of eligible patients, numbers approached, and numbers consented, including reasons for decline. All three studies required patients to give informed written consent but each varied in the amount of research activity involved.

Results:
Study 1: low intensity with little research activity (collection of research data by staff proxies). 967 patients were eligible of these 26% (n=248) were approached. Of these, 248 potential participants, 97% (n=241) were recruited.

Study 2: medium intensity with completion by participants of two questionnaires (3–7 pages) at two time points, 3–5 days apart. 153 patients were eligible of these 46% (n=70) were approached. Of these, 70 potential participants, 51% (n=36) were recruited.

Study 3: high intensity with completion by participants of four questionnaires (6–7 pages) at four time points (each 3–5 days apart). 88 patients were eligible of these 38% (n=33) were approached. Of these, 33 participants, 39% (n=13) were recruited.

Conclusion: This review of three palliative care studies with varying research burden shows that less than 1 in 2 (sometimes as low as 1 in 4) eligible patients are approached for research. Recruitment rate then varies markedly by research burden; while almost all can be recruited to low intensity studies, only 1 in 3 are recruited to studies with high intensity.
Comparative Study of Competence Profiling in Health Care

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Introduction: This research analyzes the extent to which existing procedures contribute to the determination of the different levels of competence facing death in health care providers.

By assigning profiles to different groups based on their manifest skills can help to define the variables that affect their daily practice and facilitate the implementation of training plans and corrective actions. For this purpose, the results obtained by two commonly used classification techniques in unsupervised learning are compared: K-means clustering and Self Organized Maps

Goals: Perform a comparative study of the effectiveness of two different approaches at determining the degree of competence facing death of a sample of health care providers.

Methodology: Quantitative study. A survey using the Collet-Lester and Bugen questionnaires is conducted to 116 health professionals from different levels of assistance. Statistical analysis performed using Weka and PASW 20 software for Windows.

Results: Both K-means procedure and Self-Organized map technique are executed over the same sample of data, but shifting the values of the parameters: number of clusters, neurons per level, learning rates and distance function. The percentage of instances in every group, average distance and variance to the centroids and also the intergroup distance are compared. Finally the plot analysis of clusters and bias found are reported.

Conclusions: Main advantages and drawbacks to define competence facing death when using self-organizing maps against the k-means approach are shown.
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Methodology for Double-blind Placebo-controlled Research in Hospices: Challenge or Feasible Procedure?

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Death rattle (DR) occurs in about half of the patients in the dying phase. Relatives often experience this as disturbing. Anticholinergics are recommended to treat DR, although there is no evidence for the effect of these drugs. Whereas anticholinergics do not affect existing mucus, it may be effective when given preventively. We designed a study to test this hypothesis in patients admitted in a hospice. We describe how we followed the medical-ethical rules for this frail patient population. We designed a randomized double-blind, placebo-controlled, multi-center study. Inclusion criteria:

- admission in one of four hospices,
- patient knows he is dying,
- life expectancy is at least 3 days,
- clear consciousness at the moment of being informed and signing informed consent.

Patients will receive the study medication (SM) from the start of the dying phase. The SM will be administered until death or until the occurrence of DR, which is defined as grade ≥ 2 according to the scale of Back. Ethical rules for good research involve several bottlenecks when carrying out a study like this. One of these is the informed consent procedure. We choose for “advanced consent”. Actual participation starts at the start of the dying phase. Randomization occurs at the moment participation starts. We further considered the extent to which participation in a medication trial during the dying phase may affect patients’ quality of dying. We integrated the protocol for the study in the standard operating procedures of care of the participating hospices. This is a double-blind placebo-controlled studies conducted in hospices. Legal and medical-ethical requirements for clinical trials are extensive and rigorous. A translation into hospice practice was challenging but seems manageable. Literature suggests several ethical and organizational strategies for research with vulnerable patients. Applying these strategies make robust research in end-of-life care, although complicated, feasible.
How to Study ‘Persons with a Migrant Background’ – Lessons Learned from a Qualitative Study

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Background: To explore the views, concerns, and preferences of palliative care patients regarding end-of-life care, a qualitative interview study was performed.

Aim: To clarify the challenges of research in patients with migration background, findings from a methodological/theoretical point of view are presented.

Methods: Two-armed study using open interviews without a structured manual, grounded theory approach including field and research notes (rich data). Both migrant and non-migrant adult patients receiving palliative care in Upper Bavaria were included. Data was organised and thematically analysed using MaxQDA 12 software.

Results: Of 36 interviewees, 17 had a migration background. Regarding methodology, the findings included:
(a) Non-structured, open interviewing technique revealed the lack of knowledge about a ‘palliative care’ concept.
(b) Thematic description of rich data (as opposed to analytical categorization) was able to uncover information hidden by language use. While openly addressing issues of ‘death and dying’, patients were deeply reluctant to talk about ‘end of life’ which implied fear of suffering, being a burden, and loss of autonomy.
(c) For historical and biographical reasons, it was difficult to discriminate between migrants and non-migrants if typical ‘migrant’ features were absent.
(d) Only by deliberate inclusion of both migrants and non-migrants it was possible to detect considerable overlap of views and concerns across the entire cohort.

Conclusion: Careful selection of research methodology is critical to avoid creation of culture-bound myths about migrants being ‘special people with special needs’. The grounded theory approach used here revealed knowledge gaps regarding palliative care on behalf of the patients, emergence of non-observable topics such as ‘end of life’, and poor discrimination of migrant status. These findings should alert health care professionals of topics that are not directly addressed by patients.
Use of Photovoice Methodology to Explore Household Wellbeing, Costs and Experiences of Palliative Care in Blantyre, Malawi: Experiences and Lessons Learned

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Background: Photovoice is a participatory photo-elicitation methodology first described by Wang and Burris in the late 1990s. It utilises the collection of photographic material by people from affected vulnerable communities which is used to promote critical dialogue. There are a variety of ways that Photovoice maybe utilised in palliative care settings.

Aims: The aim of the study was to describe patient and family understanding of wellbeing and the contribution of palliative care following a diagnosis of advanced cancer in Blantyre, Malawi (Central Southern Africa).

Methods: Over a period of five weeks, nine households (in which a patient was living with advanced cancer) were invited to participate in a series of seven group sessions. They were trained in the use of cameras, introduced to concepts of visual literacy and invited to gather photographs which depicted aspects of their daily lives. Prompts were used during subsequent group sessions to facilitate a process of critical dialogue. Participants were provided with hard copies of their photographs which they grouped into thematic areas. Themes subsequently identified from analysis of transcriptions of audio recordings of group sessions were shared with participants. Finally photographs were chosen and captioned by participants to be displayed at a national event to which a key stakeholder audience was invited.

Results: We will discuss and outline our experiences with Photovoice (data collection is currently underway) to provide insight and direction to those in other settings interested to utilise this methodology for palliative care research and advocacy.

Conclusion and discussion: Over recent years there has been an increase in use of Photovoice methodology across a variety of language, cultural and subject areas. It is suitable for use in marginalised communities, and maybe considered for use in palliative care populations particularly in settings of low literacy. Experiences and lessons learned will be shared.
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Building a Comparative Qualitative Evidence Base of Palliative Care (PC) Within and Across Countries

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Global organisations as WHO and WHPCA and regional organisations as EAPC and APCA have set up general goals for the development of PC; policy making, availability of services at all levels (including technologies, with a focus on drugs), education, research based documentation and funding. There is a global agreement, that more evidence is needed. There is also an agreement on taking into account the cultural, social and economic context of each and every PC setting, community, country and region.

The main purpose is to contribute to a comparative qualitative evidence base of PC within and across selected settings and countries, by:

1. Describing the societal frame for the development of PC in (three countries, in three regions (Europe, Asia and Africa)
2. Exploring the care and the perspectives of people (patients, relatives and staff) involved in the local PC in (for a start) two countries

1. A descriptive meta level, building on a scope review, documents, interviews with stakeholders and a theoretical framework
2. An explorative meso- and micro level, building on ethnographical methods, observations and interviews

The main results of part 1 and the plans for part 2 will be presented at the conference.
Development of a Data Extraction Form for the Review of Hospital Medical Records in Six European Countries. The EU FP-7 Funded International ACTION Study on Advance Care Planning


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Background: The extent to which care adequately addresses patients’ preferences and the reduction of healthcare costs are two important, yet difficult to measure, outcomes of advance care planning (ACP). The ACTION study is a cluster-randomised clinical trial (CRCT) in 22 hospitals in six European countries which aims to study whether the Respecting Choices ACP programme improves quality of life and symptoms of patients with advanced cancer. As part of the study, hospital medical records are being reviewed one year post-inclusion to assess:

1) the effect of the ACP programme on the extent to which care as received is aligned with patients’ documented preferences; and

2) the cost-effectiveness of the programme. A standardised extraction form for the review of medical records needed to be developed.

Methods: A draft extraction form was developed based on a literature review. Face validity was assessed by the international consortium. A feasibility study was undertaken by collecting data from medical records regarding the 12-month period prior to the death of a lung and a colorectal cancer patient in 14 participating hospitals. Informed consent was sought from patients’ relatives.

Results: After the feasibility study, the form was adapted where necessary (e.g. instructions were improved, wording and structure were refined, answering options were added). The final form takes about half an hour to complete and consists of 30 items regarding survival, date and place of death, presence and content of advance directives, assignment of a proxy decision-maker, physician orders for treatment, diagnostic procedures and treatment received, hospitalisations, and specialist palliative care. The form is currently being used in all participating hospitals.

Conclusion: Within the context of the CRCT, the medical record extraction form will enable us to compare the outcomes of the intervention and control arm and to generate valid conclusions about the intervention’s effectiveness.
Recruiting Family Caregivers to a Randomized Controlled Trial via Patients in Palliative Home Care – The Experiences of Health Care Professionals

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Background: Randomized controlled trials (RCT) are considered the safest way to build evidence on intervention effectiveness. In palliative care, recruitment problems to RCT’s have been frequent. Health care professionals (HCP’s) are usually responsible for recruiting eligible participants to trials and hence their experiences could be very important to explore in order to meet the need for future evidence based interventions in palliative care.

Aim: To study how HCP’s experienced recruiting family caregivers to an RCT via patients in palliative home care.

Methods: Data was collected from an ongoing psycho-educational intervention trial where patients and family caregivers were recruited by HCP’s. The intervention was designed for family caregivers and patients were not included in active data collection. However, patients were asked for their consent and to nominate family caregivers for the trial. Thus, the recruitment process included two steps, recruiting patients and recruiting family caregivers. HCP’s from the trial were invited to group, couple and individual interviews about their experiences of recruiting participants.

Results: Recruiting to the RCT was considered challenging by the HCP’s and going via the patient was something that made it more complicated. The patients often acted as gatekeepers towards the family caregivers and felt that they should not be burdened. Informing patients and family caregivers about the trial design with allocation to one of two arms was also viewed as complicated and could lead to misinterpretations. The HCP’s found that recruiting was a process and that collaboration with researchers and other HCP’s made it possible to develop strategies on how to approach patients and family caregivers with the invitation to the trial.

Conclusion: To avoid recruiting problems in future RCT’s in palliative care, HCP’s could be in need of more information and education prior to commencement of the trial.
The KINDLE Project: Identifying Key Themes and Messages from the Palliative Care Research Network (PCRN)

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Background: Research networks that facilitate collaborative research are increasing both regionally and globally and such collaborations contribute greatly to knowledge transfer particularly in health research. The All Ireland Institute of Hospice and Palliative Care’s (AIHPC’s) Palliative Care Research Network (PCRN) seeks to support and promote research collaboration and innovation to inform policy and practice in this area both nationally and internationally.

Aim: The current study aimed to identify cross-cutting messages which indicate how dissemination outputs can be optimised, to ensure that key messages and shared learning from palliative care research reaches all knowledge users.

Method: A thematic synthesis was carried out to identify higher-order themes from a body of dissemination products generated by the projects in the PCRN (N = 25). A series of reflection groups with key stakeholders provided further interpretation of the themes identified.

Results: The dissemination output (N = 142) included in the analysis ranged from peer-reviewed papers, conference presentations, published abstracts, poster presentations, policy briefs, social media posts, and published reports. The complexities of conducting palliative care research, the need for support for caregivers, inequalities related to service provision, and the importance of collaboration in this field were some of the themes that emerged from the research.

Conclusion: The messages identified encompass a range of issues that are relevant to palliative care highlighting the greater potential impact of this project for research, education, and policy and practice. A diverse dissemination plan will maximise the impact of the KINDLE project as well as the projects within the PCRN and will ensure that these messages reach all relevant stakeholders.

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# Beyond the Questions – Shared Experiences of Palliative and End-of-Life Care

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**Background:** The Palliative and end of life care Priority Setting Partnership (peolcPSP) aimed to collect the unanswered interventional questions which mattered most to carers, healthcare and social professionals and people in the last years of life using the James Lind Alliance (JLA) methodology. It became clear early in the process that not all of the survey responses could be translated into questions which might be answered by interventions. Many people described their experiences and raised more general questions, such as about the purpose of palliative care.

**Aim:** In this project we present the findings of a thematic analysis of the raw data collected during the PeolcPSP. This ‘out-of-scope’ analysis was conducted with the aim to recognise the broader non-interventional questions raised by people at the end of life.

**Method:** This project thematically analysed the data to supplement the standard James Lind Alliance methodology for identifying all emerging themes from the palliative and end-of-life survey responses. Direct quotes from the survey responses steered the project, with all 1,403 responses grouped into categories, illustrating the themes that were raised repeatedly.

**Results:** The thematic analysis generated six themes, of which five received interventional questions. The only theme not to receive interventional questions was “perception of palliative care” which asked about the purpose of palliative care and the terminology; the difficult topics of assisted dying; and whether it is right to use aggressive or ineffective treatments at the end of life. Many of these issues would be answered best by research that is conducted by social scientists, to understand more about how we can improve the experience of death and dying for all.

**Conclusions:** This thematic analysis highlighted that besides more interventional research, more social science research is also needed in specific areas.
How to Get your Hospice through an MHRA Inspection

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Background: There is increasing recognition that hospices (Specialist Palliative Care Units – SPCUs) should be conducting research. SPCUs need to comply with several regulatory requirements for research to happen safely and legally. If a SPCU is participating in a drug trial, they could potentially be inspected by the Medicines and Healthcare products Regulatory Agency (MHRA) for compliance with UK clinical trials regulations. The MHRA is a government body responsible for protecting and improving public health. Following an inspection, the MHRA provide a detailed summary of findings to the sponsor and site. In the unusual event of critical findings (the most serious) this could lead to the suspension or termination of the study’s Clinical Trial Authorisation and this may have implications for future trials involving the site and sponsor.

Aims: We present tips on how your site can have a successful MHRA inspection.

Methods: Written collaboratively with the MHRA, sponsor pharmaceutical company and local NHS Trust Research and Development Support Service, the inspection process is outlined from the initial notification of inspection through to post inspection feedback and reflection. A range of systems and strategies are discussed to help prepare for and run a successful inspection.

Results: We will discuss our experiences under the following headings:
• Preparation
• Study staff interviews
• Closing meeting, findings and reflection

Conclusion: The inspection process provided useful learning for our SPCU. We hope that our experience can help other SPCUs to have successful inspections.
Some Aspects of Burnout Detection among Palliative Care Medical Workers

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Background: Providers of palliative care (PC) often suffer from burnout. It leads to reducing efficiency and quality of work, increasing conflicts in the workplace and staff turnover. So it is important to early detect burnout in order to prevent its outcomes.

Aims: To establish burnout of PC medical staff, and to develop easy screening technology.

Methods: There were interviewed 389 medical workers of various health care facilities in Ivano-Frankivsk who had different degree of contact with incurable patients (regular – 211, periodic – 111, and rare – 67). Our questionnaire had 2 parts: valid questionnaire of V. Boyko (adapted K. Maslach method) for burnout evaluation, and questionnaire on various medical and social factors.

Results: More than half (54.0±2.5%) surveyed health care workers suffered on burnout, including high (7.7±1.4%) and critical (9.0±1.5%) levels. It was found that valid questionnaire is difficult for self evaluation. That’s why we were going to develop much easier screening technology. It was identified some factors of social and psychological desadaptation (e.g. complaints of constant stress, divorce, alcohol abuse etc.) which were significantly in 1.5–7 times more spread among medical staff with high and critical levels of burnout vs. ones without one. On base of our research outcomes screening technology was developed. It fully meets the screening criteria of WHO, has sufficient sensitivity (69.2%), high specificity (87.4%) and good quality according ROC-analysis (AUC=0.81±0.05).

Conclusion: Developing screening technology should be recommended for health care workers for self diagnosis burnout and monitoring its level among the staff by managers.
Scoping Review (ScR) Methodology: Definitional Issues in a Review of Delirium in Palliative Care (PC) Settings

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**Background:** A published analytic framework of delirium in PC with related research questions identified the need for a ScR of published literature. ScRs represent a novel approach to mapping the landscape of published literature, often on broad topics, thus helping to determine knowledge gaps and the potential (based on the volume and nature of literature) for systematic reviews on more specific aspects or questions.

**Aims:** To report definitional issues in the screening phase of a ScR to determine the scope and nature of the scientific literature on the assessment, management, outcomes and impact of delirium in PC.

**Methods:** A search strategy involving an information specialist was conducted across multiple databases. Multiple synonyms for “delirium” and “palliative care” terms were used.

**Results:** Of 2463 records in our initial search, 237 were included at Level 1 (title & abstract) and 68 at Level 2 (full text) screening. Initial broad screening definitions required modification because data heterogeneity posed the risk of an ultimately major compromise in meaningful interpretation. First, given the expanding remit of PC, we only included studies of subjects who received PC service input, thus excluding many studies, e.g. those that contributed to the rapidly expanding knowledge base on delirium in critical care. Second, due to ambiguity in reported delirium terminology and the need for rigour, we only included studies in which delirium was diagnosed using Diagnostic and Statistics Manual (DSM) criteria or a score on a validated delirium assessment tool, thus excluding, e.g. studies of hepatic encephalopathy, in which non-psychiatric definitions were used.

**Conclusions:** In conducting a ScR on delirium in PC, major definitional challenges exist due to the expanding scope of PC service settings and the variability of reported delirium terminology. Flexibility in ScR methodology allowed adjustment of the review’s scope to address these definitional challenges.
Coping with Death and Quality of Life in Palliative Care Team Members in Argentina (GEISER Study)

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**Background:** Palliative care team members (PCTM) are frequently exposed to emotional distress in relation with the end-of life care they provide. Coping with death and professional self-care has been recognized as relevant issues in research and education in palliative care setting.

**Aims:** To evaluate the levels of professionals’ coping with death and professional quality of life in a sample of PCTM working in Argentina.

**Design and methods:** The study was performed by leaders of GEISER group: it is a cross-sectional study based on an online survey completed by palliative care professionals in Argentina. Survey included demographic data and personal and professional scales on several constructs related coping with death (Buben scale), self-care, self-awareness and professional quality of life (ProQOL scale version IV, with subscales of compassion satisfaction, compassion fatigue, and burn-out).

**Results:** From 491 professionals invited to participate, 271 (55%) responded the survey (F:M=8:2), they were mainly physicians (50%), psychologists (16%) and nurses (14%). With a maximum possible score of 210, the study showed appropriate levels of coping with death (mean 158, SD 24). We found low levels of compassion satisfaction in 63% PCHM, and low to medium levels of burn-out in 90% and compassion fatigue in 81% of PCHM.

**Conclusions:** This survey shows appropriate levels of coping with death in palliative care professionals in Argentina. Self-care strategies are recognized as important factors preventing risks associated with low quality of life in professionals working on palliative care, such as compassion fatigue and burn-out.

**Main sources:** This work was supported by a grant provided by the National Cancer Institute (Buenos Aires).
Bereaved Relatives’ Perception of Emotional and Spiritual Support Provided at the End of Life – Results from Post-bereavement Interviews in a Restructured Hospital in Singapore

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Background: Provision of emotional and spiritual support is integral in palliative care (PC) and at the end-of-life (EOL), where focus is on holistic care to reduce suffering beyond physical symptoms.

Aim: To understand bereaved relatives’ (BR) perceptions of care provided at the EOL.

Methods: 15 consenting BRs were phone-interviewed monthly. Respondents were purposefully selected from 3 subgroups – (A) patients in the PC ward, (B) seen by PC consultation team and (C) never seen by PC. BRs were contacted 1–2 months after the death. Patient’s final hospitalisation had to be > 48 hours; those who died in ICU/ED were excluded. Among other questions, BRs were asked on their perception of how often emotional and spiritual support were provided.

Results: A total of 135 BRs were interviewed between February and August 2016, with 45 in each subgroup. Mean age was 51.2 years and most reported to be patient’s child (83%), spouse (10%) or sibling (5%). 85% in Group A reported emotional support was ‘Always’ or ‘Usually’ provided towards the EOL, while this was 65% in Group B and 40% in Group C. 40% in Group A felt emotional support was ‘Always’ or ‘Usually’ provided after death, but 31% felt it was ‘Never’ provided. Comparatively, 20% in Group C responded ‘Always’ or ‘Usually’, and 62% ‘Never’. Majority in each group indicated ‘Did not want/need’ spiritual support at the EOL (Group A-38%, B-42%, C-53%), while those who responded ‘Always’ or ‘Usually’ made up 31% in Group A and 2% in Group C. Qualitative comments showed that some wanted more emotional support to be provided.

Conclusion and discussion: Post-bereavement interviews offer insight into quality and preferences of EOL care. Contrary to conventional practice wisdom, our data suggests spiritual support may not be a perceived need for majority. Results affirm the difference PC makes in emotional and spiritual care. Efforts should be made in enhancing similar support across various teams, and after the death of the patient.
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## Patients’ and Caregivers’ Existential Needs: How to Identify them Using a Semi-structured Interview

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**Background and aim:** Our study was based on a one year experience of philosophical and pedagogical counselling for hospice inpatients (pts) and their caregivers to better understand the existential needs arisen from disease and prognosis conditions. Through an exercise focusing on interviews with pts and their care givers we proceeded to “bring out specific questions of more immediate relevance to the question of general search” in order to allow the definition of specific aspects of interest and the consequent exclusion of misleading categories.

**Method:** Based on the experience briefly described above, a semi-structured interview has been designed to explore the emergence of pts’ considerations and existential themes and the need to help and support practices; at the same time a semi-structured interview concerning similar themes was planned for care givers. The interview was articulated around five questions.

**Results:** In a period of ten months 34 pts and 32 caregivers were involved in the project.

Among pts, 71% were females with an age between 45–65 years; caregivers were represented by partner (54%), adult children (28%) and parents or siblings (6%).

The comparison of pts and caregivers interviews showed that there are some categories that both groups most valued: awareness for diagnosis and prognosis; need for communication with each other (pts/caregiver); changes of the body and at global existential level; fear and loss about the future; anger; the need to make sense of what is happening.

**Conclusion:** From these interviews emerge needs of multidimensional and combined support to the whole family group to facilitate communication and following choices and to disclose existential questions about end of life.
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Is Spirituality Related to Survival in Advanced Cancer Inpatients in Korea?

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Background: Spirituality is something that gives people meaning and purpose in their life, and has been recognized as a critical factor in well-being of patients in their end-of-life. There have been many studies which demonstrated a relationship between spirituality and health outcomes such as quality of life and mental health. While several studies suggested spirituality can be associated with mortality, the results are inconsistent.

Aims: We aimed to determine whether spirituality is related to survival in advanced cancer inpatients in Korea.

Methods: This multicenter study recruited adult advanced cancer patients who were admitted in 7 palliative care units in Korea from May 2015 to Aug 2016. Patients were with estimated survival of < 3 months and then were followed until death. Spirituality was measured at admission using Korean version of Functional Assessment of Chronic Illness Therapy-Spiritual well-being (FACIT-sp), which is comprised of 2 subscales (Meaning/Peace and Faith). Clinical and demographic information, including Palliative Performance Score, was also collected. Kaplan-Meier curve was shown according to the level of spirituality (data was dichotomized at the median for FACIT-sp scales), and univariate regression analysis with Cox-proportional hazard model was performed.

Results: A total of 199 adults (mean age, 64.5 years ; 47.7% female) were enrolled in the study. Lung (22.1%), colorectal (19.0%), and liver/biliary tract (13.3%) were among the most common of diagnosis. Median survival was 20.0 days (95% Confidence Interval [CI]: 22.4 – 30.4). Total score of FACIT-sp was not related to survival time (hazard ratio [HR]=0.992, 95% CI 0.976 – 1.008). Neither were two subscales: Meaning/Peace (HR=0.989, 95% CI 0.963 – 1.016) and Faith (HR=0.983, 95% CI 0.953 – 1.015).

Conclusion and discussion: Spirituality was not related to survival in advanced cancer inpatients in Korea. Plausible mechanisms and possible other relationships merit further investigation.
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Improving Spiritual Care in Hospitals in the Netherlands: Health Care Chaplains Involved in an Action Research Study

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Background: Palliative patients report healthcare professionals’ attention to their spiritual needs to be important. In a national multidisciplinary guideline for spiritual care (SC) in palliative care (PC) concepts and tasks for physicians and nurses are elaborated, and healthcare chaplains are identified as specialists in the field. Implementation of the guideline creates a demand for SC training, but quality indicators still lack.

Aims: To explore an implementation strategy for the SC guideline by training health care professionals, with chaplains in the role of trainers and co-researchers. Research questions were: is it possible to train physicians and nurses effectively within reasonable time limits, what are quality indicators for training SC, and what do the chaplains learn in this research project?

Methods: In an action research design, we planned a multicentre trial. Healthcare chaplains in 8 hospitals, performed a pilot training (SC) in (PC) to multidisciplinary clinical teams on regular curative departments where also palliative patients receive treatment. Data were collected in semi structured interviews with the chaplains 1 month before and 1 month after the intervention. Interviews were audio recorded, transcribed verbally, coded by 2 researchers using ATLAS.ti, discussed until consensus was reached in a problem-driven content analysis.

Results: In 9 pre intervention interviews chaplains reported that doing research created opportunities for improving SC and developed new relations with physicians, nurses and managers. Result based on the 11 post intervention interviews, and the characteristics of the pilot training spiritual care they administered, will be presented at the conference.

Conclusions: Action research is a feasible approach to explore this new field of training and implementing SC, training is effective, and healthcare chaplains develop multidisciplinary competencies in performing research projects.

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Analysis of What Patients Say during Music Therapy Sessions: An Explorative Study

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Introduction: Some patients hospitalised in palliative care units receive music therapy at the bedside. They often express positive sentiments (Oppert 2012). However, do they consider it a musical interlude, time for relaxation, pleasure, or distraction from the present moment? On a deeper level, could music therapy reach out to the person in all its human vitality, its search for unity, its aspiring to beauty, an existential window?

Method: A retrospective, exploratory study by a music therapist/cellist intervening weekly for 4 years, in collaboration with the care team, in the palliative care unit. Study concerned 357 patients; combined total of 478 sessions. Average age 75 years (25 - 102), 80% oncological, 10% neurological; 20% dementia, 5% psychotic. Precise language used by patients to describe their experience was recorded respecting words and terms enunciated. The entire corpus was analysed in units of meaning and collated thematically.

Results: First results show 90% of patients evoked themes of “beauty”, “wellness”, “goodness”, describing the motions of “life”, “opening”, “unity”, “vibration”, “joy” and the impression of there being a connectedness “between their heart and their body”. Emotions such as pleasure, tranquillity, gentleness; also sadness, an inability to name, tearfulness perceived as an emotional outlet, a similarity with the human voice, a new capacity to experience their body, a feeling of inner energy, an inter-human communion, an opening to transcendence, existential dwelling in time and an evocation of death. The study will complete and clarify these data.

Perspectives: We aim to construct some anthropo-philosophical hypotheses taking account of the effect of music used therapeutically on seriously ill patients. We will base our study on the Greek concept physis, vital motion, reanimated by the elements of music. We will study the unifying dimension of music in the light of the disintegration attributable to the illness and suffering.
Ungendered Benefits of a Spirituality Intervention in Patients

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Background: World’s largest fashion retailer launched in 2016 its ‘Ungendered’ clothing. That genderless line of products was, somehow, controversial. Let’s think in gender perspective in professional practice in palliative care. What’s about patients’ intervention at the end of life? Is it ungendered? Are their benefits equally perceived by men and women?

Aim: To study the effects of sex on the benefits of an intervention named KIBO and based on three Spirituality dimensions.

Design and participants: Multi-centric randomized trial with equivalent control group (n=50). The intervention in spirituality was applied to the experimental group. Pre-test and post-test measures were taken with reliable and previously validated measures in demoralization, intra, inter and transpersonal spirituality, quality of life, among other outcomes. Data consisted of 25 patients involved in experimental group (14 women and 11 men). Correlations, MANOVA, T-test corrected for error inflation and effect size measures were reported.

Results: Patients at the intervention group had gains in the expected direction in all the variables. We focused in the gain at Spirituality domain for present research. Although the three areas showed encouraging results, not only the Transpersonal was statistically significant with a satisfactory effect size but it showed interesting relations with resilience (.49, p=.03), social support (-.532; p=.01). None of Spirituality gains showed statistically significant differences by sex (Pillai’s trace=.027; F(3,42)=.394; p=.758; h²=.027). The rest of benefits or outcome targets show a variety of differences depending of sex. Some of them with larger gain scores for men (demoralization) other for women (resilience).

Conclusion: Although present research is still ongoing towards the sample size according its a priori statistical power, the effects of this nationwide spirituality intervention seem to be equally successful for both sex. Funded by SECPAL and VALi+d
The Experience of Spiritual Pain for Dying Migrants Away from their Birth Countries

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Spiritual pain can be linked with aspects of life meaning, culture and religion that arise for address in the dying period. Population demographics in New Zealand mirror most developed countries in showing a rise in the ageing population statistics and a projected increase in ethnic diversity. These statistics will impact palliative care, and the needs of the migrant population will require a deeper understanding of what it means to have a life-threatening/end-of-life illness. Migrants face challenges of living and integrating into a new society. Coupled with an end-of-life illness, this can impact their quality of living and dying immeasurably.

Aims: This study sought to ask dying migrants what their experience and thoughts were on dying away from their country of birth/origin.

Methods: Ten migrants in end-of-life were recruited through hospices for this phenomenological study. Their stories were interpreted using the Heideggerian notion of ‘being’ in the end-of-life ‘clearing’ to understand their experiences of dying in adoptive country.

Results: Three prominent notions were identified from the stories for discussion. The first notion emerged of the participants contemplating identity and belonging as a direct result of having lived in two countries, and the experienced differences between both. The second notion identified the participants as being in life review. The third notion noted their positions in seeking resolution and transformation.

Discussion: A vision for the future for this group of people would be to optimise their quality of dying. The implications for palliative care and other health practitioners who care for ageing and sick migrants include a need for awareness and a deep understanding of the experienced discord that may be present. An approach in care that facilitates resolution of this dissonance can improve the dying experience for migrants and their families.

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‘I am Religious, but I Don’t Believe in Church …’

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Background: Having a meaningful relationship with patients in terms of listening, understanding, and responding to their individual needs is the essence of palliative care. ‘Otherness’ has been reported as barrier in addressing the spiritual dimension in patients’ with different social and religious background.

Aim: To explore the spiritual dimension in adult patients with and without migration background receiving palliative care, a qualitative study was performed.

Methods: Non-structured interviews were conducted using grounded theory approach. Thematic content analysis was applied by means of MaxQDA 12 software.

Results: 36 patients (19 native Germans, 17 patients from Europe and the U.S., Israel, Turkey, and Indonesia); age: median 68 [32–96] years; 25 women; in palliative care 2 [1–24] months; diagnoses: malign [28], non-malign diseases, such as COPD, hepatic cirrhosis, kidney failure [8]. In terms of religious allocation a significant fuzziness occurred. Patients reported that (1) they are religious; religious, but do not believe in church; believer, but do not believe in God; believe in life and nature. The most common empowerment strategies were (2) prayer, meditation, time spent in nature, gardening, smoking (hashish), sitting behind computer, time spent with family, friends or grandchildren. Some of patients (3) believed in resurrection or afterlife, others argued that “there is nothing”. Patients (4) wished to see more of the world, ride a bicycle (once again), go to work, write a book, to see family/relatives living abroad/overseas and to inform physicians about the importance of palliative care.

Conclusion: Migrants reported that they have strived for integration all their lives and do not wish to be addressed as ‘the others’. Compared to non-migrants topics such as ‘home sickness’ and ‘wish to be buried at home’ occurred frequently. These could emerge as relevant to control pain and find inner peace in palliative situation.
First Evidences Using KIBO: Effects of a Nationwide Intervention Focused in Spirituality

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Background: Spirituality is widely reported to be important at the end of life. There is an increasing need for development and empirical validation of intervention protocols focused on this universal tool for healing (Breitbart, Ando,..).

Aim: To measure the effects of a three dimensional Spirituality based intervention held by a wide range of palliative care professionals on patients wellbeing.

Design: A randomized trial with equivalent control group was conducted between 2015–6. The intervention in spirituality named KIBO, was designed by interdisciplinary researchers and clinics. Palliative care professionals (54% doctors, 28% psychologists and 16% nurses) were trained for KIBO implementation and pre-post data gathering following CONSORT guidelines.

Participants: 50 patients (mean age=66; SD= 10; 60% women; 68% attended at hospital; 60% basic studies; 56% married) fulfilled inclusion criteria. Equivalence of groups was tested. Data were collected in both groups pre and post-intervention using validated questionnaires on physical symptoms, resilience, spirituality and several self-reports on wellbeing & quality of life outcomes.

Results: Patients at the intervention group had positive gain mean scores on wellbeing and quality of life indicators. As main benefit of the intervention a statistically significant result with high effect size was found for resilience ($F(1, 40) = 9.898, p = .003, \eta^2 = .198$).

Conclusion: The effects of KIBO intervention provides evidence on a positive effect of an integral palliative care working with patients their own spirituality. Future research should focus on identify the most effective elements depending of the palliative care context and patient’s characteristics. This study was approved by Ethical Committees at the participant university and health care centers involved.

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“So This Is It, Is It Over Now”? – Nurses Meeting the Patient’s Need to Talk about Existential Questions in End-of-Life Care

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Background: Nurses in Specialized Palliative Care (SPC) identify patients with a need to talk about Existential questions. A trusting nurse-patient relationship needs to be established.

Aim: To describe the presumptions that enable nurses to support patients in Existential crisis.

Method: Qualitative method; focus group interviews included seven (n = 7) informants from SPC-units who had completed an intervention on Existential support. Manifest content analysis with inductive approach was used.

Results: Security was identified as a cross-cutting theme, four categories were identified: dialogue, knowledge, support and stability. Factors with negative impact: lack of time, high level of stress, high workload, low staffing, organizational change, limited opportunity for reflection. Sense of security is the study’s key findings. The results shows the nurse’s need for security from various perspectives. Factors essential to experience security was: time for dialogue with colleagues, to share difficult experiences with others who can truly understand. An in-depth theoretical and empirical knowledge of existential challenges, how to offer support, time for reflection and knowledge of one’s own coping strategies was vital. A stable organization, a leadership that prioritized the nurse’s need for guidance and reflection was also important.

Conclusion and clinical implications: The results of the study may have contributed to a deeper understanding of the complex needs and factors affecting the nurse’s ability to provide Existential support to patients within SPC. The nurses work requires extensive expertise, experience, self-awareness in a work which also affects the nurse on a personal level. The study shows that nurses use different tools to meet the patients need of Existential support; theoretical knowledge, knowledge about one’s own coping, self-reflection and team-reflection. To prioritize reflection and tutoring is vital to gain professional stability.
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(In)visible Resources: Assessment of Spiritual Religious Coping and Spiritual Struggles in Palliative Care

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Spiritual care is essential in palliative care. Thus, evaluating religious/spiritual (r/s) resources and needs of patients facing life-threatening diseases helps in making decisions about the provision of holistic care. Despite the Brazilian population being very religious, there are few quantitative studies on r/s and palliative care. The aim of this study was to evaluate the use of spiritual religious coping (SRCOPE) and the prevalence of spiritual struggles among patients with cancer and elderly inpatients. The study was quantitative in nature, and the methodology was descriptive, cross sectional and consisted of the application of the Brief RCOPE Scale, the Spiritual Religious Struggles Scale (SRSS) and a socio-biodemographic Questionnaire. The study enrolled 50 cancer patients and 51 elderly inpatients. The data collection happened in the first semester of 2016 in a hospital in a capital city of Brazil. The results show that both cancer patients and elderly inpatients use the positive religious coping more than the negative religious coping. The most widely used methods were “Benevolent Religious Reappraisal” (cancer patients: M=4.42; elderly inpatients: M=4.41); and “Religious Focus” (cancer patients: M=3.92; elderly inpatients: M=3.98). Although the prevalence of spiritual struggles is low, a significant and positive association between negative religious coping and all dimensions of SRSS was found for both populations. The most common spiritual struggles were: Moral (cancer: M=2.48; elderly: M=2.40) and Ultimate Meaning (cancer: M=2.47; elderly: M=2.40). It draws attention that 54% of cancer patients stated they would like to bring r/s issues to the treatment, but only 14% had been questioned about these issues. The small sample, though adequate for an initial study, does not allow generalizations, but points out the need and importance of broadening and deepening this theme within palliative care research.
Abstract number: P01-458
Abstract type: Poster Exhibition

Frequency of Spiritual Pain in Palliative Care Cancer Patients and its Association with Patient-reported Optimism and Meaning in Life – Possible Intervention Targets?

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Introduction: Advanced cancer patients (ACP) experience physical, social, emotional and spiritual pain (pain deep in your soul/being that is not physical). Limited data exist about frequency and correlates of spiritual pain (SP) in advanced cancer patients.

Aims: To report the frequency of SP in a cohort of ACP referred to a PC clinic and its association with physical and psychological symptoms, patients’ reported optimism and meaning in life (MIL).

Methods: ACP attending an outpatient clinic were enrolled in a longitudinal observational study and were assessed at baseline. Demographics, symptom intensity using the Edmonton Symptom Assessment Scale (ESAS), Karnofsky performance status (KPS) and SP (0 to 10 scale) were assessed. Patient self-reported optimism (0 to 7 scale) and MIL with the MIL questionnaire were also assessed. Univariate and multivariate analysis were performed.

Results: 106 patients were enrolled at baseline. Mean age was 62, 58% were female. 52% reported SP with a mean SP of 3.7. In the univariate analysis, SP correlated (Spearman correlation) with fatigue (r=.22, p=.03), depression (r=.29, p=.003), anxiety (r=.24, p=.01), well being (r=.25, p=.01), dyspnea (r=.26, p=.008) and sleep (r=.20, p=.04). SP also correlated with KPS (r=.22, p=.02), optimism (r=.45, p<.000) and MIL (r=.39, p<.000). In the multivariate analysis, SP was independently associated with optimism (coef -.65, 95% CI(-1.07, -.24), p=.002) and there was a trend with MIL (coef -.17, 95% CI(-.35, .003), p=.054).

Discussion: SP is frequent in ACP attending a PC clinic and is correlated with physical and psychological symptoms, with worse performance status, with being less optimistic and with lower MIL. Interestingly, in the multivariate analysis, only optimism remained significantly associated with SP. Future research should explore the impact of interventions in symptoms, optimism and MIL on SP.
Depression and Spiritual Distress in Adult Palliative Patients in Primary Care

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Background: Palliative care patients have high probability of having depression and spiritual distress but few studies about the prevalence of spiritual distress in palliative patients, particularly in primary care, have been conducted. Also, the differential diagnostic between depression and spiritual distress often lack clarity.

Aims: To identify the prevalence and the clinical indicators of depression and spiritual distress in palliative patients in primary care.

Methods: Observational and cross-sectional study conducted in 2016 in a Portuguese primary care unit.

Patients with chronic disease and Prognostic Indicator Guidance (PIG) criteria were recruited from the General Practitioners patients’ file. Patients were interviewed for collection of demographics, clinical data, presence or absence of spiritual distress and depression.

Depression diagnosis comprised DSM-5 criteria and was supported by HADS scale. Spiritual distress diagnosis comprised a three component criteria: the researcher’s classification, the patient’s confirmation, and a FACIT-Sp score below 36.

Data treatment comprised Independent t-test, Shapiro-Wilk test, Pearson’s χ², using SPSS 22. The study was approved by the ethical Commission of the Universidade Católica Portuguesa.

Results: A total of 1,457 adults were identified, of which 200 met chronic disease criteria, and 39 met PIG criteria. A total of 30 patients completed the study. Palliative patients had a mean age of 72.7 (SD ± 13.4). The majority of palliative patients were married or living together (67%). Most of the palliative patients had a low-medium socio-economic status (87%). The prevalence of depression was 23% (N=7) in this sample. The prevalence of spiritual distress was 23% (N=7) in this sample.

Discussion and conclusion: Palliative care patients’ depression and spiritual distress need to be accurately identified towards the most correct decision-making, and the most effective treatment and holistic caring, including family.
Non-communicable Diseases: An Emerging Epidemic, Where Are Religious Leaders?

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Background: Reports have shown non-communicable diseases (NCDs) are the number one cause of deaths globally. They account for a 2/3 of global deaths and over 60% of these deaths occurred in the lower income countries. High prevalence of NCDs increased the demand for palliative care nonetheless, capacities to offer the services country wide is very low. Engaging religious leaders is a critical step to meet the needs.

Aim: To share the experience of working with religious leaders in addressing the burden of NCDs and scale up palliative care services in Tanzania.

Methods: Religious leaders were empowered with knowledge and skills in order to engage them in the fight against NCDs focusing on cardiovascular diseases: diabetes, hypertension, and stroke, and cancers of: breast, cervical, and prostate. Through series of focus group discussions, mechanisms of communicating health related issues among religious leaders and health providers were established. Mechanism of handling practical issues including referrals, consultations between the two was set to work.

Results: Position of religious leaders and health care providers were re-installed and were no longer perceive as competitors to each other and rather important players in improving quality of life of people with life threatening illness. Religious leaders revise some of beliefs associated demons with illnesses.

Discussions: Active bilateral referrals between and among health care providers and religious leaders has been attained. We also learned that, religious congregations can effectively facilitate community’s accessibility to palliative care health services. Also the congregations have unexplored resources if well mobilized can enhance strengthening systems for health service delivery, indeed palliative care services.

Conclusion: Religious leaders have vital roles in optimize palliative care services. It is possible to work with religious leaders in promoting palliative care.
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Spirituality: “The Elephant on the Table” at the Workplace in Healthcare

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Background: Spirituality is a central workplace dimension but healthcare managers often emphasis more on staff’s intellectual development than their spiritual needs.

Aim: To review and describe what is characteristic of healthcare managers’ spiritual leadership, the characteristics and spiritual attitudes of healthcare staff, and workplace spirituality.

Methods: This study used a mixed studies review, a focus group interview and a questionnaire. The results in the 11 included articles were transformed with a thematic synthesis.

Results: Personal characteristics of managers’ spiritual leadership include being a role model and spiritual guide; and those of healthcare staff include being a team role model and sensing spiritual wellbeing. Workplace spirituality comprises the work climate, community and finding meaningfulness in work. Spirituality needs to be addressed and shifted to be the core of daily clinical work.

Conclusions: The evidence concerning healthcare manager’s spiritual leadership and staff attitudes is ambiguous. Future observational studies may provide more complete evidence on the theme.
Synergy of Compassion: Spirituality and Nursing in Palliative Care

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Aim: Spirituality and spiritual well-being have been shown to be part of patients’, caregivers’ and health-care providers’ (HCP) quality of life in in palliative care. Aim of our work was to introduce compassion and spirituality-based interventions for nurses to enhance awareness of compassion in caring and as part of professional quality of life (compassion fatigue and compassion satisfaction) of HCP in palliative care.

Method: During the past 5 years, ‘Compassion and Spirituality Based Care’ interventions have been integrated for the interdisciplinary team of Hemato-oncology and Bone Marrow Transplant and Oncology Departments at Davidoff Cancer Center, as well as for specialized courses and forums for nurses throughout the Rabin Medical Center.

These interventions draw on palliative care integrative, culturally competent mind-body-spirit approaches such as assessment and cultivation of meaning and spiritual resources facing illness, loss, suffering and end-of-life issues, self-compassion and self-care practices, contemplative and mindfulness based practices for HCP, and at the bedside interventions for patients.

Several levels of assessments were conducted including satisfaction questionnaires and pre-post professional quality of life questionnaires and open ended qualitative assessments in order to assess feasibility and satisfaction of interventions.

Results: Content analysis of qualitative assessments and quantitative analysis suggest high satisfaction of HCP following these interventions. Themes included enhancement of compassion satisfaction, sense of meaning, empowerment and resilience both personally and inter-personally with patients, family members and within the teams as well as reduction of some aspect of compassion fatigue.

Discussion: Integration of spiritual care approaches and skills in nursing was conducted successfully throughout the hospital. Future studies are needed to evaluate the impact of these interventions on care of patients.
V.A.S. (Visual Analog Scale) of Life. Presentation and Preliminary Results

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Aim of the goal: This work is contextualized in an early stage of design and development of a diagnostic and therapeutic tool in the clinical care of palliative care, based on a visual analogue scale, indicator Current Vital Moment (CVM) as a subjective measure.

Objectives:
● Validate the scale as a simple screening measure of suffering in palliative population.
● Develop a brief psychological intervention, explore the spiritual dimension using narrative techniques.

Methods: The scale consists of a continuous line of 10cm with the to extremes being birth and death; the two respective symbols are * and †. The subject is instructed to mark on the line the Vital Current Moment (CVM) found. Objective measures are subject age and Life Expectancy (LE); evaluation of expectations is quantified by the difference between Chronological Age (CA) and Biographical Age (BA), with the resulting value of the equation BA = LExCVM / 10.

Results: In March 2016 a study of 36 graduate students, mostly psychologists (70%), women (81%) and with an average chronological age (CA) of 35 was conducted. LE: female 86 and male 80. Proper adjustment of lifetime expectations is obtained, the average biographical age (BA) = 37 years being higher. No significant differences in gender, age range or profession. The results of preliminary studies targeting population show a tendency to maintain high life expectancy, being less biographical than chronological age.

Conclusion: The V.A.S. of Life is a simple and reliable test the approach reflects the subjective perception of lapse in biographical time and the degree of adjustment of life expectations, offering a possible analysis in quantitative and qualitative terms.
Spiritual Support in the Context of Palliative Care at Home; Unknown and so Unloved. An Assessment of the Situation in the Netherlands

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Patients who are incurably ill and remain in their home situations often do not receive the spiritual support they need. There are a number of different reasons for this. In 2016 Agora* assessed the problems at the request of Martin van Rijn, the Dutch State Secretary for Health, Welfare and Sport. Recommendations were also made on how to improve accessibility. The recommendations for the government, care providers and spiritual carers have been combined into a booklet with title ‘The world of existential questions’ [De wereld van de trage vragen].

The assessment has revealed numerous problems at a variety of levels, i.a.:

- Spiritual support is often linked to church and religion, but is actually aimed at a wide range of themes and target groups.
- Numerous care providers are unknowingly inept when it comes to recognising the existential distress of patients and their loved ones. As a patient you are dependent on sensitivity and competencies.
- Within primary healthcare, there is insufficient awareness of the role and expertise of spiritual carers, resulting in a failure to refer in many instances.

For improvements to be made it is necessary for:

- the knowledge and skills of formal and informal care providers to be improved.
- the added value of specialist spiritual support to become visible;
- there to be a connection between spiritual carers and healthcare structures;
- structural funding to be available for specialist spiritual support and for training in this field.

Spiritual care is an integral aspect of the palliative approach to caring for people who are incurably ill (WHO, 2012). The issue is to pay attention and provide assistance to patients and their loved ones and to guide them when it comes to tackling ‘existential questions’ as there are what happens after death, guilt-related doubts, sorrow and letting go. An absence of spiritual support can cause people to feel lonelier and suffer more than is necessary.
The Spiritual Dimension during an Advanced Disease/A Terminal Illness: A Grounded Theory Study on Italian Patients and their Caregivers

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**Background:** Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they express their connectedness to the moment, to the self, to the others, to nature or the significant and sacred. (Puchalsky et al. 2009).

In the last years, especially in Oncology, there has been a growing interest in this theme (Edwards et al 2010), and the research’s questions are multiple: what patients’spiritual needs are, (Dose 2014, Herman 2001, Cobb 2012, Hodge 2010); which the role of the culture in this dimension is; what the spiritual assessment could be (Delgado 2014, Vasblom 2015, Yardley 2009); if a spiritual care exists and how its efficacy could be evaluated (Gijsbers 2013; Delgado 2013, Best 2015).

**Aims:** The aim of this study is exploring the spiritual dimension of oncologic and especially non-oncologic Italian people together with their caregiver’s experience. The research question is: how does spirituality (spiritual needs) change during the disease process (from the diagnosis to the end of life)?

**Methods:** The study is a grounded theory qualitative research study. The instrument of the investigation will be semi-structured interviews. The interviews’ area are a) faith, meaning and vision of life b) their influence on interwieds’lives c) relationship with others, with health professionals and community.

**Results:** The interviews will take place at the beginning of 2017. Preliminary data would be showed at the Congress.
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Understanding Socioeconomic Influences on Perceptions of Palliative Care

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Background: Socioeconomic (SE) status can influence referral to palliative care and place of death but reasons for this have not been robustly investigated.

Aims: To explore variations in understanding and expectations of specialist palliative care services between patients from different SE groups and healthcare professionals to investigate reasons for inequities.

Method: We conducted a focus group of palliative care clinical nurse specialists (CNS) and interviews with patients from the highest and lowest SE groups (as defined by the Scottish Index of Multiple Deprivation, 2012). Data were analysed thematically, compared and contrasted using the principles of grounded theory.

Results: Five CNSs participated in the focus group. Five patient participants were interviewed from SE groups 1+2 (most deprived) and six from SE groups 4+5 (least deprived). Three master themes emerged: understanding of palliative care, information seeking and expectations of palliative care. Understanding was poor overall but improved following engagement with the service and was influenced by CNS input. There was a variable desire to seek information, irrespective of SE status, but barriers exist to those from the lowest SE groups seeking information. Expectations were linked to understanding and more affluent patients could be more forceful following engagement with services.

Conclusion: Misunderstanding of palliative care causes anxiety and influences expectations which, in turn, could impact on referral patterns. Barriers may exist to the lowest SE groups seeking information, yet desire is similar. More affluent patients may be better prepared to effectively navigate healthcare systems which could explain the greater likelihood of hospice admission for end-of-life care. Future work should explore the assessment of health literacy to enable practitioners to provide appropriate, timely and individualised information.
Do we Face Significant Changes in the Demographic and Social Profile of Candidates for Hospice / Palliative Care Volunteering? Summary of a Single Institution 11 Year Educational Program

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Background: Voluntary activities are essential in many different aspects of hospice and palliative care. Better knowledge of volunteers’ characteristics and wider understanding of their motivations seem to be crucial for sufficient recruitment and retention of volunteers.

Methods: Self-reported demographic details and data on motives for volunteering were collected from questionnaire forms completed by all consecutive participants of the course for medical voluntary cancer patients caregivers (18 editions; April-2006–November-2015; no data for 2009) at Rev. Eugeniusz Dutkiewicz Hospice SAC, Gdańsk, Poland.

Results: All 662 records were analyzed: 1) mean volunteers age was 37.72±15.71 years, significant trend (p < 0.001) for increasing age was observed (2007: 28.41±11.82; 2011: 37.19±14.93; 2014: 41.31±12.16); 2) the vast majority of the volunteers were females (84.03%); 3) 71 of study participants declared professional connections with medicine (10.72%), 51 (7.70%) – pedagogy or 45 (6.79%) – psychology; 4) 354 (53.47%) volunteers declared full current professional activity, 236 (35.65%) were unemployed, 72 (10.88%) – retired; 5) participants mostly reported motives for volunteering which might be categorized as altruistic (67.08%: “I want to help others”) – this percentage increased significantly during the study period (p < 0.012); 6) the next two most frequently indicated motive categories were for personal improvement (29.36%: “I want to improve my skills”; 26.87%: “volunteering is my way of my personal development” – not significant trend for time).

Conclusions:
1) results showed that some demographic features as well motives for hospice / palliative care volunteering changed over the time in our community – it warrants some individualization in recruitment process recognition for volunteers coordinators; 2) the study will continue to identify the volunteers’ subgroup with the greatest probability to retain at service for longer period of time.
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Psychosocial Health and Life Situation of Young Adults who Lost a Parent to Cancer

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Background: Losing a parent to cancer is a particularly difficult experience for young adults since the transition from childhood to adulthood already challenges life. Few studies have focused on the characteristics of this group.

Aim: To describe the psychosocial health and life situation for young adults who lost a parent to cancer.

Method: This study has an observational design. Participants of the survey were recruited through palliative care services and were about to attend support groups. A questionnaire was answered by 86 young adults (16–28 years) 5–8 months after the loss of a parent to cancer. It comprised sociodemographic and loss-oriented data and self-assessment scales: Young Person's Grief Perspective Scale; The Hospital Anxiety and Depression Scale; and The Rosenberg Self Esteem Scale. Descriptive statistics was used.

Results: Median age for participants was 23 years, a majority was women (85%), 42% were in a relationship and 89% were working or studying. Almost 60% had lost their mother. One fifth (19%) of the young adults reported not to have been aware about their parent’s impending death, and one fifth (19%) became aware a few days before. As many as 81% reported feeling lonely and 33% were not able to talk to others about their feelings. Many reported low self-esteem (75%) and anxiety (severe 42% and mild 30%). A third of the participants (31%) reported symptoms of depression (severe 5% and mild 26%). One forth (26%) had difficulties coping with their grief.

Conclusion: This study enhances knowledge about the life situation and psychosocial health of young people who lost a parent to cancer. The results reveal specific needs and thus inform future supportive interventions.

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How Do Hours of Care and Caregiving Context Impact on the Psychological Distress and General Health of Family Carers of Patient with Cancer at End of Life?

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Background: Family carers provide substantial support for patients at end-of-life. It is important to understand how caregiving impacts on carer outcomes to guide appropriate interventions to improve carer wellbeing.

Aims: To investigate how hours of care and caregiving context impact on carers’ psychological distress and general health within end-of-life cancer care.

Methods: Four-month post-bereavement postal survey of a national census sample of relatives reporting a death from cancer 1–16th May 2015. Data collected included carer demographics, caregiving hours and tasks, patient symptoms and activities of daily living (ADL), and carer psychological distress (GHQ-12) and health (EQ-5DVAS) during the patient’s last three months of life. Exploratory univariate analyses were used to describe the data and inform multivariate mixed effects models.

Results: Surveys were completed by 1504 (28.5%) of 5271 carers. Univariate analysis results at p< 0.001 indicate that increased hours of caregiving had a negative impact on carer distress and health, and hours of relaxation a positive impact. The patient’s symptoms and ADL were negatively related to carer distress and health. Carer age, sex, work situation and level of deprivation also appeared to have an impact. Further analysis, to be presented at EAPC, will consider the impact of other support (informal/formal) and assess multivariate relationships.

Conclusion: Hours of caregiving and caregiving context appear to have an impact on carer wellbeing. Our multivariate analysis will clarify these relationships further. Although caregiving hours and context are likely to explain only part of the variance in carer outcomes, they make an important contribution that need to be understood in order to help inform appropriate and effective interventions.

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End-of-Life Care Setting Transition Issues and Solutions: A Qualitative Study of Key Informants to Identify Issues and Solutions

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Background: A qualitative research study was conducted in 2016 out of concern for effective and appropriate end-of-life care (EoL) setting transitions associated with moves in the last year of life. Many concerns over EoL care setting transitions exist in Canada and elsewhere.

Aims: The study purpose was to gain insights and advice from key informants (healthcare providers, healthcare managers, government representatives, lawyers, healthcare recipients, and their family/friends) about EoL care setting transition issues and solutions.

Methods: In-depth interviews of 39 key informants in the Canadian province of Ontario were conducted, with constant-comparative grounded theory data analysis.

Results: Three themes, each with a number of categories, emerged:
(a) communication complexities and related solutions,
(b) care planning and coordination gaps and related solutions, and
(c) health system reform needs and related solutions.

Conclusion and discussion: Clearly, EoL care setting transition issues were of widespread concern. Many given solutions overlap themes, indicating these are both necessary and possible to implement. Moreover, the extensive list of issues and solutions reveals much more must be and can be done to prevent EoL care setting transition issues. Action is essential to eliminate the possibility of low quality transitions such as mistakes and other mishaps occurring with moves from one care setting to another. Frequent or repeated moves from one care setting to another as death nears should become unnecessary. Delayed and denied necessary or desirable transitions similarly should no longer occur. The move home from hospital for people who want to spend their final hours or days of life there should be a patient right and thus a normal and supported practice. Action on care setting transitions is needed now as care setting transition issues could grow exponentially with the increase over the next 10–20 years in people requiring EoL care.
Hyoscine Butylbromide Induced Parotitis: A Case Report

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Aim: To increase awareness of a rare side effect of hyoscine butylbromide, a commonly-used medication in palliative care. Hyoscine butylbromide has previously been reported as contributory in the development of bacterial parotitis in a palliative care setting but it is a rare complication and hyoscine butylbromide was not listed as a drug which causes parotitis in a 2012 literature review on the subject due to a lack of case reports.

Approach taken: A 47 year old man with adenocarcinoma of his transverse colon, liver metastases and malignant small bowel obstruction developed painful bilateral parotid swelling following 29 days of treatment with hyoscine butylbromide at a dose of 120mg over 24hrs via continuous subcutaneous infusion for colic. It was presumed that hyoscine butylbromide, an antimuscarinic medication, had caused sialadenosis and that superadded infection caused parotitis and severe pain. The pain was poorly opioid responsive and did not respond to cessation of the hyoscine butylbromide, to a heat pack or to non-steroidal anti-inflammatory medication (parenteral and topical).

Results: Intravenous coamoxiclav 1.2g three times daily was commenced to treat infection and for pain control. Within 24 hours the pain had improved significantly and within 48 hours of antibiotic treatment, the pain had resolved completely. Antibiotics were continued for a total of five days before discontinuing.

Conclusion: Although rare, it is important to consider parotitis as a complication of hyoscine butylbromide treatment. In this case, pain control was difficult to achieve and parenteral antibiotics were required for effective analgesia. A three-time daily parenteral antibiotic regime can be challenging in a hospice setting but this was the only treatment found to be effective for hyoscine butylbromide induced parotitis in this case.
Poster Exhibition
(Poster Set 2)

Assessment and Measurement Tools
Basic and Translational Research
Development and Organisation of Services
Ethics
Family and Caregivers
Health Services Research
International Developments
Medical Sociology
Non-cancer
Pain
Palliative Care for Older People
Social Care and Social Work
Volunteering
Validation and Cultural Adaptation of the Integrated Palliative Care Outcome Scale (IPOS) for the Portuguese Population

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Context: IPOS is a patient-centered outcome measure developed by merging the Palliative care Outcome Scale and the Palliative care Outcome Scale-Symptoms.

Aim: Culturally adapt and validate IPOS to the Portuguese population.

Methods: Multi-centred observational study. Data was collected in 9 centres using convenience sampling. All patients attending the participant services were screened for eligibility. Inclusion criteria: ≥18 years, mentally fit to give consent, diagnosed with an incurable, potentially life-threatening illness, read, write and understand Portuguese. Exclusion criteria: patient in distress, cognitively impaired. A standard operating procedures manual was developed and distributed to all centres in the person of the facilitator leading the study locally. The measure had been previously culturally adapted translation, back translation and cognitive interviews. For psychometric testing the COSMIN checklist was used.

Results: 1703 individuals were screened between July 1st 2015 and February 2016. 135 (7.9%) were included. Mean age is 66.8 years (SD 12.7), 58 (43%) are female, 74 (54.8%) have up to 4 years of formal education, 74 (54.8%) are from the Northern region. Most patients had a cancer diagnosis 109 (80.7%). Data were missing at random (Little’s MCAR test with Chi-Square = 2452.946, DF = 2398, Sig. = .213). Missing data varied between 1% and 5% and imputation of the median was used. Internal consistency assessed with Cronbach’s alpha varied between 0.68 and 0.72. For reliability between patients and healthcare professionals scores, intraclass correlation was higher for mobility (ICC=0.726) and lowest for practical problems (ICC=0.088). Similar constructs showed convergent validity (pain: Spearman’s Rho for EQ-5D was .515 and for QLQ-C30 was .772). Discriminant validity was also good.

Conclusion: The Portuguese IPOS is a reliable and valid measure.

Funding: Fundação para a ciência e tecnologia Grant number PD/BD/113664/2015
Improving the Assessment of Symptoms and Palliative Care Concerns: Validity and Reliability of the Staff-version of the Integrated Palliative Care Outcome Scale (IPOS)

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Background: The Integrated Palliative Care Outcome Scale (IPOS) is a brief yet comprehensive, valid and reliable outcome measure. Staff-proxy report ensures data completeness at the end of life when patients can no longer self-complete questionnaires.

Aim: We aimed to validate the staff-version of the German IPOS using both classical test theory and new psychometric approaches.

Methods: National, multi-centre, longitudinal study including a representative sample of palliative care patients from the hospital, hospice and home care in- and outpatient setting in Germany (n = 677). Psychometric evaluation using both classical and Rasch analytical approaches included assessment of structural validity, scaling assumptions and item quality, known-group comparisons, and inter-rater and test-retest reliability.

Results: Factor analysis confirmed two subscales: Physical symptoms and Psychological and information concerns. Rasch analysis showed overall support for the psychometric properties of the two subscales, however, scaling analysis in some symptom items indicated a problem with the response format of the IPOS. The variable “setting” had a strong influence on response patterns with a differential item bias in 4 items. Staff-reported IPOS Physical symptom scores discriminated well between participants with different Karnofsky performance status (t=4.5, p< 0.001) and phase of illness (F=2.6, p=0.02). Test-retest reliability of ratings of stable patients over time was excellent. Inter-rater agreement showed low agreement in items fatigue, drowsiness, family anxiety and sharing feelings with family/friends.

Conclusion: The staff-reported version of the IPOS is a valid and reliable outcome measure. For assessing and monitoring palliative care outcomes at the end of life training staff will help ensure adequate data quality.

Funding: In Germany, this research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.
Abstract number: P02-003
Abstract type: Poster Exhibition

Wearable Smartwatch Technology to Assess Pain in Palliative Care

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Aim or goal of the work: This collaborative project between Computer Science and Palliative Care aimed to develop a smartwatch app to assess pain.

Design, methods and approach taken: The app was coded for the ‘Apple Watch’ using the Apple Xcode developer program. A numerical rating scale (0–10) and a descriptive pain assessment scale were used to record pain. The ability to sync, tabulate and share pain scores with a paired mobile device was tested.

Results: The developed app facilitates pain assessment and syncs data with a mobile (smartphone and/or tablet). Collated aggregated symptom scores were generated to provide historical pain assessments. The app facilitated ‘push notifications’, which asked the user to rate their symptom intensity at specified, time intervals (e.g. four times a day, pre-meals etc. etc.).

Conclusion: We have successfully developed a smartwatch app that facilitates on-going symptom assessment. This may potentially be useful to patients and healthcare professionals to facilitate personalised on-going assessment of pain in a dynamic, digital, sync-able format. Further work will potentially involve data linkage of ‘symptoms’ with ‘patient activity’ (via the activity-tracker capabilities of wearable devices) in order to explore associations between pain and activity. This may potentially facilitate the development of predictive algorithms to predict symptom burden (and the need for specific interventions) according to the daily routine of individuals.
Developing a Measure for Patient Experience of Care towards the End of Life

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Background: Although patient experience constitutes one of three pillars of quality of care along with effectiveness and safety, to date no validated measure exists to assess patient experience of care towards the end of life. However, such a measure may be useful for evaluating services.

Aim: To develop a measure of patient experience of care at the end of life.

Methods: A review of key reports on end-of-life care (EOLC) and a thematic analysis of interview excerpts provided by the database ‘healthtalk.org’ helped to identify domains of interest. A preliminary bank of questions was devised using components of three existing measures and newly developed items. A modified online Delphi study comprising two rounds consulted a panel of professionals and ‘public and patient involvement’ groups. Numerical ratings and free-text comments informed the steering group’s decisions on items’ modification and exclusion. Cognitive interviewing then served to pre-test the items for their usability, comprehensibility and pertinence to patients.

Results: 9 domains relevant for good patient experience of care were identified covered by 47 closed-ended candidate questions: Communication and information, Patient-centred care, Physical, psychological and emotional needs, Social and practical needs, Spiritual, religious and cultural needs, Coordinated care, Urgent care, Centrality of people important to the person and Environment. Changes emerging from the Delphi study involving 70 and 22 participants in round 1 and 2, respectively, and the cognitive interviews with 18 hospice patients resulted in a final questionnaire comprising 20 items.

Discussion: We describe the development of a measure assessing patient experience of care at the end of life that addresses 9 key domains applicable to all care settings. The 20 pre-tested items were found to be acceptable and understandable to patients receiving EOLC. Additional psychometric testing is needed to establish reliability, validity and responsiveness.
Abstract number: P02-005  
Abstract type: Poster Exhibition

Translation and Validation of the Swedish Version of the VOICES (SF) Questionnaire

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**Background:** Swedish questionnaires for evaluating the quality of end-of-life care for longer periods of illness trajectories are currently lacking. The Voices (SF) (Views of Informal Carers- Evaluation of Services (Short form)) is a postal questionnaire about bereaved relatives experiences’ of care in the last three months of life of a deceased family member, focusing on quality of care and services received. The original VOICES questionnaire was developed in the UK.

**Aim:** To translate, adapt and validate the VOICES (SF) questionnaire to be used in Sweden.

**Methods:** The validation process consisted of translation/back translation, cognitive semi-structured face-to-face interviews and discussions to reach consensus in an expert group of researchers and clinicians. A strategic sample, based on place of death of the deceased, of 35 bereaved relatives was recruited from three settings; home care, hospital ward and nursing home. The participants were 13 men and 22 women, age ranged between 20 and 90+ (mean age 66), who were relatives (husband/wife, children, parents and friends) of persons who died from life-limiting conditions. The participants’ views and responses to the questionnaire were analyzed and summarized according to a protocol.

**Results:** The questions were found relevant provided some adjustments, smaller changes were made based on the participants’ reported difficulties in understanding the questions. Cultural adaptations of questions about ethnicity and religion were made due to Swedish regulations. Two more categories of care were added to suit Swedish conditions; home care services and specialized health care at home.

**Conclusions:** The VOICES (SF) is regarded by bereaved relatives and experts to be feasible in the Swedish context, provided cultural adaption, i.e. the translation alone is not enough. A Swedish version enables research on the quality of end-of-life care and comparison internationally.
Validity Evidence for a Verbal Format of the Portuguese Version of the Revised Edmonton Symptom Assessment System (VP-ESAS-r)

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Background: Compliance problems have been reported in the completion of the ESAS and ESAS-r in advanced disease. A verbal rating scale format may be more appropriate for these patients. To our knowledge, only a French verbal form of the ESAS has been developed and validated.

Aims: To investigate the psychometric performance of a Portuguese 7-level rating verbal scale, created by experts, based on the 10 items of the ESAS-r (VP-ESAS-r); to assess patient preference for either format.

Methods: Cognitively intact outpatients receiving palliative radiation for metastatic bone pain rated the Portuguese versions of P-ESAS-r, VP-ESAS-r (day 1 to 7), EORTC QLQ-C30 and Epworth Sleepiness Scale (day 7), as well as patient’s global impression of change (PGIC) and their preferred symptom assessment format 3 weeks later (w3).

Results: Of 75 participants, 62 (83%) regardless of education (median age 62, median PPS 70%, 45% with at least secondary level of education) preferred the verbal format. The VP-ESAS-r had good internal consistency (Cronbach alpha 0.74). The 24-hour retest reliability coefficients ranged from 0.45 (pain) to 0.79 (appetite). Equivalence reliability between VP-ESAS-r and P-ESAS-r was found (intraclass correlation coefficients over 0.8 for all items). Moderate to strong correlation was found between individual symptoms on the VP-ESAS-r and PGIC had a weak inverse correlation(r = -0.31). VP-ESAS-r total score, depression and wellbeing item scores were also negatively correlated (r = -0.28 to -0.35) with functional status.

Conclusions: In addition to being the preferred format by patients with metastatic bone disease to assess their symptoms, VP-ESAS-r also proved to be a reliable and valid tool. Further investigation should explore its potential utility in diverse clinical and cultural settings.
Experience with NECPAL Tool
Identifying Patients with Advanced Chronic Conditions

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**Background:** To improve the quality of care to patients with advanced chronic conditions (PACC) through the early identification of Palliative Care Needs (PCN) and early intervention shared. Our Hospital has incorporated the “NECesidades PALiativas CCOMS-ICO” (NECPAL CCOMS-ICO) tool for screening of PCN.

**Aim:** To analyse the usefulness of NECPAL tool in such detection.

**Methods:** Sample: 316 patients. Setting: Area of Integral Medicine of a Hospital attending patients with advanced chronic conditions. Study design: Observational, prospective.

**Methodology:** Rating NECPAL and Multidimensional was applied. Statistical analysis: PCN prevalence was estimated and the differences between NECPAL + and NECPAL- patients using T Student, Mann-Witney and Chi2 were analysed (SPSS / PC 15.0).

**Results:** 69% of patients (218) were NECPAL + and identification was made in the first week of hospitalization in 97% of cases. 63% of NECPAL+ patients were subsidiaries of PCN on admission. PCN by NECPAL tool were detected in 62% of convalescence patients and in 21% of Long stay ones. 70% of patients in convalescence and NECPAL + changed to palliative care process, and 43% of patients in Long stay. From 175 patients classified as non palliative on admission, 46% were NECPAL +. 157 patients with nononcologic pathology and non Palliative on admission, 47% were identified as NECPAL +. The NECPAL + patients, compared to NECPAL - ones, were older, with shorter hospital stay in the referring hospital, prior lower score on the Barthel Index, higher Charlson and CONUT Indexes, more frequent delirium criteria and prescription of major opioids and corticosteroids. 72.5% of NECPAL + patients died during hospitalization episode, compared with 2% in the NECPAL- group (p < 0.001).

**Conclusions:** In a Hospital for patients with advanced chronic conditions, NECPAL allows early identification of patients with PCN, especially in non-oncologic patients, allowing the adaptation of care interventions to these needs.
Abstract number: P02-008  
Abstract type: Poster Exhibition

Palliative Sedation on Basis of a Standardized Form According to the EAPC Framework for the Use of Sedation in Palliative Care – First Experiences

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Background: Palliative sedation (PS) is generally considered to be a necessary treatment in the therapy of selected palliative care patients. Procedural guidelines such as the EAPC framework from 2009 were established to set standards for best practice and emphasize that PS is accepted and ethical when used in appropriate situations.

Aims: In early 2013, a form to meet the recommendations of the EAPC regarding indication, informed consent, methods of sedation and monitoring was developed and introduced in clinical practice at our ward in July 2013.

Methods: All forms for PS in our ward were collected from July 2013 to September 2016, the data was entered in a database and statistically analyzed.

Results: During 38 months, 1078 patients were hospitalized at our ward. A total of 233 forms were collected in this timeframe, of which 4 had to be excluded from this analysis because of missing data. The remaining 229 forms referred to 197 patients, implying a need for PS in 18.3 %, respectively. The median age was 65 years (range 23–93) and there were 105 female and 92 male patients. The indications for the use of PS is shown in Table 1.

Conclusion: The application of this form in clinical practice is feasible and the collected data provides better insight in the indications of PS and therefore delivers a lot of useful information for clinicians especially regarding better symptom control.

<table>
<thead>
<tr>
<th>Dyspnea/Pain</th>
<th>uncontrollable Vomiting/Delir</th>
<th>massive Hemorrhage/ Asphyxation</th>
<th>refractory Sleeplessness</th>
<th>refractory Depression/ Anxiety/ Distress</th>
<th>agonizing dying process</th>
<th>other</th>
</tr>
</thead>
<tbody>
<tr>
<td>31.1 %</td>
<td>10.1 %</td>
<td>23.6 %</td>
<td>35.8 %</td>
<td>37.6 %</td>
<td>26.6 %</td>
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(Table 1)
What Are the Mechanisms of Action of a Measure to Improve Assessment in Care Homes for People with Dementia: A Qualitative Study of Family and Professional Caregivers before and after Implementation?

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Background: Many with dementia require care home admission. Care staff should be skilled in assessment of residents but there are few evidence-based interventions to support this.

Aim: To understand the mechanisms of action of a measure to support assessment of residents with dementia and their family.

Methods: A two-phase pre- and post-implementation qualitative study in three care homes, underpinned by a theoretical model. The Integrated Palliative care Outcome Scale for Dementia was used in the care of residents for 12 weeks. Phases one and two included focus groups and interviews with family and professionals (care staff, general practitioners and district nurses). Phase two data collection also included non-participant observations of health care consultations. Data were analysed using content analysis. Family and professional, and phases one and two data were compared.

Results: Challenges to integrated working in this sector were identified. Five mechanisms of action were: improved awareness and collaborative assessment, comprehensive ‘picture of the person’, systematic record keeping and monitoring, changes to care planning and provision, and enhanced communication. Outcomes were comprehensive care needs addressed, improved symptom management, and increased family empowerment. Measurement properties that enhance acceptability were touch-screen technology, and being trusted across sectors. Leadership is essential to ensure that the measure is embedded into care processes, and ensure care staff understand the value of the measure in care provision.

Conclusion: In a sector where comprehensive symptom assessment is challenging and there are barriers to integrated working, a measure used in routine care can improve resident assessment and monitoring, and facilitate collaboration and communication. Outcomes are resident health and care needs being addressed and family empowerment.

Funders: Cicely Saunders International, Atlantic Philanthropies, NIHR
**How to Identify Doctors who Are Best at Recognising Dying Patients**

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**Background:** There are some concerns about doctors’ ability to recognise dying patients. Little empirical research has previously compared the prognostic performance of different doctors.

**Aims:**
1) To assess the accuracy of specialist palliative care doctors’ ability to recognise dying patients
2) To investigate factors that may be related to better performance.

**Methods:** In a prospective observational study, 20 case summaries of real palliative care patients were used to develop an online “test” of prognostic ability. All members of the UK Association of Palliative Medicine (APM) were contacted via email to participate. Participating doctors were asked to read a summary of each case, including information about current observations, physical condition and medication. They were asked to provide a percentage estimate for the probability that the patient will die in the subsequent 72 hours. The accuracy of each prediction was calculated as a “Brier score” (from 0 [complete accuracy] to 1 [complete inaccuracy]) comparing doctors’ estimates with the patients’ actual outcome.

**Results:** A total of 166 doctors started the test and 99 doctors (60%) provided a prognostic estimate for all 20 case summaries. The mean Brier score for the 99 completers was 0.24 (sd 0.04, range 0.14 – 0.37). This score suggests that the performance of doctors was very similar to chance (Brier score = 0.25) at recognising dying, with some doctors performing better than others. There was no relationship between the Brier score and participants’ gender, age, years since qualifying as a doctor, or years working within palliative care.

**Conclusion:** The proposed prognostic test was able to identify a range of prognostic abilities among respondents and may find a role in benchmarking the prognostic skills of individual clinicians and evaluating the effect of prognostic skills training programmes.

**Funding:** Part of a UCL Marie Curie PhD studentship


Abstract number: P02-012  
Abstract type: Poster Exhibition

Anxiety and Depression Deteriorate Following Discharge from a Palliative Care Ward – Results of the Prospective “PaRoLi” Study (Palliative Care in Rostock: Focus on Quality of Life)

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Introduction: Quality of life (QoL) is an important outcome measure in palliative care (PC) given that maintaining/maximizing QoL is the overall goal of PC. Mood is an important part of QoL being negatively influenceable by depression and anxiety. Here, we report on results of a prospective study screening for depression and anxiety in a large German PC cohort.

Method: From 5/2013 to 12/2013 consecutive PC pts being admitted to the interdisciplinary PC unit of Rostock University Medical Center were enrolled. QoL and mood were assessed 24h after admittance (P1), within 24h before discharge (P2) and 2 weeks after discharge (P3) using the HADS-D.

Results: Of 206 inpatients, 102 consented to participate in the study. The most frequent reason for non-participation was bad general health condition. The study cohort consisted of 45% females and 55% males with a median age of 69yrs (range:44–89yrs). 30% of the pts died during the hospital stay, median overall survival was 2.1±3.3 mths.

A total of 176 HADS-D questionnaires were completed with a mean anxiety score of 7.21±3.71 and a mean depression score of 9.27±4.80. Probable depression or anxiety was present in 46% of the pts. In longitudinal analysis both subscales showed little improvement during hospitalization (P1–P2; p=n.s.) but significant deterioration between discharge and 2 weeks after (P2–P3; anxiety (p=0.046), depression (p=0.003)). Pts with first diagnosis of the underlying disease < 365days had higher anxiety and depression scores at P1 (p< 0.05, both). Further detailed data will be presented.

Conclusion: It is difficult to conduct a QoL study in advanced PC pts as answering questionnaires is difficult or impossible due to poor performance status. Our results demonstrate that PC pts suffer more likely from depression than other patient groups. PC pts stabilize during their stay at a PC ward in regard to anxiety/depression but worsen after discharge demonstrating the need for an improved discharge management.
Nurses' Ability to Assess the Level of Interference with Daily Living Due to Pain and Identify the Cause of Pain in Cancer Patients: A Preliminary Analysis

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Background: For effective pain management, assessing the level of interference with daily living due to pain and identifying the cause of the pain are essential. Although patient reported outcome is the gold standard for pain assessment, proxy ratings are needed for patients with poor general condition and cognitive dysfunction.

Aims: The aim of this study was to clarify the concordance between patients' and nurses' assessments in level of interference with daily living due to pain, and the ability of nurses to accurately identify the cause of the pain.

Methods: We conducted a cross-sectional survey of consecutive cancer patients admitted to a University Hospital. The research nurse asked each patient to rate the level of interference with daily living due to pain. We used a 5 point verbal rating scale which was derived from the Palliative Care Outcome Scale. As a proxy for patients, charge nurses rated interference with daily living using the same scale and assessed whether cause of the pain was cancer or not. Palliative care physicians also assessed the cause of the pain after examining patients and their medical records.

Results: Ninety-eight patients were recruited and 67 were included in the study. The mean age was 62 and 66% were male. Fifty-eight percent had pain and 19% had cancer pain. Twenty percent had bone metastasis or invasion and 94% had ECOG Performance Status of 0 to 2. Concordance between nurses and patients in assessment of interference with daily living was moderate; weighted kappa coefficient 0.41 (95%CI: 0.27 – 0.56). Concordance between nurses and palliative care physicians in determining cause of the pain was high; kappa coefficient 0.69 (95%CI: 0.44 – 0.93).

Conclusion: For cancer patients, nurses are able to accurately assess the cause of pain, and provide useful information regarding level of interference with daily living due to pain.

This work was supported by a Health Labor Sciences Research Grant.
Abstract number: P02-014
Abstract type: Poster Exhibition

What Features of Oncologic Patients at Admission in a Universitary Hospital PCU Can Help us to Predict Survival?

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Background: The possibility to determine survival in advanced cancer is important for clinic, organizing and ethical purposes.

Aims: To analyze factors related to survival in patients at admission in Acute PCU.

Methods (design, data collection, analysis).

Prospective study. All cancer patients admitted PCU January 2012–April 2015. Collected demographic variables, source admission, tumor types, metastatic locations, time from diagnosis to PC (TTD), ESAS, Global Distress Score, ECOG and Charlson’s Index. Descriptive statistics and Cox regression analysis were made with OR and IC 95%.

Results: 1294 admissions: 959 patients met the inclusion criteria. Mean age 70.1±14.5 y. Males 57%. Sources of admission were: 41% emergency room, 39% other hospital departments, and 20% home-based palliative care services. Average stay was 10.4 ±8.4 days. Average TTD was 12 months (Range IQ 2–34). Average time referral to PC resources-death 41 days. Symptomatic charge was moderate-severe (ESAS Global Distress Score > 30) in 72% (average DS 12.9). ECOG were: 2 (9%), 3 (50%) and 4 (41%). 83% had a high score in the Charlson index (average of 7).

Conclusion: The most important factors related to survival were source of admission, a short TTD, the need for a hospital admission short after derivation to PC resources, hematologic neoplasms and tumors with many metastatic locations, severity of symptoms, and performance status of the patients.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Survival Time (days) (IC 95%)</th>
<th>OR (IC 95%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home-based services Admission</td>
<td>33 (23.06–42.93)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Emergency</td>
<td>19 (14.04–23.95)</td>
<td>1.45 (1.22–1.74)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>TTD (months)</td>
<td></td>
<td>0.99 (0.99–1.00)</td>
<td>0.012</td>
</tr>
<tr>
<td>Days from referral to PC to be admitted</td>
<td></td>
<td>0.99 (0.99–0.99)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Head and neck cancer</td>
<td>48 (36.91–59.08)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Hematologic</td>
<td>16 (7.77–24.23)</td>
<td>1.71 (1.10–2.66)</td>
<td>0.016</td>
</tr>
<tr>
<td>&gt; 2 metastatic locations vs 0–1≥</td>
<td>19 (15.74–22.25)</td>
<td>1.21 (1.06–1.39)</td>
<td>0.004</td>
</tr>
<tr>
<td>ESAS Global Distress Score</td>
<td></td>
<td>1.01 (1.00–1.02)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>ECOG 4 vs 1</td>
<td>10 (7.66–12.34)</td>
<td>1.62 (1.46–1.79)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

(Table 1)
**Advanced Care Planning at End of Life: A Review of Anticipatory Decision-making about Ceiling of Care in Patients with a CMC Record: Interrogation of an Electronic Clinical Care Record**

*Broadhurst H., Droney J., Shaw M., Riley J.*
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Coordinate My Care (CMC) is a clinical service underpinned by a digital information care exchange which allows patients to have their medical details and wishes about care recorded. CMC can be accessed by all healthcare providers and facilitates the integration of health care services. In November 2015, Ceiling Of Care (COC) options were added patients CMC files to guide decision-making in emergency situations.

The aim of this study was to determine the demographics of those utilising COC decisions and what effect these decisions have on outcomes for patients. CMC records from December 2015 to March 2016 were reviewed. Patients were grouped by their COC plan and comparisons were made between these and those without COC plans.

Results demonstrated that 501 patients (82.5%) out of 607 with a COC decision died in their preferred place of death (PPD). This is compared with 145 patients (63.9%) out of 227 without a COC decision dying in their PPD (p< 0.0001). A higher proportion of non cancer patients 71.9% made a COC plan compared with 61.5% (p< 0.0001) of patients with a cancer diagnosis. Correlation is seen between patients’ COC plan and their place of death – the more active the medical interventions described within the COC plan the more likely a patient is to die in hospital.

35.6% of patients with a COC plan had their file accessed by acute medical services compared to 25.2% of those without a COC plan. Cancer patients had their file accessed more frequently by acute care services compared with patients with non cancer diagnoses. Analysis of free text data in the COC plan showed that 10.5% of comments centred on decisions for future antibiotic treatment and 10.3% of comments stated that patients were unable to make advanced decisions regarding COC.

In conclusion, patients with a COC plans are more likely to die in their preferred place and COC decisions do effect patient outcomes. We suggest COC is a powerful tool helping end of life patients manage their diseases.
The Korean Version of CAGE-AID/Opioid: Cultural Adaptation, Validation, and Application to Opioid-prescribed Patients

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**Background:** National opioid and psychoactive agent consumption in South Korea has been increasing. But, substance abuse disorders (SUD) have been out of sight except alcohol and tobacco in South Korea. This may be related to the scarcity of validated screening tools translated in Korean. Therefore, we devised both the Korean CAGE-AID and an opioid-specific version (CAGE-Opioid).

**Aims:** To validate CAGE-AID/Opioid and conduct psychometric evaluation

**Methods:** A single center prospective observational study was designed. During the first phase of the study, linguistic adaptation was carried out to establish the Korean version of CAGE-AID/Opioid. During the second phase of the study, feasibility, internal consistency, and validity compared with the Korean version of DAST-10, which was the only reliable Korean SUD screening tool, were assessed among 100 opioid-prescribed patients visited our pain clinic.

**Results:** A hundred patients completed questionnaire, 41 were with cancer and 59 were without cancer. Two groups showed similar characteristics in pain intensity, comorbidities. More than half of the respondents considered cutting-off their dosage. The feasibility of CAGE-AID/Opioid was better than DAST-10. The internal consistency was lower than previous English studies, but their scores converged well on the DAST-10 score. Interestingly, item inter-correlation analysis exhibited that the thinking to cut-off drugs was related with the complaint from the family member, and other psychometric factors. In addition, Korean women were more likely to reduce narcotics and feel guilty, despite of much smaller narcotics use.

**Conclusion:** The Korean CAGE-AID/Opioid is easy but effective for SUD screening in primary health care situations. This study disclosed the family-dependent factor of problems related with opioid use in South Korea, and the women’s psychologic susceptibility. Small sample size is a limitation of this study.
**Abstract number:** P02-017  
**Abstract type:** Poster Exhibition

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**Frequency of Vulnerable Geriatric Oncological Cancer Patients**

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**Background:** Cancer patients (pts) of >=75 years are an increasing population at risk both for under- and overtreatment by anticancer interventions. Comprehensive geriatric assessment (Wildiers H J Clin Oncol 2014) and associated geriatric and palliative interventions may improve reversible vulnerability promoting conditions.

**Aim:** To assess the number of vulnerable patients in in- and outpatient cancer clinics in one institution

**Method:** Prospective, one month assessment of all patients >=75 years by the G8 screening tool (Decoster L AnnOncol 2015), oncologist’s perception of need for a supportive/palliative oncology consult. In the medical charts of all eligible pts the screening tool and a brief letter was provided, up to 3 reminders were applied. In still missing data (12%) oncology charts were reviewed for weight loss, oncologists’ documented anorexia, poor function, cognitive impairment or depressive symptoms, and number of medications, pts self-perception of health was set as “unknown”.

**Results:** Of 1356 pts screened, 173 (13% of population) were >=75 years old. 157 G8 were completed (response rate: 91%), of them 86 pts (55%) were identified as vulnerable (1 out of 16 overall). For 12/86 (14%) oncologists’ perceived spontaneously a palliative oncology consult as appropriate. In 5 not vulnerable (G8 >=14) pts, however, relevant comorbidities (e.g. cardiovascular) were clinically significant with regards to anticancer treatment decisions. Oncologists interest is raising with regards to impact of vulnerability and anticancer decision-making. Analysis of selected G8 items contributing to vulnerability as well as applied geriatric and palliative interventions is ongoing.

**Conclusion:** A relevant number of unselected cancer pts is vulnerable based on G8 screening. Application of tailored oncology geriatric and palliative oncology interventions to achieve short- to midterm improvement may assist to avoidance of both over- and undertreatment.
Abstract number: P02-018
Abstract type: Poster Exhibition

**Individual Quality of Life and Important Areas in Terminally Ill Patients**

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**Background:** Palliative care is an approach that improves the QOL of patients. However, individual QOL widely varies depending on what the patient considers important. The aim of this study was to examine important areas and their relative weight and individual QOL in terminally cancer patients.

**Methods:** Individual QOL was assessed using the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) on palliative care outpatients and inpatients consecutively. The SEIQoL-DW is a semi-structured interview that elicits 5 areas considered important by the patients and produces individual global QOL score(SEIQoL-index), calculated as $\sum$ (satisfaction levels $\times$ relative weights of each area). We analyzed important areas, and relative weights for each areas and SEIQoL-index.

**Results:** Fifty-five terminally ill patients (mean age 67±8) completed the SEIQoL-DW.

The most frequent of areas were family(98%), hobbies/activities(60%), health(57%), friends(51%). The largest average weight of areas were family(42±19%), health (33±19%), mental state(19±10%). The mean SEIQoL-index of each patient was 73.6±18.4.

**Conclusion:** While the areas that patients consider important vary, family and health have great impact on the individual QOL in terminally ill patient.
Abstract number: P02-019
Abstract type: Poster Exhibition

Life and Death: A Comparison of ICU Physicians’ and Internists’ Survival Predictions for Patients Assessed for Intensive Care

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Background: Expected improvement in survival is the main justification for admitting a patient to intensive care (ICU), but seriously ill patients are at high risk of dying in the ICU. Physicians’ ability to accurately prognosticate survival of a patient assessed for intensive care is not known.

Aims: Assess referring internists’ and ICU physicians’ abilities to predict patient survival on the ward and in the ICU, and determine whether the survival estimates correlate with the admission decision and with observed survival.

Methods: All consecutive requests for ICU admission made for patients hospitalized in the division of internal medicine were identified. The ward and the ICU physicians involved were contacted within 12 hours and asked to estimate patient survival using predefined categories of probabilities. The admission decision and patient characteristics were collected. We used regression models for the analysis.

Results: 201 patients were included, of whom 140 (69.7%) were admitted into the ICU. Overall 58 patients (28.9%) died within 28 days. Physicians predicted a survival benefit from intensive care for most patients. Agreement between internists and ICU physicians was good (Spearman rho 0.5). Higher survival ratings by both groups of physicians were associated with higher proportions of admitted patients, but the admission decision was more strongly influenced by the ICU physicians’ estimates. Observed patient survival was strongly associated with predicted survival by both physicians. The internists’ prediction however was more accurate than the ICU physicians’, whether the patient stayed on the ward (areas under the ROC curves 0.74 vs 0.69) or was admitted into the ICU (area under the ROC curve 0.76 vs 0.63).

Conclusion: Internists more accurately predict survival probabilities for patients assessed for admission to intensive care than ICU physicians. However, ICU physicians’ estimates more strongly influence the admission decision.
Introducing the Comfort App: Connecting Patients and Families in Palliative Care

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Background: Comfort is an important outcome for patients with life-threatening illness, and symptom management is crucial in this endeavour. But this could be difficult in some contexts, such as in home care. E-health can bring an opportunity in promoting comfort.

Aim: To develop an app to monitor comfort remotely in PC home patients.

Methods: Feasibility study, according to the Medical Research Council Framework for the development and evaluation of complex interventions. Conceptual framework included a systematic literature review and a qualitative study regarding comfort in PC settings. Content validity was discussed by a panel of experts in PC (n=5). A web-based custom domain, compatible with Android, iOS and Windows was used to the app design. The aesthetics was chosen through an online survey (n=120). Participants were recruited from two hospitals with home care visits. Eligibility criteria included life-threatening illness diagnosed, be at home, and have a computer device with internet access. The study was approved by the ethics committee.

Results: The Comfort app is a free and web-based app, which is intended to be completed by PC home patients through a smartphone, tablet or computer with internet access. It includes 11 symptoms in a Likert scale, based on the Portuguese Edmonton Symptom Assessment System and the Spiritual End of Life Portuguese Comfort Questionnaire. Preliminary results from the feasibility study conclude that the app is feasible, intuitive, and easy to use. Main problems are related with patient’s recruitment, due to the late referral to PC.

Conclusions: This app promises to be a useful tool to monitor comfort as a compliment to PC teams work in improving communication, organization of care, and promoting early and individual comfort interventions.
**Psychometric Properties of the DEDC Scale: A New Tool for the Detection of Emotional Distress of Caregivers of Patients with Advanced Illness or at End of Life**

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**Background:** Primary caregivers of advanced illness patients usually have high levels of psychological distress. To alleviate the emotional distress suffered by these caregivers is necessary to assess it.

**Purpose:** To determine the psychometric properties and the clinical utility of the new tool Detection of Caregivers Emotional Distress (DCED) of advanced cancer patients attending in a Palliative Care Unit (PCU). DCED scale have two parts: the first contains three questions addressed to the caregiver: two related to mood state and coping perception and another that records the main concerns; the second part consists of an observation of external signs of emotional distress made by the health professional.

**Methods:** 132 primary caregivers of advanced cancer patients admitted to PCU participated in this study. The caregivers responded DCED and the following tools: Reduced Zarit Scale (RZS), Emotional Thermometer (ET), and Anxiety (A) and Depression (D) by analogue visual scale.

**Results:** Mean age of caregivers of patients were of 59.69 (SD 13.3). It was noted that 54.3% had moderate to severe emotional distress. The cut-off point for DCED evaluated by means of Receiver-Operating Curve (ROC) suggested that the best ROC curve is a value $\geq 10.5$, with a specificity between 75% and 97% and a sensitivity between 68% and 83.3%. It was found positive and significant statistically intraclass correlations with ET, RZS, A and D. The internal consistency measured by alpha of Cronbach was .76.

**Conclusions and discussion:** The DCED present a good psychometric properties, is an useful and easy tool to use for the screening of emotional distress of caregivers. Our results justify the systematic use of DCED as a screening instrument in the clinical praxis and it allows deriving a specific professional if necessary.

**Acknowledgements:** This study was supported, in part, by the Grant PSI2013–43555-R from the Ministerio de Economía y Competitividad MINECO (Spain).
Abstract number: P02-022
Abstract type: Poster Exhibition

**PANA: A Palliative Approach for Nursing Assistants’ Scope of Practice – Instrument Development**

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**Aim:** Nursing assistants are the largest aged care workforce providing direct care to older people in residential aged care facilities (RACF). A palliative approach is a large component of this care. Determining nursing assistants’ knowledge, skills and attitudes when providing care with a palliative approach is yet to be evaluated using an instrument specific to their scope of practice. This study aimed to develop such an instrument.

**Method:** The development and testing of the new instrument comprised four separate, sequential phases: items were generated from qualitative interviews (n=25) with nursing assistants in Phase One; item content was validated with experts in Phase Two; three separate questionnaires were pilot tested as one whole instrument in Phase Three; and, the psychometric properties of the new instruments were evaluated in Phase Four.

**Results:** A random sample of 348 nursing assistants across 17 RACFs in metropolitan Sydney completed the instruments. Individual items were analysed for difficulty, discrimination and item-total correlations. Three separate instruments were finalised: the PANA_Knowledge Questionnaire, the PANA_Skills Questionnaire and the PANA_Attitudes Questionnaire which addressed the criteria for validity and reliability.

**Conclusion:** This study provides preliminary evidence for the acceptability, validity and reliability of three new instruments to evaluate nursing assistants’ knowledge, skills and attitudes and a palliative approach in the context of strong growth in the aged care sector, increasing numbers of frail elderly residents and a steady rise in number of nursing assistants.
Validity and Reliability of the Integrated Palliative Care Outcome Scale Staff Version (IPOS-SV) in an Inpatient Hospice

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Background: Singapore lacks a validated screening and palliative outcome measure. It is timely to determine if the Integrated Palliative Care Outcome Scale staff version (IPOS-SV) is a valid and reliable tool for our local population in an inpatient hospice.

Objective: The primary aim is to test the validity, reliability, responsiveness to change, acceptability and floor-ceiling effects of the IPOS-SV. The secondary objectives are to categorize the open-ended questions and identify the worst symptoms for patients near the end-of-life (EOL).

Method: A retrospective, longitudinal, analytical approach was used. 150 patients died in an inpatient hospice in Singapore between 1st May–31st August 2015. 105 patients (70%) met the inclusion criteria. Patient data was systematically entered into a purposefully designed spreadsheet. Analysis was done using IBM SPSS v22.

Results: The IPOS-SV is valid and reliable on measures of known group comparisons (p < 0.05). It has an internal consistency of Cronbach’s alpha 0.7, is responsive to change in 35% (6 out of 17) of the items tested and has good acceptability with < 5% missing data. However, it lacks adequate floor effects, thus limiting content validity and reducing reliability and responsiveness. Fever and restlessness/confusion were the top two ‘Other Symptoms’ reported. Dyspnea, drowsiness and informational needs improved at the EOL (p < 0.05). Although weakness and poor mobility were statistically significant, these symptoms are accompaniment of the dying phase which are harder to reverse. Nurses’ were able to use IPOS-SV to assess spiritual well-being where the feeling of ‘at peace’ scored more than zero 82% of the time.

Conclusion/discussion: Data for this study relied solely on IPOS-SV. While it is valid and reliable in some aspects, full status validation will require further testing for face/content validity, convergent/discriminant validity, time to completion, test-retest and inter-rater reliability.
Comparative Assessment of Mindfulness Interventions in Palliative Care Professionals

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Background: Among the profits of full attention practice for health: self-regulation of emotions, greater cognitive flexibility, ease to cultivate positive traits and states. This potential perfectly fits professions with high emotional demands as palliative care or police, with long turns, large workload and daily contact with death and grief. Stressful situations can diminish professional efficiency, attention and concentration, even hamper decision taking or hinder the therapeutic alliance.

Aim: To compare effectivity of mindfulness interventions in palliative care vs other stressful professions.

Design and participants: Separated meta-analysis to estimate the mean effect size. Mindfulness interventions in 3 groups (18 sanitary and 18 non sanitary palliative care professionals, 25 police). Pre-test and post-test measures of PROQoL (burnout, compassion fatigue and compassion satisfaction) and FFMQ (5 factors) were assessed. Means, effect size (g index) Q and the I² were calculated.

Results showed a statistically significant mean effect for four of the five dimensions FFM-Q: observing ($g=0.86$, 95% CI = 0.33, 1.39, $Q(2)=6.271$, $p=.040$, $I^2=68.83$), describing ($g=0.46$, 95% CI = -0.41, 0.96, $Q(2)=6.976$, $p=.031$, $I^2=71.33$), acting with awareness ($g=0.33$, 95% CI = 0.08, 0.58, $Q(2)=1.125$, $p=.570$, $I^2=0$), non-judging of inner experience ($g=0.55$, 95% CI = 0.001, 0.11, $Q(2)=7.946$, $p=.019$, $I^2=74.83$) and non-reactivity to inner experience ($g=0.65$, 95% CI = 0.38, 0.92, $Q(2)=0.998$, $p=.607$, $I^2=0$). From PROQoL, only compassion satisfaction showed a statistically significant pooled effect size.

Conclusion: A medium to large pooled effect size of mindfulness interventions is found in compassion satisfaction, acting with awareness, and non-reactivity dimensions. These outcomes work similarly independent of the context. In conclusion sanitary and no sanitary palliative care and police professionals could both equally benefit of that useful intervention.
Abstract number: P02-025
Abstract type: Poster Exhibition

Outcomes of Care among Patients Supported by Specialist Palliative Care Services in Mulago National Referral Hospital

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Background: Makerere Palliative care Unit (MPCU) is a hospital based specialist palliative care service in MNRH providing PC services using a model of specialist support alongside intermediate and generalist PC provision integrated within training, service provision and policy. This model is a relatively new concept in Africa needing evaluation.

Aim: To determine the physical/psychological, interpersonal and existential outcomes among patients supported by specialist palliative care (PC) services in Mulago National Referral Hospital (MNRH).

Methodology: This was a prospective study recruiting patients referred to MPCU who were then assessed and managed alongside the core clinical teams. Patients were assessed on three consecutive visits three days apart noting changes in APCA scores underpinning physical/psychological, interpersonal and existential domains. Demographic, performance status and clinical assessment of complexity were recorded.

Results: There was improvement in physical/psychological, interpersonal and existential outcomes across the three study visits with statistical significance in median scores. Patients with more advanced illness receiving higher opioid doses (>5mg) and dying in hospital experienced 13% and 19% poorer physical/psychological outcomes respectively while ECOG 4 patients experienced 21% poorer existential outcomes. This reflects poorer outcomes in patients presenting with complex and advanced PC need.

Conclusions/ discussion: The MPCU model of specialist support alongside intermediate and generalist PC providers has improved outcomes across physical/psychological, interpersonal and existential domains among patients with PC needs in MNRH. Whilst MPCU has demonstrated a practical model to address the high unmet need of hospital based PC in Mulago hospital, there is need for improving awareness among health providers on the role played by the specialist PC team in supporting intermediate and generalist PC providers.
Strengthening Health Systems through the Integration of Palliative Care in Public Hospitals in Kenya and Malawi

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Background: The Waterloo Coalition (Coalition), comprised of The True Colours Trust; Diana, Princess of Wales Memorial Fund; African PC Association (APCA); Global Access to Pain Relief Initiative; International Children’s PC Network; and Worldwide PC Alliance, was an initiative to improve access to palliative care (PC) in Malawi and Kenya.

Aims: To measure the impact of the first phase of the project.

Methods: A consensus meeting of experts agreed upon 11 indicators as essential for PC integration in Africa and specific to measuring outcomes for the Coalition. The Coalition supported work at 13 public hospitals in Malawi and 11 in Kenya from 04/2011 to 12/2012. Data was collected by country project teams supported by APCA and focused on a 3 month period (09/2012 to 11/2012) for indicators 5, 6, 7, 8, 10, a cross-sectional snapshot in 12/2012 for indicators 1, 2 and 11, and 1 year period for indicators 3, 4 and 9 (baseline 07–10/2011 and endpoint 09–12/2012) (Table 1).

Results: In Kenya, the number (no.) of hospitals with PC services increased from 1 to 6. The no. of hospitals with protocols and guidelines (P&G) including PC increased from 2 to 11; the no. of professionals trained from 76 to 238; the no. of patients receiving morphine from 64 to 272; the no. of patients receiving PC from 122 to 897; the no. of patients assessed for PC from 330 to 746; and the no. of patients receiving pain relief from 251 to 788.

In Malawi, the no. of hospitals with PC services increased from 1 to 12. The no. of hospitals with P&G including PC increased from 1 to 13; the no. of professionals trained from 79 to 253; the no. of patients receiving morphine from 77 to 463; the no. of patients receiving PC from 72 to 1,463; the no. of patients assessed for PC from 938 to 1,482; and the no. of patients receiving pain relief from 95 to 1,460.

Conclusion: The Coalition made tremendous achievements in establishing and progressing PC services in Malawi and Kenya.
Does Agreement between Patient and Nurses Reported Symptom Burden Improve Over Time? A Longitudinal Study

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Patient self-assessment is the gold standard to assess symptom burden. However, the proportion of hospice patients able to self-assess symptom burden declines towards death.

Aim: To study if agreement between patient- and nurse reported symptom burden improves in the first weeks after admission?

Method: A longitudinal research study was performed from. All patients admitted January 2012 to January 2015 to a 7-bed hospice with dyads of paired patient- and nurse-reported symptom burden, were enrolled. Per patient, the first dyad per week was selected for the first 4 weeks after admission. The main research variable was symptom burden. The Utrecht Symptom Diary(USD), a Dutch adapted translation of the Edmonton Symptom Assessment System, was used to self-assess symptom intensity on a 0–10 numerical scale. Nurses used the USD-professional to assess symptom intensity on a 0–4 Likert scale.

Observed agreement was the difference between the USD and USD-p. Agreement beyond chance was calculated using the squared weighted Kappa.

Results: In total 147 patients, 85 women (58%), aged 70 were enrolled.

The observed agreement was high for anxiety (m69%, 64%-74%), nausea (m69%, 66–72%) and dysphagia (m64%, 63%-66%). The observed agreement of dry mouth (m37%, 32%-46%) and fatigue (m40% 33%-44%) were low. Moderate to fair agreement beyond chance was found for dyspnea (κ = 0.63), anorexia (κ = 0.51), fatigue (κ 0.45), nausea (κ 0.41) and pain (κ 0.41). Only poor agreement was found for anxiety (κ 0.19).

Symptoms with the highest intensity, had the lowest observed agreement, in contrast, symptoms with a large bottom effect showed a high observed agreement. Both observed agreement and agreement beyond chance were stable over time.

Conclusion: Observable symptoms have a better agreement than symptoms which cannot be observed directly and low intense symptoms show high agreement but low agreement beyond chance. The observed agreement and agreement beyond chance did not improve over time.
Abstract number: P02-028
Abstract type: Poster Exhibition

**Validity and Reliability of the Pain Catastrophizing Scale for Psychological Assessment of Cancer Pain**

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**Background:** Pain Catastrophizing is an important psychological factor for assessing and treating of pain based on biopsychosocial model. The Pain Catastrophizing Scale (PCS) has been developed and validated as an assessment tool of pain catastrophizing for patients with chronic non-cancer pain. However, the method for assessing the pain catastrophizing in cancer pain patients has not been established.

**Aim:** The aim of this study was to assess the validity and reliability of the PCS for psychological assessment of cancer pain.

**Methods:** Data from 100 patients (55 male, 45 female; age = 60.7 ± 13.9) with cancer-related pain were employed to investigate construct validity by confirmatory factor analysis. As absolute fit indices, the χ², χ²/df, the root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR) were used. On behalf of incremental fit indices, the comparative fit index (CFI) and the Tucker-Lewis Index (TLI) were used. Concurrent validity was examined by Pearson correlation coefficients among the PCS, Brief Pain Inventory (BPI), the subscale “catastrophizing” of Coping Strategy Questionnaire (CSQ), Hospital Anxiety and Depression Scale (HADS), and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative (EOLTC QLQ-C15-PAL). Internal consistency was investigated by Cronbach’s alpha, and test-retest reliability was indicated with intra-class correlations (ICCs) in 24 patients within two weeks.

**Results:** The PCS showed goodness-of-fit with the data (χ²; 103.79, χ²/df; 1.67, RMSEA; 0.08, SRMR; 0.088, CFI; 0.95, TLI; 0.94) and sufficient reliability (Cronbach’s alpha; 0.93, ICCs; 0.84) in patients with cancer-related pain. Pearson correlation coefficients among PCS, BPI, CSQ, HADS and EOLTC QLQ-C15-PAL ranged from -0.46 to 0.54.

**Conclusion:** This study demonstrated the validity and reliability of the PCS for psychological assessment of cancer pain.
Introducing Patient Outcome Measures to A Hospice – Valuable Lessons Learnt

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Background: In 2014, Public Health England published a joint statement about plans to work together to explore the feasibility, options and costs of collecting individual-level adult palliative care data nationally. Marie Curie Hospice, West Midlands was one of these pilot sites.

Aims: To collect the data set information over a 3 month period at the end of 2015 within an electronic patient record and assess this process to guide widespread implementation for the future.

Method: There were 3 parts of this dataset collection
1. Education of staff:
   Introduction of patient outcome measures is a much needed tool. It requires a major shift in culture of hospice staff from a clinician perspective to a patient perspective. 5 different tools were required to be introduced. Engagement meetings were held with all staff within the hospice. Champions within each team were identified.
2. Design of data collection tools within the electronic patient record (SystmOne)
   Having had an electronic patient record for 5 years at the hospice, we were clear from the start that any outcome measures would need to be collected within the system and not as a stand-alone paper exercise but this was challenging
3. Extraction of data:
   Alternative methods of data extraction using external agencies were required at a cost both financially and timeliness.

Results: Data collection occurred during the 3 month period as required. The data quality was fairly poor at the beginning and improved over the period. Methods Raw data was extracted and uploaded to public health England.

Conclusions: The turnaround time for preparing to collect this dataset was 3 months. For the amount of work required to introduce new patient outcome measures, educate staff, change culture, restructure an electronic patient record and report on it, a much larger period of time would.
Interdisciplinary Coordination Reduces Undignified Ambulance Services and Costs

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Background: When a general practitioner is not available, the usual approach when confronted with pre-terminal crisis situations in residents of a care home is to call the emergency ambulance or request an emergency medical service.

Aim: To assess whether the number of undignified ambulance services and deportations to the hospital can be reduced by medical coordination in the nurse home. Economic aspects will be addressed.

Methods: We compared three test care homes (266 residents) with medical coordination, and 3 reference care homes (151 residents) and 4 additional reference care homes that were not involved in the project. The regional rescue center provided data concerning the number of emergency medical services, emergency doctor’s calls, and medical transport services. The data were obtained as follows: data were collected from the test care homes for the period of the pilot project (1.9.2014–31.8.2015) and for the same period in the preceding year (1.9.2013 to 31.8.2014).

Results: The three test care homes were able to reduce their rescue missions during the year of the project and stabilize the number of emergency doctor’s visits, i.e. maintain the number at the same level. This was seen on comparison with the preceding year, and with the primary as well as secondary reference care homes, in which the number of emergency doctor’s visits as well as rescue missions had risen in the second year. While the test care homes were able to reduce their emergency care costs by €17,784, the costs rose in the primary reference homes by €10,277 and in the secondary reference homes by €32,216.

Conclusion: Interdisciplinary coordination in nurse homes improves anticipatory planning and avoids undignified hospitalizations in palliative crisis situations. The saving for the health economy exceeds the overall costs of medical coordination, excluding the cost of hospitalization.
Patient Empowerment, What Is it and What Does it Mean for Adults in the Advanced Stages of a Life-limiting Illness? A Systematic Review and Critical Interpretive Synthesis of Existing Evidence to Inform Palliative Care

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Background: Patient empowerment, defined by the World Health Organization as “a process through which people gain greater control over decisions and actions affecting their health”, has evolved as a key theme within health and social care strategies globally in recent years. The majority of published empirical research has been focused on persons living with chronic health conditions in the context of health promotion.

Aim: We sought to identify and synthesise the international published evidence on definitions of patient empowerment for persons living with advanced, life-limiting disease.

Methods: Broad-based searching of 4 electronic databases, hand-searching three journals with bibliographic searches of relevant papers conducted. Relevant systematic reviews were examined for secondary data searching. Inclusion criteria: Empirical research including descriptions of, or references to, patient empowerment within the study results irrespective of the primary objectives. A critical interpretive synthesis was performed with 25% of coding cross-examined to enhance reliability.

Results: Of 20184 retrieved references 11 studies, of substantial heterogeneity, met inclusion criteria. Of 7 primarily qualitative studies just 2 explored patient empowerment as a study objective. Whilst 4 studies described interventions with the outcome of empowering patients, including question prompt lists, patient satisfaction questionnaires and patient-centred services with educational and self-management facets. Themes identified from the synthesised results included; self preservation, knowledge in theory and in practice, acknowledging life in the context of terminal illness, negotiating personal and healthcare relationships and navigating continued losses.

Conclusions: There is a paucity of research and absence of a consensus definition currently. We present a preliminary conceptual model of patient empowerment as a foundation for future research towards a consensus definition.
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Who we Are and What Palliative Care Professionals Do When we Deal with Advance Care Planning

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Background: Recent contributions on Palliative Care (PC) research have emphasized the need to know how to incorporate an Advanced Care Planning (ACP) process into a regular patient care.

Aim: To estimate the levels of implementing ACP process through the regular care actions from the professional practice’s perspective.

Methods: Cross-sectional descriptive study of ACP in Spain. A 68-item self-administered questionnaire (IMPLANT-PAD) 5 points Likert-type scaled response was designed to collect data about professional’s decision on ACP on 7 dimensions: Palliative Identification; Impact-illness trajectories disease; Resignification-Meaning of life; Treatment Options Discussion; Coordinating Health equipment and resources; Following and Updating and Training-Innovation Research. All the participants were enrolled in palliative activities since the questionnaire was administered via network of Spanish Palliative Care Society (SECPAL).

Results: 191 participants (124 female and 67 male) with a mean age of 49.1 (range 28 to 70 years). The participants represented 20 autonomous communities with most participants coming from Valencia Community (19.9%), Cataluña (15.7%) and Madrid (12.0%). Most of the professionals are physicians (66.5%) and nurses (19.9%). More than half (55.3%) have a palliative experience background with more than 10 years and 61.4% have a chronical illness experience with more than ten years. Mean values±standar deviation for each subscale were:Palliative Identification (3.3±1.0); Impact-illness trajectories disease (3.4±0.9); Resignification-Meaning of life (3.3±1.0); Treatment Options Discussion (3.3±1.0); Coordinating Health equipment and resources (2.9±0.9); Following and Updating (3.3±1.0) and Training-Innovation Research (2.5±1.0).

Conclusion: The lower impact levels for coordinating and Training-innovation research subscales indicate the need to improve coordinating health resources and training concerning ACP best practice.
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Evidence of Validity of the Case Complexity Index (ICC)

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Background: Given that there is no consensus on the definition of the construct “complexity”, the number of validated instruments is scarce. In this context, it was designed the “Case Complexity Index (ICC)” in order to identify complex patients requiring case management.

Aims: To analyse the level of concordance between The Case Complexity Index (ICC) and the Clinical Risk Groups (GRGs). Examine the ability of the Case Complexity Index to identify different profiles of the cases.

Methods, design and sample: A cross-sectional study. The sample consisted of 518 patients identified as new complex case during January 2014 in 11 health departments.

Data collection: The instrument consisted of 14 indicators divided into two dimensions: clinical complexity and community complexity. 30 case manager nurses were in charge of data collection. CRGs in each of the selected patients were obtained from electronic medical records (SIA-Abucasis).

Analysis: Frequencies and percentages of the number of complex patients according to the ICC by CRG level were obtained. A descriptive analysis of all possible combinations of presence/absence of the 14 indicators was carried out in order to identify the different profiles of complexity.

Results: The 88.4% of patients identified as complex cases were classified at levels 6 to 9 of the CRGs.

On the other hand, the analysis of different profiles identified 314 types of patient profiles. Most cases identified (n = 245; 47.3%) were unique and individual.

Conclusion and discussion: The ICC showed a high concordance with the higher levels of the CRGs. The ICC is able to identify common elements in many cases and a variety of cases with individual profiles. CRG are based on morbidity whereas ICC combine clinical and community complexity.

The 11.6% of non-concordance may be due to cases with lower clinical (morbidity) but higher community complexity identified as “complex” by ICC but not by CRG.
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Professional Self-care in Argentina, Brazil and Spain: A Translational Research in Palliative Care Teams

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Background: Kearney and Weininger’s model provides a helpful roadmap of the variables implied in palliative care professionals’ quality of life. Model includes as antecedents specific training, awareness and self-care, as mediators coping with death and burnout, satisfaction compassion and fatigue compassion as outcomes. Although the increasing interest for professional self-care, research in palliative context from a translational perspective is scarce.

Aim: To compare the prevalence of self-care dimensions through different health care systems using the Professional Self-Care Scale (PSCP) measuring physical, inner and, social self-care.

Design: Cross-sectional studies with online survey were held from 2014–16. Once ethical committees’ approvals were obtained, main professional associations in each country (Pallium Argentina, ANCP Brazil and SECPAL Spain) launched nationwide invitation for anonymous participation.

Participants: 817 professionals from Argentina, Brazil and Spain (33%, 20% and 47%, respectively) fulfill criteria with a response rate ranging from 34 to 55%. Multidisciplinary respondents in all samples were mostly women (doctors or psychologists, nurses, social workers,..).

Results: Scale reliability and factor validity was equivalent and satisfactory in all samples. It also was sensitive enough to reveal significant cross cultural differences with MANOVA (Pillai’s trace=.058, p< .001, $\eta^2$=.03). Each dimension reaches its highest mean in a different country (physical in Spain, inner in Brazil and social in Argentina).

Conclusion: As palliative care practice is very demanding, ignoring professional self-care could negatively affect professionals’ quality of life. Consequently, the role of professionals as instruments for the relief of suffering in patients and their caregivers is putting at risk. Hence, having a new, short and reliable valid measure for professionals’ self-care monitoring, becomes a step forward in the global healthcare system improvement.
Construct Validation of a Palliative Care Needs Assessment Tool for Use in Primary Care

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Background: The Australian needs assessment tool for progressive disease (cancer) (NAT:PD-C) was designed to help non-palliative care clinicians identify and triage palliative needs of cancer patients and carers. It is a one-page, clinically acceptable tool shown to reduce unmet needs in the oncology clinic. We adapted the tool for use in UK primary care.

Aims: To test the construct validity of the NAT:PD-C primary care.

Methods: General Practitioner (GPs) participants assessed a cancer patient using the NAT:PD-C. The patient and carer (if available) completed comparator tools relating to NAT:PD-C constructs (Edmonton Symptom Assessment Scale [ESAS-r], RUG-ADL, Palliative Care Outcome Scale [POS], Carer’s Supportive Needs Assessment Tool [CSNAT], Caregiver Strain Index [CSI]). 38 patient-assessments were needed for >90% power to detect agreement. Kendall’s Tau-b correlation coefficient was used to assess the correlation between the NAT:PD-C patient items and patient-report outcomes.

Prevalence-and-bias- adjusted kappa (PABAK) was used to assess agreement between NAT:PD-C carer items and carer-report outcomes and those relating to information needs.

Results: 17 GPs with a wide range of clinical experience assessed 39 patients (age 74 years, SD 13.6; 56% male) and 22 carers. Patients had a median Australian-modified Karnofsky Performance Score of 60% (IQR 60 to 70) There was significant agreement for 4/6 of the patient domains (physical [p=0.027] and psychological ([p=0.012] symptoms; physical functioning [p< 0.001]; spiritual concerns [p=0.009]) and 5/8 of the carer domains (moderate agreement for providing physical care (PABAK 0.583), coping with psychological problems (PABAK 0.475); strong agreement for information needs (PABAK 0.692) and impending grief (PABAK 0.64). The stronger correlation between GP and patient assessment of function than symptoms is notable.

Conclusions: The NAT:PD-C has construct validity despite the broad constructs and range of clinical expertise.
How Do We Know how People Die? An Attempt to Assess the Dying Process at Home

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Introduction: The evaluation of quality of death is object to current end-of-life research. In this project we evaluate the dying phase of patients of our home based specialised palliative care team (SAPV) by using a novel paper based evaluation form.

Methods: We implemented an evaluation form that was filled out immediately after the patient had died. Besides general data it included an assessment of the patient’s ability to give consent, to communicate and his consciousness 24h and 12h before death and at the last visit of a team member. In addition to other items screened at this last visit, a problem severity score (at time of death) for the patient (PSS patient) and the relatives (PSS relatives) was implemented to describe the dying phase itself.

Results: In 2014 108 patients died at home.

PSS patients:
78% calm, settled (score 0)
8% “dying work” (score 1)
4% intervention required (score 2)
6% crisis (score 3)
4% n.a.

PSS relatives:
19% calm, relieved (score 0)
40% calm, sad (score 1)
25% burdened (score2)
9% crisis (score 3)
7% n.a.

Despite the use of continuous parenteral medication via syringe drivers (79% of patients), verbal communication was possible 24h before death in 66%, 43% of patients were even able to give consent. 12h before death 55% were able to communicate, 26% to give consent. At the last time the patients were seen by our team, 31% could still communicate verbally; 20% were unsettled but helped by demand medication, 6.5% were moaning and needed crisis intervention.

Discussion: The implementation of problem severity scores together with the evaluation form enables us to assess the dying phase. Most patients are still able to communicate shortly before death. We can demonstrate that most patients die peacefully, that some interventions are required and crisis are rare. However, families remain often burdened. The limitation of this method is that it is based on subjective assessments – but how else at the very end?
Validation and Application of the “Palliative Outcome Scale” (POS) in Brazil

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Background: The Palliative Outcome Scale (POS) rates quality of life of people who have life-threatening chronic diseases.

Aim: The objective is to present results of psychometric measures of three validation studies in chronic diseases patients in Brazil.

Method: It’s a methodological research. The POS has 10 items, 2 domains and Cronbach’s alpha of 0.65 in patient version (Hearn; Higginson, 1999). The steps for translation and cultural adaptation were followed as proposed by Beaton et al (2000). 50 patients with different types of cancer (Experiment 1), 50 patients in oncologic palliative care (Experiment 2) and 1698 subjects with oncological and non-oncological chronic diseases (Experiment 3) were enrolled in the validation studies. Exploratory analysis to determine the domains existents and the total Cronbach’s alpha of the scale were done.

Results: In the Experiment 1, factor analysis indicated the presence of four factors and the Cronbach’s alpha for the total scale was 0.535; the exclusion of items 4 and 9 led alpha values to 0.56 and 0.55, respectively. In the Experiment 2, two factors were identified and the Cronbach’s alpha value for the total scale was 0.45; the exclusion of items 9 and 10 led to alpha to 0.51. In the Experiment 3, factor analysis showed four factors and the Cronbach’s value was 0.558; if the item 5 was excluded the alpha achieve 0.587. Convergent validity tested by correlation of the POS-Br and the dimensions of the European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire-Core-30 (EORTC QLQ C-30), for Experiment 1 and 2 showed moderate correlations.

Conclusion: The validations studies of POS developed in Brazil, comparing with the original study, showed different results: we found more domains and the Cronbach’s alpha were lower. POS Brazilian version has limitations to be used in clinical and research contexts.
Measuring Specialist Palliative Care in England – Results of a New National Data Collection Pilot to Measure Patient and Carer Outcomes

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Aim: There is currently no population-based data or comprehensive source of outcomes data in specialist palliative care (SPC) services in England. We therefore aimed to pilot a new national data collection set for specialist palliative care to collect individual-level data, including patient and carer outcomes, service activity data and case mix.

Methods: Ten SPC pilot sites tested collection of the data set of 47 data items derived by expert consensus, and using valid and reliable outcome tools. Feasibility, practicality and costs of data collection were measured using mixed methods (process and implementation evaluation, and qualitative interviews).

Results: The data set was feasible to collect although only 8 sites provided complete data submissions within the 11 months allowed. There were delays due to the consent process which was included to allow sharing of patient-identifiable data and assess impact of consent on feasibility. Staff reported that the dataset had positive impact on patient care, staff communication and working practices. Time taken to implementation was 0–11 months and depended largely on time to configure IT systems. Interviews identified that support from clinical leaders was the most important factor for successful implementation. Costs varied from £3,000 to over £100,000, depending on IT readiness and experience of outcome measures.

Conclusions: The dataset is capable of collecting individual patient-level outcome and case-complexity data. The pilots provide limited but positive evidence of patient, staff and organisational level benefits. Consent for data sharing is a major barrier and ways of addressing this for a national data collection are being explored. Further validation of the dataset as a tool to measure and assure care quality should be undertaken.

Acknowledgements: The project was funded by NHS England and Public Health England supported by partners including Monitor, NHS Digital, Hospice UK and Cicely Saunders Institute.
Validation and Clinical Utility of the Portuguese Version of the Revised Edmonton Symptom Assessment System (ESAS-r) in Patients with Metastatic Bone Disease

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The Edmonton Symptom Assessment System (ESAS) is used widely in patients with cancer to screen for key symptoms. To date there are no published literature on the validity, clinical utility, reliability and patients’ views of either ESAS version in a Portuguese setting.

Aims: To evaluate the concurrent validity, responsiveness to change and reliability of a Portuguese version of the ESAS-r (P-ESAS-r) in patients receiving radiotherapy for palliation of bone pain.

Methods: We conducted a prospective validation study in a Radiation Clinic. The P-ESAS-r [on Day 1 to 7 (W1) and D21–28], EORTC QLQ-C30 (D7), Epworth Sleepiness Scale (D7), patient’s global impression of change (PGIC) on D21–28, as well as demographic and feasibility questions were administered to enrolled patients following consecutive screening. Verbal communication difficulties, cognitive impairment or delirium were exclusion criteria.

Results: Seventy-five patients (median age 62, 45% at least secondary level of education) completed the study. The P-ESAS-r had an acceptable internal consistency (Cronbach alpha 0.78). The 24-hour test-retest coefficients ranged from 0.1 to 0.89. The mean W1 scores for pain, dyspnea, loss of appetite and depression on P-ESAS-r were strongly correlated to matching symptoms on EORTC QLQ-C30 (r=0.75 to 0.99). In D21–28 post radiation, no significant changes in patients’ morphine equivalent daily dose, pain and dyspnea scores were seen. No association was found between P-ESAS-r pain intensity differences and PGIC. One in 3 patients needed help to fill the P-ESAS-r. The meaning of well-being, drowsiness and rating lack of appetite caused most difficulty for patients.

Conclusions: The P-ESAS-r demonstrated reasonable reliability and construct validity evidence in this sample. The low correlation between some of the P-ESAS-r symptom scores and their corresponding EORTC QLQ-C30, ESS and PGIC scores prompts for further reliability and validity evidence in more diverse settings.
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**Abstract type:** Poster Exhibition

## Complexity Factors in Advanced Palliative Care at Home: A Multicenter Study in Spain

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**Background:** High complexity palliative care situations should be referred to specialized settings. ‘Hospital at home’ is considered in Spain as an advanced palliative care setting, available in different cities and rural areas. IDC-Pal is a tool designed to assess complexity factors according to clinical, psychoemotional, social or spiritual needs.

**Aim:** To describe most frequent complexity factors in ‘hospital at home’ in different regions in Spain.

**Method:** Descriptive, prospective, multicenter study, developed simultaneously in 8 HAH departments in different regions in Spain, including urban and rural areas along 3 months. No funding was received.

**Results:** We obtained a sample of 266 patients, 151 male and 115 female. Mean age was 72.79 (SD: 13.31). PPS median score was 50 %. 86.1 % of the patients showed at least 1 criterion for high complexity. The median number of criteria per patient was 6.

<table>
<thead>
<tr>
<th>Complexity Factor</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sudden change in patient’s functional autonomy</td>
<td>128</td>
</tr>
<tr>
<td>Clinical situations due to cancer progression not adequately controlled</td>
<td>125</td>
</tr>
<tr>
<td>Social-family role performed by the patient</td>
<td>108</td>
</tr>
<tr>
<td>Refractory symptoms</td>
<td>104</td>
</tr>
<tr>
<td>Presence of comorbidty not adequately controlled</td>
<td>94</td>
</tr>
<tr>
<td>Symptoms not adequately controlled</td>
<td>82</td>
</tr>
<tr>
<td>Severe constitutional syndrome</td>
<td>81</td>
</tr>
<tr>
<td>Cancer emergency situations</td>
<td>74</td>
</tr>
<tr>
<td>Last days/hours of life not adequately controlled</td>
<td>71</td>
</tr>
<tr>
<td>Existential anguish and/or spiritual suffering</td>
<td>67</td>
</tr>
</tbody>
</table>

[Most frequent items]

**Conclusion:** This is the largest study about complexity of palliative care situations in HAH in Spain. More research is needed to assess complexity and to help in decision-making when dealing with palliative complex situations at home.
Validation of the “Impact Palliative Care Teaching Questionnaire”

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Background: Palliative Care Teaching is more than symptom control. The hidden curriculum inferred from Palliative Care culture includes important aspects related to professional identity such as psychological, sociologic, cultural, and spiritual issues; dealing with decision-making and ethical dilemmas; and self-learning and self-reflection.

Methods: Our research team has developed the Impact Palliative Care Teaching Questionnaire (IPCTQ), a professional identity questionnaire, where questions (Q) were derived from thematic analyses of four qualitative studies, with medicine and nursing students of the University of Navarra who attended the Palliative Care curriculum subject. It consists of three sub-questionnaires about knowledge (KSQ, 23Q), skills (SSQ, 20Q), and experiences (ESQ, 12Q). Questions include psychological, spiritual and social issues; communication and patient-caregiver-physician relations; decision-making, and personal development. Each Q is on a 0–10 ordinal scale. IPCTQ has been tested with four-year University of Navarra medical students.

Results: 128/196 (65%) students respond to the IPCTQ, 30 repeated it 24 hours later (reliability). 66 attended a compassion workshop (CW) and 34 repeated the test one month later (sensitivity), time while students report the CW reflection portfolio about one patient.

IPCTQ shows good sensitivity (mean$_1$=412 vs mean$_2$=439), (mean difference=27, p<0.001), and reliability (Cronbach’s $\alpha$=0.87, ICC=0.93). Each sub-questionnaire showed: KSQ (mean$_1$=169 vs mean$_2$=181), (difference=12, p<0.001), ($\alpha$=0.79, ICC=0.84; CI: 0.69–0.92); SSQ (mean$_1$=150 vs mean$_2$=156), (mean difference=6, p<0.04), ($\alpha$=0.8, ICC=0.91; CI: 0.81–0.96); ESQ (mean$_1$=93 vs mean$_2$=101), (mean difference=8, p< 0.00), ($\alpha$=0.86, ICC=0.87; CI: 0.84–0.97).

Conclusion: The IPCTQ’s first version shows good psychometric characteristics. A simple version with the most accurate items should be developed.
Death-related Attitudes at the End of Life – A Systematic Review of Measurement Tools

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Death-related attitudes are regarded as multidimensional and can change over the course of a lifetime. Research showed that under specific circumstances, e.g. in contexts of end-of-life care, negative attitudes, such as death anxiety, are shown more often. Using valid measures of these attitudes communication on this sensitive topic can be enabled to strengthen the well-being of a person. So far no comprehensive review of measurement tools and their fit to the context of end-of-life care is published. This systematic review gives a broad overview of the variety of measurement tools, their design, and the dimensions of attitudes they focus on.

The databases MEDLINE, PsycInfo, PSYNDEXplus Tests and Health and Psychosocial Instruments were systematically searched. Additional hand search was conducted. Studies reporting on development and/or validation of measures to assess one or more dimensions of attitudes toward death, dying, or finitude of life, and beliefs about afterlife were included for further review. Following evaluation criteria were used for analysis: Description of development (e.g. sample of construction, design of measure) and dimensions of death-related attitudes.

The initial search generated a total of 4586 studies. 167 studies (published 1933 to 2015) met the inclusion criteria describing 98 measures of death-related attitudes. The majority of measures was designed as questionnaire using Likert-type scales. Most of the studies developed measures in a sample of undergraduate students for research purpose. About a third of the tools approached negative attitudes, e.g. Templer’s Death Anxiety Scale, and another third focused on additional neutral and positive dimensions, e.g. Death Attitude Profile Revised by Wong and colleges.

This review indicates some shortcomings of existing measures regarding their fit to the context of end-of-life care. Further studies should focus on the modification of measures to the needs of this specific research area.
Personalized Symptom Goals in Comprehensive Cancer Center in Japan

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Backgrounds: Personalized symptom goals (PSG) have been proposed as a good indicator of symptom management. However, the nature of PSG in Japanese cancer patients and the differences between PSG achievement and other indicators remain unknown.

Purpose: The aim of this study is to explore the nature and usefulness of PSG in Japanese cancer patients.

Methods: We performed a cross-sectional study among cancer patients who visit a palliative care outpatient clinic in National Cancer Center Hospital East from April to August of 2016. We assessed participants on the Edmonton Symptom Assessment System-revised (ESAS-r) and PSG. We analyzed the distribution of the PSG scores and the prevalence of PSG achievement defined as ESAS-r score \( \leq \) PSG score. We compared the prevalence of PSG achievement to achievement of mild intensity in ESAS-r (ESAS-mild) using the McNemar test.

Results: A total of 148 patients were enrolled (45.1% female, median 72 years old). The median PSG scores were 2 (pain, tiredness, somnolence), 1 (lack of appetite, dyspnea), and 0 (nausea). The prevalences of the PSG achievement were as follows: pain (40%), tiredness (39%), somnolence (47%), nausea (84%), lack of appetite (63%), and dyspnea (62%). PSG achievement is lower than ESAS-mild achievement in pain (40% vs. 54%, \( d = 0.14 \) [95%CI 0.07–0.22], \( p < 0.001 \)), tiredness (39% vs. 56%, \( d = 0.18 \) [0.09–0.26], \( p < 0.001 \)), and somnolence (47% vs. 73%, \( d = 0.26 \) [0.17–0.35], \( p < 0.001 \)).

Conclusion: We first showed the prevalence of PSG in Japanese cancer patients. The PSG achievement might be appropriate for individualized symptom management in pain, tiredness, and somnolence.
Factorial Structure of a Questionnaire on Advanced Care Planning for Palliative Care

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**Background:** As there are no instruments to measure the impact of Advanced Care Planning (ACP) during advance disease, we have designed an ACP questionnaire IMPLANT-PAD to know the different levels of implementing an ACP process through regular patient care actions.

**Aim:** To explore the factorial structure and internal consistency of a survey on ACP in patients with chronic advance disease.

**Methods:** A 60-item self-administered questionnaire (IMPLANT-PAD) with 5-points Likert-type scaled response was designed to collect data about professional’s decision on ACP on 7 dimensions: Palliative Identification (5 items); Impact-illness trajectories disease (15 items); Resignification-Meaning of life (9 items); Treatment Options Discussion (9 items); Coordinating Health equipment and resources (7 items); Following and Updating (7 items) and Training-Innovation Research (8 items). A survey was made (Google Forms) between partners of the Spanish Society for Palliative Care from June-September 2016. Internal consistency analysis (Cronbach’s alpha) and exploratory factor analysis (principal component analysis with Varimax rotation) were carried out.

**Results:** 191 completed questionnaires were received. Most physicians had experience in the chronic care but little in the research field. The internal consistency of the original distribution was high, from “Following and Updating” ($\alpha = 0.863$) to “Resignification and Meaning of life” ($\alpha = 0.961$). On factorial analysis, a five-factor solution was proposed that accounted for 68% of the variance. Correlations of the items with 5 factors showed, to some extent, the original structure, but revealed possible redundancies and misclassifications.

**Conclusions:** Our study suggests that IMPLANT-PAD is a reliable and consistent scale with a multidimensional factor structure on measuring the impact of ACP in Palliative care. A simplification and reorganization of some items would be advisable in future releases.
Integration of Palliative Care in Cancer vs CHF/COPD in Europe

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Aim: Palliative Care (PC) has originated initially from cancer; however, it has been recently applied to other chronic, non-malignant diseases as well. This study presents a comparative analysis between the levels of integration of PC for patients with cancer and CHF/COPD in Europe.

Methods: For the comparison and a qualitative evaluation between integrated PC in published guidelines for cancer and CHF/COPD in Europe, we employ the results of two systematic reviews for integrated PC guidelines in cancer and CHF/COPD. The level of the content of integrated PC in guidelines/pathways is measured via an 11 integrated PC criteria tool. A statistical analysis is carried to detect similarities and differences.

Results: Even though PC in patients with CHF/COPD is a quite recent topic, significant progress has been undertaken as the levels of integration between CHF/COPD and cancer have been shown to be statistically the same. Nevertheless, the levels of integration remain moderate hinting that there is significant room for improvement. Moreover, the ways and the times of development of the guidelines/pathways appear not to impact the PC integration.

Conclusion: Due to the fact that the guidelines provide the platforms upon which several treatment protocols and processes are build their moderate level of PC integration hints that they need to be revised and improved in the future.
Abstract number: P02-047
Abstract type: Poster Exhibition

Why is it So Difficult to Implement Evidence Based Tools in Practice? – One Successful Approach to Facilitating the Process

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Background: The Ayrshire Hospice has used a project management model to guide implementation of the Carer Support Needs Assessment Tool (CSNAT) Approach. At an early stage we wanted to understand how the CSNAT Approach was being used in practice.

Aims: To develop a monitoring form to (a) identify practitioner concerns about the assessment process and (b) identify needs highlighted by carers and support received.

Methods: The Ayrshire CSNAT tells carers it is ‘About you’, identifies it as an assessment process, then invites carers to consider the support domains. A separate monitoring form was developed (V1) to collect practitioner feedback on both the process and outcomes of carer assessments undertaken. The CSNAT and V1 form were implemented December 2015–May 2015; 90 V1 forms completed. Open text comments on process issues, carer needs discussed and support provided were analysed and coded into themes by project lead (LC).

Results: Process comments such as “CSNAT form left” and “Difficult husband became distressed – not ready for this conversation” identified practitioners who had not embraced practice change and adopted the CSNAT approach. Carers identified need for more support in all support domains except beliefs/spiritual concerns: most frequently with knowing what to expect in the future, dealing with feelings and worries, having time for self in the day. Responses to needs were most often providing explanations/guidance, written information, listening, internal and external referrals; well within the hospice’s remit.

Conclusions: The monitoring form has been a key part of the implementation process. It has resulted in adoption of an ‘issues log’ for ongoing feedback on practitioner concerns. Analysis of carers’ needs and support provided has facilitated transition to an electronic record system through identification of fixed response categories. Most crucially the monitoring form has evidenced assessment and support provided for carers by the hospice.
Validation of a Set of Neuropsychological Tests: A Study in Patients with Metastatic Cancer

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Background: Few studies described cognitive function in metastatic cancer patients and very few described these tests’ psychometric properties.

Aim: To verify the psychometric properties of Trail Making Test (TMT), Continuous Reaction Time (CRT), Finger Tapping Test (FTT), Digit Span Test (DST), and Mini Mental State Examination (MMSE) for use with Brazilian patients with advanced cancer.

Methods: A total of 178 patients with advanced cancer and 79 controls participated. For both groups, sociodemographic and clinical data were retrieved, and cognitive status was measured using the TMT, CRT, FTT, DST and MMSE. The psychometric properties verified were: discriminant validity (comparison between groups), concurrent validity (convergent and divergent validity between patients’ tests performance and sociodemographic and clinical variables), and reliability (39 patients and 10 controls were retested after 3–7 days).

Results: Discriminant validity between patients and controls was observed in TMT A+B, DST, and MMSE. Measures of concurrent validity were consistent with expected directions. Specifically, cognitive performance was positively correlated with physical performance, education level, and better performance on the MMSE. Negative correlations were observed between cognitive function and pain, anxiety, and depression. All instruments demonstrated very good stability, with the exception of FTT difference.

Conclusions: The cognitive tests showed psychometric properties that permits use in clinical and research palliative care contexts. The exception is the FTT, which revealed poor discriminant and concurrent validity and partial reliability.
Skin Changes in Terminally Ill Patients Near and at the End of Life Receiving Palliative Care: A Prospective Cohort Study

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Background: Skin is considered the largest organ of the body and, as other organs, may become dysfunctional at the end of life. In this context, skin dysfunction is associated with decreased cutaneous perfusion, which leads to local hypoxia, and for failing to maintain its normal function, inevitable changes may occur.

Aim: To estimate and evaluate the incidence and predictors of skin changes in hospitalized patients in terminal phase of the disease and at the end of life.

Methods: This prospective cohort study was conducted in an inpatient palliative care unit. Twenty-four patients were followed until discharge, transfer, or death. Some instruments, including the Edmonton Symptom Assessment System, Malnutrition Screening Tool, Palliative Performance Scale, Braden Scale and Pressure Ulcer Scale for Healing, were used in the assessments of patients. The Wilcoxon-Mann-Whitney U-test, chi-square test, Fisher’s test, Kaplan-Meier curve, Log-rank test, and Classification and Regression Tree analysis were performed for data analysis.

Results: Most patients were women (13, 54.2%), the mean age was 67.6 years (SD=21.8), the majority of patients (23, 95.8%) had lost ≤50% of their functional capacity and had some degree of malnutrition (15, 62.5%). The incidence of skin changes was 16.7%; cases of grayish skin (n=2), yellow-greenish skin (n=1), and pressure ulcers (n=9) were detected. The number of patients who died was significantly higher among those with skin changes than among those without such changes (p=0.035), and patients with skin changes were 17 times more likely to die than those without changes. Age ≤50 years was predictive of skin changes in the study population.

Conclusion: The incidence of skin changes was 16.7%, with predominance of pressure ulcers. It was also found that patients with skin changes at the end of life were more likely to die when compared to those without such changes.
Validating a Palliative Prognostic Model Incorporating Functional and Biologic Variables in Advanced Cancer

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Background: Patient prognostication is integral to the practice of palliative care. Clinical and biochemical prognostic indices that were developed are limited by relatively low discriminant ability for short-term survival. We hypothesize that a prognostic model encompassing the PPSv2 with bio-clinical variables can accurately predict short-term survival in advanced cancer.

Aim: The primary objective is to refine and validate a 90-day prognostic model for patients with advanced cancer.

Methods: This is a prospective cohort study where recruitment for the training dataset was conducted in a tertiary hospital. The risk groups stratified by the training dataset will be used for patients suffering from advanced cancer in the following 12 months. These patients form the test dataset. Univariate Cox proportional hazards regression analysis will be conducted on the training dataset of 370 patients (power of 80%, survival of 70%, with 15% increase in sample size for missing values.) Multivariate Cox proportional hazards regression model is constructed by entering variables significant in univariate analysis, and tested on a validation group of another 370 patients.

Results: 653 patients were recruited with a mean age of 70 years. The mean (SD) Edmonton Symptom Assessment Score (ESAS) summative score and Palliative Performance Scale (PPS) at first review were 10.0 (9.7) and 49.9 (20.6) respectively. Mean survival time was 84 days. Survival time had a weak but statistically significant correlation with PPS at first review ($r=0.226$, $p<0.0001$), and the ESAS summative score ($r=-0.136$, $p<0.005$). Additionally, it has mild correlation with biochemical markers including albumin ($r=0.241$, $p<0.0001$), hemoglobin ($r=0.103$, $p<0.02$), total white count ($r=-0.109$, $p<0.02$), lymphocyte count ($r=0.140$, $p<0.001$) and C-reactive protein levels ($r=-0.110$, $p<0.05$).

Conclusion: Preliminary results show that incorporating PPS and biochemical indices to form a composite measure may improve prognostic accuracy.
Poster Exhibition (Poster Set 2)

Abstract number: P02-051
Abstract type: Poster Exhibition

Patients on Radiotherapy: Do They Have Palliative Care Needs?

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Background: Palliative Care focuses on the prevention of suffering experienced by patients and their family members. Cancer patients might need special care because they do not suffer from complications of the disease only, which causes a lot of pain but also from complications of therapy. Palliative Care is a new field – at least in Sudan – of comprehensive care for patients in their later stages of the disease.

Objectives of the study: In this study we are evaluating whether or not the patients receiving radiotherapy services in general have got palliative care needs.

Methodology: This is a cross-sectional descriptive study conducted in the period 1st of August 2016 up to 30th September 2016. All patients assessing the radiotherapy services at the National Cancer Institute Medani, were included in the study. The APCA African POS was used as a tool to collect the data. 144 patients and their careers were interviewed. 66 were men and 78 were women. During my studies I ruled out children below the age of 6 years and the patients with deteriorated level of conscious and patients who presented without careers were requested to bring their career for the next treatment session.

Discussion and recommendations:
Q1: This question reflects clearly that pain is not controlled in patients receiving radiotherapy. 46.6% of the patients had moderate to severe pain.
Q2: The presence of other symptoms had a grade of 2 to 3 out of 5 in 50% of the patients, not so evident as pain.
Q3: 39.6% of the patients had moderate to high level of anxiety (grades 3–5).
Q4: This question reveals there is generally no lack of communication.
Q5: This result is expected especially in our culture where life expectations are low.
Q10: This graph clearly reflects that there is a high level of family anxiety.

There is clearly a need for PC interventions for all patients accessing radiotherapy services specially pain management and the family anxiety.
Abstract number: P02-052
Abstract type: Poster Exhibition

Transcultural Adaptation and First Psychometric Validation of a French-language Version of the FAMCARE-Patient Scale

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Background: There is no French questionnaire assessing satisfaction with care in outpatients with advanced-cancer. The FAMCARE-Patient Scale is a validated English one, used in international research to evaluate benefits of palliative care teams’ intervention.

Aims: The purpose of this study was to translate, culturally adapt and validate first psychometric properties of the FAMCARE-Patient Scale for use in France.

Methods: Traditional back-translation and the decentering stance were utilized and assessed. Experts in palliative care clinic, psychology and anthropology were involved. The French FAMCARE-Patient instrument was then discussed with advanced-cancer outpatients who were asked to comment on items and offer suggestions for improvement of the French version before final psychometric testing in a second study. Inclusion criteria were locally advanced pancreatic cancer, metastatic gastrointestinal, genitourinary, breast, lung or gynecological cancer, age > 18 years and French native speaker outpatient.

Results: Significant discrepancies were not revealed by back-translation. Cultural adaptation was assessed by a scientific committee included experienced health and psychosocial professionals. Acceptability and comprehension were assessed by 27 patients and were considered as good or very good, except for three items. Some patients seemed not to make the difference between the way they were informed about their prognosis and their prognosis itself (item 9). Other patients did not understand the difference between their oncologist and the « specialists » (item 11). Some patients were not concerned about « family » (items 14 and 16).

Conclusion: Content validity of the French FAMCARE-Patient Scale version was obtained. This new tool has good face validity but some items need to be reworded before final psychometric validation in 250 patients in 2017.
Abstract number: P02-053
Abstract type: Poster Exhibition

**Does Profession Influence the Completion of Outcome and Complexity Assessments in the Palliative Care Setting?**

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**Aims:** Does concordance vary between different professional groups?

**Background:** The Phase of Illness (Pol) and Australia-modified Karnofsky Performance Status (AKPS) assessments are part of the Outcome Assessment and Complexity Collaborative (OACC) project. OACC has been introduced into palliative care settings around the UK (run by the Cicely Saunders institute and Kings College London).

The effectiveness of outcome measures has been studied in Australia but the influence of profession on the outcome measures has not.

**Method:** In a 15 bedded palliative inpatient unit the multidisciplinary team completed the Pol and AKPS assessment on all patients twice weekly throughout February 2016.

**Pol:** 292 patient assessments. **AKPS:** 290 patient assessments.

N = 83 (Time specific patient number excluded if one assessment only (12)).

**Results:** Patient group characteristics-40% of patients had ‘stable’ Pol. The most common assessment for AKPS was 50% (considerable assistance required).

The overall concordance was 48% for Pol and 25% for AKPS.

Within professional groups the highest concordance for Pol was HCAs (68%), for AKPS it was AHPs (48%).

For Pol the highest concordance between professional groups was HCAs and AHPs (77%). The lowest concordance (42%) was between doctors and HCAs. AKPS concordance was highest (52%) between nurses and AHPs. The lowest concordance (18%) was between doctors and AHPs.

**Discussion:** The sample size was relatively small therefore larger studies would be needed to further explore this finding. Previous studies in Australia have demonstrated low inter-rater variability. Our study suggests the concordance may not be as high in some settings and that professional background may play a part in differing assessments.

**Conclusion:** Factors that influence assessment of Pol and AKPS likely includes professional background of the assessor, this should be taken into account when introducing these measures.

<table>
<thead>
<tr>
<th>Concordance (%)</th>
<th>Pol</th>
<th>AKPS</th>
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<tbody>
<tr>
<td><strong>Overall</strong></td>
<td>48</td>
<td>25</td>
</tr>
<tr>
<td>Doctors</td>
<td>66</td>
<td>44</td>
</tr>
<tr>
<td>Nurses</td>
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<td>48</td>
</tr>
<tr>
<td>Healthcare Assistants(HCAs)</td>
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<td>30</td>
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<tr>
<td>Allied Health Professionals(AHPs)</td>
<td>50</td>
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*Table 1*
New Development Method of Patient-first Assessment for Hospice/Palliative Care

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Background: It has been important to evaluate hospice/palliative care staffs what did we do for the patients. But it was difficult for the staffs to adequate method of assessment method for palliative care which going on. Then we need to develop better assessment method for hospice/palliative care.

Aims: It was easy to get vital signs which were quite objective data. But in the field of hospice/palliative care, subjective data have been vital such as pain, dyspnea, fatigue and so on. Because these symptoms were experience who feels about only, not to know by staffs, then we need subject-oriented assessment method which was easy to get patients feeling with their words directly.

Methods: We already had STAS developed by Higginson last two decade. We also had Japanese version of STAS, but it translated front part of it. Then we translated all part of it in addition to SOAP system from medical record that comes from general medical record. It was quite new in combination with SOAP and STAS. We respected patient’s saying that shows directly first priority of the patient’s will.

Results: When we used renewal STAS with SOAP system, we maintain ability to communicate 59% of 34 terminal patients until the day of death, 38% until the day before death, 3% until seven days before death. There was no patient not to be able to communicate until death.

Conclusion: It was suggest that our assessment system that consist of SOAP and STAS original were very useful and helpful for terminally ill patients as well as staffs working in the field of hospice/palliative care.
Abstract number: P02-055
Abstract type: Poster Exhibition

Screening for Anxiety in Advanced Disease Using One Item of a Patient Reported Outcome Measure

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Context: Anxiety is often present in patients with advanced disease due to uncertainties in diagnostic, treatment and prognostic.

Aim: To assess the use of one anxiety item of the Portuguese Integrated Palliative Care outcome Scale to screen for anxiety among people with advanced disease.

Methods: Multi-centred observational study. Data was collected in 9 centres using convenience sampling. Inclusion criteria: ≥18 years, mentally fit to give consent, diagnosed with an incurable, potentially life-threatening illness, read, write and understand Portuguese. Exclusion criteria: patient in distress, cognitively impaired. The Portuguese IPOS has been culturally adapted and validated. The Hospital and Anxiety Depression Sub-scale total score was used to assess presence or absence of anxiety. Cut-off used was 10/11. IPOS Item 3 on anxiety is the measure under study. Cut-off used 2/3. Receiver operating characteristic (ROC) curves determined area under the curve. Positive and negative predictive values were computed.

Results: 135 (7.9%) patients included. Mean age is 66.8 years (SD 12.7), 58 (43%) are female, 74 (54.8%) have up to 4 years of formal education, 74 (54.8%) are from the Northern region. Most patients had a cancer diagnosis 109 (80.7%). Data were missing at random (Little’s MCAR test with Chi-Square = 2452.946, DF = 2398, Sig. = .213). Missing data varied between 1% and 5%. Imputation of the median was used. Prevalence of anxiety was 23.7% (C.I. 16.9%-31.9%). Sensitivity was 65.6% and specificity was 68.0%. Positive predictive value was 38.8% and negative predictive value was 86.4%. Area under the ROC curve was 0.70 (C.I.:0.60–0.80), p< 0.001.

Conclusion: The Portuguese Integrated Palliative care Outcome Scale appears to be good for excluding true negative cases of anxiety. It can be used in patients with advanced disease. Item 3 is appropriate to screen for anxiety.

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Abstract number: P02-056  
Abstract type: Poster Exhibition

**Frequency and Prevalence of Voluntary Stopping of Eating And Drinking (VSED) in Switzerland – Development, Testing and Translation of a Questionnaire**

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**Background:** Autonomy and dignity are a great good for all people at all times and especially at the end of life. „Voluntary Stopping of Eating and Drinking“ (VSED) represents a serious alternative to assisted suicide for death fasting. There are no data available about prevalence and frequency of VSED in Switzerland.

**Aims:**
(a) The development of an evidence-based questionnaire about the phenomenon of VSED in Switzerland.
(b) The performing of a standard pretest and (c) to proof content validity.
(d) At least a forward-backward translation process into French and Italian were conducted.

**Method:** The development of the questionnaire was based on a systematic search and review, which were updated in 2016. The questionnaire was tested by Palliative Care Specialists using standard pretest and content validity index (CVI). Subsequently, a standardized translation account of linguistic and cultural aspects was made.

**Results:** The questionnaire includes 38 items. The feedbacks of the 15 participants who engaged in the standard pretest were positive in terms of intelligibility and handling. After adjustment of the questionnaire 27 experts validated the items into rounds on linguistic clarity, content comprehensibility and completeness. Overall, the questionnaire achieves excellent I-CVI values, i.e. between 0.91 to 1.00 and S CVI values of 0.97. The forward and backward translation was carried out by two independent translators for each language. Subsequently, the consensus was prepared by consultant and was completed with proofreading.

**Conclusion:** The high participation in the standard pretest and validation process confirms the importance of the phenomenon of VSED. The excellent I-CVI values indicate a large agreement between the literature and the experts’ experiences in VSED. Overall, very good values in content validation could be demonstrated. The scientific translation of the questionnaire is the foundation of a nationwide survey of the phenomenon in Switzerland.
Not Only ONE but SEVERAL Types of Palliative Sedation: Interest of a New Clear Typology

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Aim: During End Of Life (EOL) phase, Palliative Sedation (PS) is used when reducing patients’ consciousness is required to control refractory symptoms and/or relieve unbearable suffering. But there is different situations requiring PS. We propose a clarifying Typology for PS (TPS). It excludes euthanasic sedation and parenteral anxiety treatment but includes deep and continue until death PS, because it’s, for the new French law, a right for patients in some circumstances.

Results: The simplified (ABCD) and detailed TPS

A Emergency PS:
A1 Massive EOL hemorrhage
A2 Acute EOL asphyxia
A3 Incontrollable acute EOL agitation

B Temporary PS with stop programmed:
B1 Short PS for care
B2 Nocturnal PS for refractory insomnia
B3 PS for refractory suffering
B3a Patient able to consent
B3b Patient unable to consent

C PS for refractory suffering without programmed reversibility:
C1 Patient able to consent
C2 Patient unable to consent

D Deep and continuous PS until death:
D1 Patient able to request
D1a At patient’s request with poor prognosis (≤ several days)
AND with refractory suffering
D1b At patient’s request refusing life-sustaining treatment (LST)
D2 Patient unable to tell his wills, after a pluridisciplinary decision to stop LST.

Discussion and conclusions: This tool was presented to 150 MD involved in palliative care field, to check comprehensibility, clarity and understanding and to test it with 15 clinical vignettes of PS stories. For simplified form the unique parameter to consider is how reversibility is decided. Determinant parameter for detailed form is patient ability to consent/request for PS. Simplified TPS can be use as a daily pedagogic tool and detailed TPS as a research tool (permitting retrospective and prospective studies). For example any studies discuss the life-shortening effect of PS, but it would be better to examine this question for each type according to our PST.
A Transcultural Aid to Evaluate Palliative Care Knowledge in Portugal

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Background: Palliative care (PC) increases quality of life and optimizes the use of health resources. However, misconceptions and lack of knowledge of health professionals about PC may represent a barrier to their provision. Considering the lack of tools to assess these aspects, this study aimed to cross-cultural adapt the Bonn Palliative Care Knowledge Test (BPW) to evaluate undergraduate students and registered nurses (RNs) in Portugal. BPW is a german instrument composed of two sections: the first contains 23 items that evaluate knowledge about PC and the second includes 15 questions about self-efficacy.

Methods: Methodological study, conducted by Beaton guidelines, which recommends several stages in the process of cross-cultural adaptation. 60 nursing undergraduate students and RNs participated on the pretest, which included a sociodemographic survey.

Results: The data confirms lack of incorporation of PC topics in nursing undergraduate curriculum and a high proportion of respondents who considered themselves unable (76.7%) for the provision of PC. The mean score of correct answers in knowledge section was only slightly different between the groups of students (57%) and RNs (62%). In relation to self-efficacy, the difference was more pronounced (Students – 56.57% / RNs – 80.65%). The adjustments made by the experts on the instrument achieved the desired equivalences. There were no reported difficulties in completing the questionnaire, and no commentaries were made by the developers about the Portuguese version.

Discussion/conclusions: The results obtained confirm a level of knowledge considered low, according to the BPW developers. The final Portuguese version of the BPW presented semantic, idiomatic, cultural and conceptual equivalences appropriate to the original instrument. The BPW may become an important tool to assess the level of knowledge and self-efficacy beliefs of RNs and students, highlighting specific areas for training and education.
Are Publications on Palliative Care a Good Indicator of Palliative Care Development in Africa?

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Background: Palliative care (PC) research in Africa has grown in the past few years.

Aims: To study whether the number (no.) and/or quality of published articles on the development of PC in countries in Africa can be used as an indicator of PC development.

Methods: A scoping review of published articles (2005–2016) on the development of PC in each country in Africa was conducted using PubMed, CINAHL, and Embase. All titles, abstracts, and full texts were read by 2 separate investigators and graded for inclusion based on the WHO PC Public Health Strategy and vitality and using preset exclusion criteria. A simple linear regression model was applied to each of the following with level of development of PC in the country using Lynch et al’s (2013) “Mapping Levels of PC Development: A Global Update” (PC World Map) as a proxy: no. of full articles and abstracts per country; average impact factor (IF), highest quartile of IF, and no. of Google and Web of Science (WoS) citations for articles published per country.

Results: 67 full articles were included in the final analysis. There were positive Pearson correlations (r) between no. of searches yield, abstracts included, and full articles included, independently, with the PC World Map’s level of development. No. of full articles rated for inclusion into the scoping review had the strongest positive r of 0.70 and slope of 0.39 and appeared linear on scatterplot. No. of abstracts rated for inclusion had the next strongest positive r of 0.65 and slope of 0.31. Correlations for average IF, highest quartile of journal, and number of Google and WoS citations was weak (r < 0.15) (Table 1).

Conclusion: The no. of published articles and abstracts rated for inclusion in a scoping review on development of PC in countries in Africa independently had strong positive r’s with the PC World Map. No. of published articles and no. of abstracts on PC development may be used as an indicator of development of PC for countries in Africa.
Abstract number: P02-061
Abstract type: Poster Exhibition

PAINFUL – A Mnemonic Prompt to Assist Care Home Staff When Assessing Pain

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Background: Untreated pain can have a negative impact on a person and can affect a person psychologically, spiritually and socially as well as physically. Evidence based research shows that pain is often under recognised and managed in care home. This management can be complicated when people are unable to communicate their symptoms, such as in dementia. It is therefore important that pain is recognised and assessed so that appropriate treatment can be given in order to maximise quality of life.

The Supportive Care Home Team have held training sessions on recognising and assessing pain. The training sessions were delivered in Care Homes with residents who were both able and unable to communicate their needs. These educational sessions were further developed by the role modelling of pain assessment tools with staff in care homes.

Aim: The information cards and poster were designed to provide further guidance and prompts around pain recognition and assessment for those with and without the ability to verbally communicate their pain.

Method: A memorable mnemonic using the initials PAINFUL was developed to prompt staff when assessing pain for those who could report their needs. Another addition was a reminder regarding behavioural traits which may indicate pain. This is especially important to consider when a resident is unable to verbally communicate their pain. The information cards and poster were reviewed by a multi-disciplinary expert panel within a Vanguard Care home steering group. They were then introduced at the local care home forum and then distributed to all care homes in the local area.

Results: Initial feedback from staff in care homes has been encouraging. However, a more formal evaluation has not yet been commenced. The community nursing team has expressed an interest in the use of these tools.
Does Assessment of Rate of Deterioration in Performance Status Contribute to Prognostic Accuracy?

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Background: Prognostication is important for decision-making and preparation for the end of life. Earlier research shows various, often poor results where clinicians tend to be overoptimistic about survival time when making estimations in a clinical, non-laboratory setting. Performance status (PS) does itself carry information of prognosis. Could adding the rate of deterioration to PS contribute to a more accurate prognosis?

Aims: To prospectively and clinically investigate whether assessment of the rate of deterioration and PS improves the prognostic accuracy of predicting survival.

Methods: Over a two-year period patients with metastasized, incurable cancer where consecutively recruited as they where enrolled in a specialized palliative home care program. PS (ECOG 0–4) and deterioration rate (day/days, week/weeks, month/months) with possible reversible causes, where registered. Based on this the attending physician was asked to estimate survival in one of the following categories: Today (0–1 days), days (2–5), week (6–10), weeks (11–25), month (26–35), 1–2 months (36–55), months (56–150), half-year (151–300) or year (300+).

Results: 210 patients were recruited. The median survival was 36,5 days. Over all, prognoses were 36% correct and 34% overoptimistic, i.e. the patient died earlier than predicted. Correctness varied from 17% (when prognosing Month) to 56% (Months). Overoptimism varied from 7% (when prognosing Days) to 69% (Half-year). The prognoses were estimated by nine physicians.

Conclusion and discussion: Using nine categories makes exact estimation of survival time rather difficult and probably explains why only 36% of the prognoses were correct, and also the variation in correctness. On the other hand, we believe for the same reason that an over all overoptimism of 34% was better than expected. If assessment of deterioration in PS is likely to contribute to improved prognostic precision is still to be analysed.
Abstract number: P02-063
Abstract type: Poster Exhibition

Development of a Tool to Assess the Quality of End-of-Life Care in an Acute Hospital

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Aim: In 2013, the UK Leadership Alliance for the Care of Dying People established five priorities (identification, communication, holistic assessment, respect for patient’s wishes and developing an individualised end-of-life care plan) for the care of the dying person, to ensure consistent care for people in the last few days and hours of life. The aim of this project was to develop a proxy questionnaire that incorporates these five priorities and would assess the quality of end-of-life care of the 2,500 people who die each year in our acute hospital.

Methods: By employing questions used in other validated tools, such as VOICES and CODE, a draft questionnaire encompassing the five priorities was developed. This draft was then taken to a PPI focus group for discussion. Incorporating feedback from the focus group, a final version was developed.

Results: The questionnaire is now given to the family/carer of every patient who dies in the hospital. Respondents have the option of completing the questionnaire on paper or electronically.

Conclusion: This project provides a unique opportunity to obtain data about end-of-life care for all patients who die in the acute setting, not just those known to palliative care. The tool will be one of the measures used to assess the quality of end-of-life care across the hospital and determine if the five priorities for the care of the dying person are being addressed. The data utilisation plan includes data analysis and incorporation into the hospital’s end-of-life care strategy.
Abstract number: P02-064
Abstract type: Poster Exhibition

Development and Validation of Nurses’ Knowledge, Attitudes and Assessment Practices Regarding Breakthrough Cancer Pain Management Questionnaire

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Aims: Breakthrough cancer Pain (BTCP) is one of the most important aspects result in profoundly adverse physical, psychological, social and economic impacts on cancer patients. Nurses play a key role in cancer pain control. Knowledge, attitudes and assessment practices among nurses are crucial to deliver effective BTCP management. To the best of the authors’ knowledge, there is no assessment tool to examine these three aspects of BTCP management for nurses. The purpose of this presentation is to report the development process of a self-developed questionnaire by authors and the results of its validity.

Methods: The development and validation of the instrument consisted of four phases
(1) review of international guideline and relevant literature;
(2) generation of questionnaire items;
(3) content validity;
(4) face validity.

Results: A questionnaire ‘Nurses’ Knowledge, Attitudes and Assessment Practices Regarding Breakthrough Cancer Pain Management’ has been developed. It consisted of 24 items and was divided into three parts: knowledge (11 questions), attitudes (6 statements), and assessment practices (7 statements). An expert panel consisted of 8 members was formed. The questionnaire has gone through four revisions of a panel of experts (one Professor, two Palliative Care Physicians, three Nurse Consultants, one Advanced Practice Nurse and one Department Operations Manager) to ensure the relevancy and appropriateness of all the items. The result of content validity index of each item ranged from 0.97 to 1.00. The result of face validity showed all nurses (n=12) agreed that questionnaire items were relevant, wordings were readable, instruction were clear, and question layouts were consistent in appearance.

Conclusion: The questionnaire is a valid instrument that can be used to evaluate the effect of an educational intervention on the level of nurses’ knowledge, attitudes and assessment practices regarding breakthrough cancer pain management in Hong Kong.
Abstract number: P02-065
Abstract type: Poster Exhibition

Emotional Distress in Advanced Cancer Patients: Use of DED Questionnaire for Telephonic Support

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Aim: Cancer patients and specially those in an advanced phase of the illness, may present emotional distress symptoms, which must be detected by the Palliative Care Unit (PCU). In our PCU nurse team makes telephonic follow-ups, as support task at that end-of-life phase. Most of the symptoms assessed by telephone are physical. Psychological symptoms are quantitative and qualitative scored less exhaustively. The implementation of a validated instrument to detected emotional distress can be very useful to solve this lack.

For that reason, we chose an emotional distress screening instrument to be used with cancer patients with advanced disease during the telephonic consultations, by no-psycho-oncology experts.

Results: After the bibliographic search, six screening tools fulfilled the criteria determined by the research team: Hospital Anxiety and Depression Scale (HADS), Psychosocial Distress-Inventory (PDI), General Health Questionnaire GHO-12, Distress Thermometer (DT), Detection of Emotional Distress (DED), “Are you depressed” (Chochinov, 1997).

The PCU determined that the DED is the screening method that better adjust to fulfil our objective. We decided to remove item 4 related to external observation of behavioural symptoms by a health professional which do not add up to the final score.

Conclusions: Provided DED is validated with hospitalized advanced cancer patients, we concluded DED is the instrument that better suits our needs to assess by telephone and support advanced cancer patients when are at home. We already have introduced this screening instrument in our daily work as PCU support team.
Description of the Clinical Characteristics of Patients with Advanced Lung Cancer Treated at an Integrated Lung Cancer Outpatient Clinic Palliative Care (ILCPC)

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Background: The Lung and thoracic cancer(LTC) is one of the most common tumors in our environment. Recently studies show standard cancer treatments with integrated early palliative intervention suggests improvement symptoms, quality of life and life expectancy.

Aim: To describe the clinical characteristics of patients diagnosed with advanced LTC treated in an ILCPC.

Material and method: Consecutive patients(pts) scheduled for visit at the ILCPC from June until August of 2016 were assessed at the first visit and up 90 days after. A multidimensional assessment was done: Physical symptoms by Edmonton Symptom Assessment System(ESAS), emotional dimension like anxiety and depression. Functional capacity by Barthel and Palliative Performance Scale(PPS). Emotional dimension have used open questions and punctuation of anxiety and depression and also register of the family structure and main caregiver. Other parameters were the emergency room visits in the period and number of hospital admissions.

Results: 50 pts were included, 80% were men, with an average of 66 years, 92% diagnosed with lung cancer. 25% are awaiting treatment and 8% included in clinical trial. 40% Pts have functionality preserved in 85% of cases with higher PPS and Barthel are ≥60. 30% neuropathic pain and 15% breakthrough pain. 40% present cough and more of 17% dysphonia. One out of three anxiety and depression scored above 4. Fentanil and Morphine were the analgesics more used. 10% of patients referred without main caregiver. 30% required at least a hospital admission during the period. 35% of cases diagnosis within 3 months previous and in 30% metastatic disease.

Conclusions: The study suggests that the pts with diagnosis of Lung cancer would are in an unstable clinic situation. They are a population in a shock of diagnosis of an incurable disease and with an emotional distress and is frequent high burden symptoms. A new prospective study is ongoing in this moment for assess the interventions in this population.
**Abstract number:** P02-067  
**Abstract type:** Poster Exhibition

# Applicability of Malnutrition Universal Screening Tool (MUST) at Outpatient Clinic for Early Palliative Care

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**Background:** Patients (pts) with advanced cancer are often malnourished. Nutritional support is an important and valuable part of comprehensive palliative care. It improves quality of life, help to alleviate symptoms such as loss of appetite, fatigue, depression and social impairment. MUST is a quick, inexpensive and easy to complete screening tool that is applicable to adult population, recommended by multiple professional teams. Till today at our institution we have never completed nutritional assessment in palliative care setting.

**Aim:** The aim of the study was to complete the nutritional assessment of first time visitors in outpatient clinic for early palliative care. Our task was also to analyse and compare the severity of symptoms and the duration of life among defined MUST groups.

**Methods:** We collected basic pts’ information and their nutritional characteristics (weight, height, loss of weight in previous 3–6 months, acute disease effect) from medical charts of patients in Outpatients clinic for an early palliative care from January 2013 till December 2015.

**Results:** We collected information of 153 pts (56% males, 44% females). A mean age was 71.2 (range 36–92). According to MUST 51 pts (33.3%) was assigned in group “0” with low risk, 17 pts (11%) in group “1” with medium risk and 85 pts (55.6%) in group “2” with high risk of undernutrition. An average ESAS for the whole group was 3.6; in group “0” 2.9, group “1” 3.8 and in group “2” 3.9. An average length of survival for the whole group was 6.3 months (m), in group “0” 8.7 m, in group “1” 8.0 m and in group “2” 3.9 m.

**Conclusion:** MUST is a quick and easy screening tool that is applicable for palliative care population in outpatient setting in our institution. Palliative care pts are in a high risk of undernutrition and are in a huge need for appropriate pts oriented nutritional support. MUST scoring is related with length of survival.
**Assessment of Capacity to Consent in End-of-Life Decisions of People with Intellectual Disability**

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**Background:** Studies show that people with ID are rarely involved in end-of-life decisions. As communication problems complicate the assessment of decisional capacity, decisional assessment instruments are rarely used in residential homes for people with ID.

**Aims:** The aim of the study was to develop and evaluate an instrument to assess the decisional capacity of people with ID in end-of-life decisions.

**Methods:** Four Persons with ID were interviewed on end-of-life decisions. The interviews were recorded (paper and film). Based on these documents, a volunteer sample of 20 physicians, 22 relatives and 18 carers assessed decisional capacity of the persons with ID. To analyse the reliability of the Instrument the interrater reliability was used.

**Results:** The study shows moderate interrater reliability of all raters $\gamma = 0.4$ (SE = 0.144, $p \leq .05$), assessing the documents of 4 persons regarding a total of seven end-of-life decisions. The interrater reliability was higher if persons with a low grade of disability were rated. Significant differences in the ratings were found between physicians and carers.

**Conclusions:** It is important for carers and physicians to discuss their different opinions regarding the person’s decisional capacity. These procedures are time consuming and should be planned in advance.
Abstract number: P02-069  
Abstract type: Poster Exhibition

The Quality of Life for the Stoma Patients. A Physical and Social Approach

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Background: Having a colostomy impacts the quality of a patients life in many areas – physical, emotional and social domains.

Aim: Highlighting the impact the colostomy has on the patients’ life, by identifying the main challenges they face, in the pursuit of sustaining and improving the educational process for the future stoma patients.

Method: An observational, retrospective, cross-sectional study. The questionnaire that has been used is Stoma QOL, which measures the quality of life. It has been applied face-to-face by the researcher or by telephone conversations. The data was registered and analyzed using SPSS Statistics 24, resulting in descriptive reports and analytical data.

Results: The study has been conducted on 64 patients with permanent or temporary stomas (20 women, 44 men). The results showed that the main challenges the stoma patients face are related more to the physical component than the social one. The main challenge is that the bag often times detaches from the skin. Other changes are: in nutrition (59.4%), defecation (67.2%) and sexual activity (59.4%). Half of the respondents consider that the stoma limits the choices they have in finding suitable clothing. In regard to the social component, the impact on the family relationships, friendships and other social interactions is smaller, more than half of the patients said they didn’t face such problems. But 57.8% of the patients say feel marginalized by society. There are significant statistical correlations between the need of knowing where the nearest toilet is, the concerns about the bags leaking and the fear that it might detach from the skin.

Conclusion: The quality of life for the stoma patients is affected differently for each individual. Research shows that the longer the patient has the stoma the closer his lifestyle is to the lifestyle of a patient without stoma.
Abstract number: P02-070
Abstract type: Poster Exhibition

Serum Vitamin D Levels in Palliative Care Outpatients: Relation to Selected Clinical Factors. Prospective Analysis of 1068 Cases of Single Individual Medical Practice

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Background: Patients under palliative care represent the group of high risk for vitamin D deficiency due to restrictions in UV exposure and changed nutritional patterns. Data reporting vitamin D levels in this patients setting are rather scarce.

Methods: Serum levels of 25-OH-vitamin D (25-OH-D) were investigated in 89,6% consecutive patients' samples of a single individual cancer practice located in Gdańsk, Poland (Jan-2/2014 – Sep-30/2016). One thousand sixty eight patients (female: 70,9%; median age: 63, range: 21–91 years) were admitted for palliative care due to: disseminated cancer (64,5%), side effects of anticancer therapy (16,7%), or symptoms control in non-cancer diseases (18,8%).

Results: The median 25-OH-D concentration of all cohort patients was 13,76 ng/ml (range: 0,40 – 74,32 ng/ml), 70,2% of them were deficient (25-OH-D< 20ng/ml) and 27,1% insufficient ≥20 and < 30ng/ml). In total, only 4,5% of patients were taking vitamin D supplements before they entered the study (significant increase in percentage during the observation period; p=0,048). Using the univariate analysis, the risk factors for 25-OH-D deficiency/insufficiency were: active cancer disease (as compared to patients with no evidence of cancer: p< 0,01 and non-cancerous conditions group: p< 0,02) and primary cancer location (lung cancer: p=0,034, brain tumors: p< 0,05 versus others). Age, gender, initial performance status, body mass index values at the study enter ad its changes since primary diagnosis, dominant metastatic site, antibiotic consumption did not influence 25-OH-D levels.

Conclusions:
1) 25-OH-D deficiency/insufficiency is highly prevalent in palliative care outpatients with some risk factors identified; 2) the study will continue to address the question of relation between 25-OH-D and symptom burden as well as the potential of vitamin D supplementation for improved symptoms management.
Abstract number: P02-071  
Abstract type: Poster Exhibition

**A Search for Effective Drugs for Treating Peripheral Neuropathy Caused by Chemotherapeutic Drugs**

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**Background:** Oxaliplatin (L-OHP) is a platinum-based anticancer drug used for treating colon cancer. Paclitaxel (PTX) has a botanical origin and is used to treat several cancers, such as ovarian, breast, and non-small cell lung cancers. Both induce cold hypersensitivity and dysesthesia. Cold-sensitive transient receptor potential channels, TRPM8 and TRPA1, have been implicated as candidates mediating L-OHP- and PTX-induced cold allodynia and hyperalgesia. Fasudil, a cerebral ischemia-improving agent, is known to inhibit cerebral vasospasm by inhibiting Rho-kinase. It has been recently reported to promote functional recovery after spinal cord injury.

**Aim:** We aimed to examine the effect of fasudil on peripheral neuropathy in diabetic rats and the inducing effects of L-OHP and PTX on cold allodynia in mice.

**Methods:** Goto-Kakizaki (GK) rats were used as a diabetic model rats. Tail flick and von Frey tests for the thermally and mechanically induced pain models, respectively, were used to assess neuropathic pain in the diabetic rats. For chemotherapeutic drug experiments, 6-week-old ddY mice were used. L-OHP and PTX were injected intraperitoneally day 1 only, whereas fasudil was administered intraperitoneally for five consecutive days. Cold allodynia was evaluated by the acetone test. These tests were performed on the date of administration and on five consecutive days after the administration of chemotherapeutic drugs.

**Results:** Fasudil, administered for 5 days in GK rats, improved the pain-related behavior. Single intraperitoneal administration of L-OHP and PTX induced cold allodynia on the third day in mice. Fasudil also suppressed the cold allodynia induced by the chemotherapeutic drugs.

**Discussion:** The Rho-kinase inhibitor fasudil can improve the peripheral nerve damage caused by diabetes peripheral neuropathy and chemotherapeutic drugs.
Registered Nurses’ Perceptions of Providing End-of-Life Care to Hospitalised Adult Patients: An Integrative Review

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**Background:** Numerous factors have contributed to a rise in demand for end-of-life care (EOLC), but the extent to which Registered Nurses are able to deliver proficient EOLC to patients is questionable.

**Aim:** To analyse and synthesize research evidence on nurses’ provision of EOLC to hospitalised adult patients.

**Methods:** An integrative review of papers reporting on nurses’ knowledge, skills and experience was conducted. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool was used to develop the review question. Three search strategies were employed between July and August 2016: a systematic, computerised search of databases; journal hand-searching; and ancestry searching of reference lists. The titles and abstracts were screened. Data extraction and quality assessment using the Mixed Methods Appraisal Tool were conducted. Disagreements were resolved through discussion or a third reviewer adjudicated the issue. Study findings were analysed thematically using meta-synthesis.

**Results:** Twenty studies met the inclusion criteria. Of them, ten were quantitative, nine qualitative and one mixed-method. The quality of studies varied considerably, with the qualitative and mixed methods papers being generally superior to the quantitative studies. Overall, limitations included a lack of representativeness of the sample, inadequate sampling strategies and measurements, low responses rate and limited generalisability. Four themes emerged: nurse as protecting provider, nurse as advocate, nurse as reflexive practitioner and obstacles to providing quality EOLC.

**Conclusions:** Nurses are recognized as protectors and patient advocates. It is apparent that nurses experience physical, emotional and environmental challenges in providing EOLC, and rely on reflective practices to overcome these.
Abstract number: P02-073
Abstract withdrawn
The Effect of Shitei-To, a Traditional Chinese Medicine Formulation, against Hiccups: The Mechanisms of Anticonvulsant Effect of Shitei-To

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Background: Cancer patients sometimes develop hiccups from the implementation of chemotherapy or tumor itself. Hiccups, which are considered as a form of convulsions, are characterized by rhythmic, clonic contractions of the diaphragm. Various types of tranquilizers and anticonvulsant medications such as benzodiazepines and barbiturates have been used for the treatment of intractable hiccups. The traditional Chinese medicine Shitei-To is a mixture of extracts from three medicinal herbs: Shitei (persimmon calyx), Shokyo (ginger), and Choji (clove). It has long been used as a natural herbal therapy for the treatment of hiccups in Japan and China. Because anticonvulsants are effective against intractable hiccups, Shitei-To may be effective against convulsions.

Aim: In this study, we examined the anticonvulsant effect of Shitei-To, Shitei extract, and Shitei triterpenoids on experimental convolution models with chemically induced convulsions (strychnine and picrotoxin) in mice. In addition, we examined the anticonvulsant mechanisms.

Methods: 6-week-old male ddY mice were pretreated with Shitei-To, Shitei extract, and Shitei triterpenoids (p.o.) at specified time points prior to injection of strychnine and picrotoxin (i.p.). We evaluated the latency of clonic convulsions by measuring the time in seconds from the injection of the convulsant to the development of clonic convulsions.

Results: Shitei-To and Shitei extract significantly prolonged the latency of strychnine- and picrotoxin-induced clonic convulsions, and Shitei triterpenoids prolonged the latency of strychnine-induced convulsions. Furthermore, flumazenil inhibited the prolongation effect of Shitei-to.

Discussion: These findings suggest that Shitei-To exerts anticonvulsant effects. Because these effects were inhibited by flumazenil, it probably acts on the GABA system.
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**The Impact of Palliative Care Support Teams and GP Referrals to Emergency Departments on Hospitalization Rate and Number of Hospital Days in the Last Year of Life**

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**Background:** A Care Pathway for Primary Palliative Care, aiming to improve GPs' role in palliative care, was rolled out in the zones of five Belgian palliative care support teams (PCST), supporting primary care teams to perform high-quality palliative care. The primary outcome was a reduction in hospitalization rate and length of stay.

**Aims:** To evaluate the impact of GPs and palliative care networks on the primary outcome.

**Methods:** Health care consumption data have been collected retrospectively by the InterMutualistic Agency for all people domiciled in the five zones, of at least 45 years old and having died a 'non-sudden' death during the study period. A zero-inflated negative binomial model was used for analysis, with SAS 9.4.

**Results:** This data set includes a total of 46,581 patients, from the 5 different zones (15% – 18% – 19% – 22% – 23%). Males dominate the population (53%). Though all of these people died a non-sudden death, only 1.46% were taken care of by a PCST. Averagely in the last year of life, patients spent about 6.03 (s.d. 25.79) days in the hospital. The average hospitalization rate of patients was 0.35 (s.d. 0.71). Averagely, visits to the emergency unit occurred 0.16 times with and 0.09 times without referral by the GP.

The group of patients helped by a PCST, had a 23.5% (s.d. 3.8%) reduced hospitalization rate and a 27.9% (s.d. 3.6%) reduced hospital length of stay compared with patients not helped by a PCST.

Of the patients who visited the emergency department, those referred by the GP had a 61.6% (s.d. 1.9%) reduced risk for hospitalization rate than those without GP referral. GP referrals did not have a significant impact on length of stay.

**Conclusion:** Only 1.5% of patients benefits of PCST assistance, however resulting in a decreased hospitalization rate and length of stay. Patients visiting an emergency unit after referral by their GP, needed less hospitalizations than patients not referred by their GP.
An Improved Model for Distribution of Medications to Patients Receiving Home-based End-of-Life Palliative Care

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Background: Symptom relief is usually achieved using a limited number of drugs, which need to be available. It is often predictable which symptoms a patient will suffer from, but the frequency and intensity may vary considerably. New drugs may be needed suddenly, and the amount needed is difficult to predict. The drugs may not be available at pharmacies. Earlier, patients received a prescription and hopefully received the drugs within a few days.

Aim: Patients need to have sufficient amounts of drugs available at home, but it is important to minimize the amount of opioids and the amount remaining when a patient eventually dies.

Method: In 2013 we established storages with ample amounts of typical palliative drugs at multiple sites. When a new ordination is made, a nurse brings about a week’s supply to the patient’s home within a few hours. The patient is resupplied continuously as long as needed, having quick and easy access to sufficient amounts of ordained drugs, while just a small amount is stored in the home.

Results: After six months, a survey was made among home healthcare nurses. All 32 answering stated that they had better control of their patient’s opioids, that handling took less time, that they could help patients faster, and that the patients had improved access to medications. Multiple later surveys have confirmed these results.

The total cost of opioids for these patients has been more than halved from 458 kSEK in 2012 to 136 kSEK in 2015. The amount of opioids prescribed and ordered to the hospital have been reduced by over 50 % for most formulations.

Conclusion: The availability of medicines for patients in palliative care has been improved, reducing unnecessary suffering. Time has been freed for direct patient contact, the opioid costs and the amount of opioids stored in homes has been reduced. Our concept is now being adopted by other hospitals.

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**Early Intervention Project: Can Early Hospital Palliative Care Team Input Improve the Experience of Patients with Palliative Care Needs Admitted to Receiving Medical Wards?**

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**Aims:** This project aimed to assess whether early input from the Hospital Palliative Care Team (HPCT) improved factors such as: access to Palliative Care (PC), length of Hospital stay, physical & psychosocial factors in people with PC needs admitted via medical receiving.

**Methods:** Early HPCT input was defined as post-receiving patient review in the three medical receiving wards in Glasgow Royal Infirmary. Patients were identified daily by senior acute medical nurse coordinators at morning handover, using agreed referral criteria, and on receiving ward rounds. An HPCT member also attended the unit daily. Data was collected prospectively over 14 weeks including: patient demographics, time to referral, symptoms & associated IPOS, preferred place of care, duration of admission, presence/absence of psychosocial issues. Data was collated in MSExcel & analysed upon project completion.

**Results:** Compared with the same period in 2015, more patients were referred from medical receiving wards during this project: 104 vs 63 (65% increase). Referrals for patients with non-malignant conditions also rose: 34% (n=35) during the project compared to 13% (n=8) previously. This increase was beyond that seen from “downstream” medical wards over the same period. Average length of stay among patients reduced to 9 days vs 13 days during the same period in 2015. Mean time to referral was 1.7 days vs 3.2 days in 2015.

**Discussion:** The results from this project suggest that HPCT input in this clinical context markedly increased access to PC for patients with non-malignant conditions. Early HPCT input was also associated with reduced length of admission, although confounding factors make drawing further conclusions regarding correlation difficult. Early identification of patients’ palliative care needs and access to expert symptom control for all is in line with The Scottish Government’s strategic priorities. Detailed data analysis is hoped to support ongoing service development in this area.
Evaluation of a Palliative Care Link Nurse Programme Implemented as Part of the Uganda PC Nurse Leadership Fellowship

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Background: The Link Nurse Program (LNP), developed in Mulago National Referral Hospital has been successful in increasing access to PC through building capacity of nurses on the wards. As part of a Nurse Leadership Fellowship (NLF) program in Uganda, the LNP was implemented in 8 hospitals across the country with 150 link nurses being trained.

Aim: To evaluate the impact of the PC LNP as implemented through the NLF program.

Method: An evaluation was undertaken using both quantitative and qualitative methods of data collection including: pre and post course assessment and confidence rating, course evaluation forms, review of link nurse activity data, focus group discussions (FGDs) and interviews. The evaluation was undertaken by 4 of the Nurse Fellows, supported by their facilitators and mentors, and was part of their leadership training and involvement in national level projects and advocacy.

Results: An increase in number of patients receiving PC has been seen with over 500 patients receiving generalist PC from the link nurses. A significant difference was seen in nurses knowledge/ confidence after training (p< 0.001). 60% of the nurses are using the MoH approved PC clinical guidelines to guide their practice. Provisional themes identified through the FGDs and interviews include: gaining confidence, increased knowledge, change in attitudes, provision of holistic PC, Quality, importance of clinical modelling, continuity of care, referral patterns, increase in the use of morphine and collaboration. Challenges have also been experienced including: managing complex issues, stock outs, and the need to other health workers.

Conclusion: LNP is a practical model for integrating PC into generalist services and one that can be used in a variety of settings, e.g. rural, district and national hospitals. Empowering nurses to provide generalist PC is important in health systems strengthening and integral to the integration of PC as per the WHA PC resolution (2014).
Patient Perceptions of Rehabilitation in Lung Cancer: Implications for Service Design

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Background: People diagnosed with lung cancer experience a symptom burden and psychological distress at diagnosis which impact on functional quality of life. Access to rehabilitation is recommended to reduce disability and maximise independence yet evidence of acceptability in this population is lacking in the UK. This study explored the impact of diagnosis on participation in daily activities and perceptions of rehabilitation in patients diagnosed with inoperable lung cancer to inform research and design in lung cancer rehabilitation services.

Method: Qualitative semi-structured interviews were conducted with fourteen lung cancer patients in Northern England within eight weeks of diagnosis. Interviews were guided by domains of the World Health Organisation International Classification of function, disability and health. Findings were explored using framework analysis.

Results: Participation in daily activities was affected by high and low levels of impairment relating to symptoms and comorbid conditions. Personal, family and health care professional beliefs and behaviours modulated the level of impact on usual routines and roles. Little understanding of rehabilitation to support function in daily life activities was observed. Rehabilitation was perceived as common sense, as a burden, as going away from home. Some felt the diagnosis precluded them from gaining benefit, that rehabilitation is for people who can be cured. Others were positive about accessing services to help them stay independent but did not know how to ask for such help or what it might involve.

Conclusion: Participation in daily life is affected by physical impairments, beliefs and behaviours in people newly diagnosed with lung cancer. Rehabilitation is poorly understood. Service design and research investigating acceptability and effectiveness of rehabilitation in this population should ensure that tailored interventions and potential outcomes are more effectively described and communicated.
How Change is to Be Achieved: A Theory of Change of Advance Care Planning in Nursing Homes

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Background: Despite growing evidence on the efficacy of advance care planning (ACP) interventions, it remains unclear how ACP actually works and how sustainable change in nursing home practice can be achieved. In preparation of the development of an ACP intervention programme for nursing homes, we developed a ‘theory of change’ or rationale of how and why ACP works and what is needed to bring about sustainable change in these settings. This rationale potentially enhances future implementation, organisation and sustainability and can subsequently be used in the evaluation of the intervention.

Method: Using the Theory of Change methodology, we integrated the results of two stakeholder workshops (n = 27) with the results of a contextual analysis in Flanders, Belgium and a systematic literature review.

Results: A visual representation graphically outlines the different intermediate outcomes, preconditions and intervention activities needed to achieve the main outcome of ACP i.e. to improve correspondence between people’s wishes and the care they receive. Besides having ACP conversations, critical factors are identified at different levels (resident/family, staff or facility):
- obtaining buy-in from nursing home management
- stepwise implementation of an ACP intervention programme by in-house ACP reference persons who are trained to conduct ACP conversations and involve all staff in the ACP process, preferably supported by an external facilitator who’s involvement gradually declines
- informing general practitioners, residents and families regularly
- having written records and monitoring systems in place

Conclusion: This study illustrates how ACP is expected to work while highlighting important organizational factors that potentially hinder or facilitate its implementation and sustainability in routine nursing home care. The work presented here allows us to go beyond simply asking ‘does it work’ towards more nuanced consideration of ‘how’ and ‘under what circumstances’.
Improving Delivery of Palliative Care in the Acute Medical Unit

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Background: People spend on average the equivalent of 25 days in hospital in the last 6 months of their life and although most people would prefer to die at home or in hospice 55% of people will die in an acute hospital. The quality of end-of-life care provided in acute hospitals has been rated the lowest of all settings. Hospital Palliative Care Teams can improve symptom control and contribute to reduced length of hospital stay.

Aim: To improve the care provided to patients with palliative care needs admitted to the acute medical unit (AMU) of a large teaching hospital by involving hospital palliative care team (HPCT) at an earlier stage of their admission.

Methods: A member of the HPCT made a pro-active visit to AMU on a daily basis to review and discuss patients with the post-receiving medical team, rather than providing a reactive service attending only when patients are referred by medical teams for a period of eight weeks. Outcomes were compared to the same eight week period the previous year.

Results: During the project 64% of referrals of medical patients to HPCT came directly from AMU compared to 35% in 2015. Patients received HPCT review earlier in their admission (median 2 days into admission in 2016 vs 4 days in 2015), spent fewer days in hospital (median 6 vs 11.5 days in 2015), were transferred to hospice more quickly when appropriate (median 11 vs 16 days from admission in 2015), had fewer ward moves within the hospital (mean 0.96 moves vs 1.26 in 2015) and were boarded to other wards less frequently (1 occasion vs 10 occasions in 2015) during the project.

Discussion: A proactive approach to reviewing patients with palliative care needs in the Acute Medical Unit can improve patient outcomes including fewer days spent in an acute hospital setting. It did not result in more patients referred to HPCT overall but ensured they were involved at an earlier stage in admission.
Should Resource Allocation Be Based on Needs or Outcomes? A National Qualitative Study of Stakeholder Perspectives

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Background: Demand for palliative services is changing, with mortality set to increase 15% by 2035. Although there are increasingly constrained resources, it is unclear if needs or outcomes could better drive resource allocation.

Aim: To explore stakeholder views on resource allocation in palliative care.

Methods: Semi-structured interviews with stakeholders in palliative care from hospital, hospice and community settings. Purposive sampling by location and background. Data was analysed using Framework analysis.

Findings: Managers/senior leads, healthcare professionals, patients/carers (N=65) were interviewed. Themes included:

(i) Needs in resource allocation: participants felt it important to start with needs to determine type of interventions and resources required, and that outcomes could only be understood in the context of existing needs;

(ii) Outcomes in resource allocation: there were mixed views on how outcomes could drive resource allocation based on patients’ changing health status (i.e. stable to deteriorating). Complexity should be embedded to help our understanding of achievable outcomes;

(iii) Benefits of outcomes: many highlighted how outcome measures can lead to a more standardised way of allocating resources at a population level, benchmarking and improving quality of care and;

(iv) Concerns about using outcomes: some highlighted that using outcomes in resource allocation may lead to “gaming” where services take on patients whose outcomes are likely to improve. Others highlighted that positive outcomes may not always be possible in deteriorating palliative care patients and that it may be difficult to develop suitable outcome measures with some aspects of care (i.e. spiritual needs).

Conclusion: Needs and outcomes are both necessary to underpin resource allocation, with the former embedded in the latter. The deteriorating nature of palliative care illness and the challenges of measuring outcomes must be considered.

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Changes in Professionals’ Beliefs Following a Palliative Care Implementation Programme at a Surgical Department: A Qualitative Evaluation

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Background: Palliative care should be accessible to patients and families regardless of care setting. Previous studies show many difficulties and shortcomings in the care of patients with palliative care needs in acute care facilities, but also challenges regarding efforts to implement palliative care. The aim of this study was to evaluate how implementation of palliative care, using guidance and tutorial from a palliative team as an implementation strategy, could change the beliefs of professionals in a surgical department with regard to palliative care.

Method: In order to explore professionals’ experiential outcome of an educational implementation strategy, a comparative before-after qualitative design was used. The study was based on three focus group discussions. Two discussions were conducted before the educational intervention and one was conducted after. The participants consisted of five nurses and two specialist doctors from a surgical department in Sweden. The focus group discussions revealed a variety of different attitudes and beliefs, which were analysed using qualitative systematic text condensation.

Results: Beliefs regarding palliative care were identified in seven areas; the importance of palliative care, working methods in palliative care, team collaboration in palliative care, collegial support, discussions about diagnosis, symptoms at the end of life, and families of patients in palliative care. Changes in beliefs were seen in all areas except one: team collaboration in palliative care.

Conclusion: It is possible to change the beliefs of health care professionals in a surgical department regarding palliative care through the implementation of palliative knowledge. Beliefs were changed from an individual to a collective development where the group initiated a shared palliative working method. The changes observed were palliative care being described as more complex and participants differentiating between surgical care and palliative care.
Telemedical Care for Palliative Patients with Neurodegenerative Disorders

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**Background:** Neurodegenerative diseases are a heterogeneous group of disorders like Parkinson's and Alzheimer's Disease. In absence of causal therapy there is a strong need of palliative care because of high symptom burden during the progression of the disease. Patients suffer from severe immobility and restriction of communication. The patients are extensive in care and because of speech disabling the patients will is difficult to obtain. From our own findings relatives, acting as caregivers, are most experienced in understanding the needs of the patient. To reach highest quality of life for these patients, a palliative outpatient setting is needed. In Germany special ambulant palliative care (SAPV) teams care for only a small number of neurological patients since expertise in this field is often lacking.

**Aim:** To create a telemedical neuropalliative support accessible for SAPV teams.

**Methods:** We conduct a prospective single arm pilot trial to establish a telemedical system for the SAPV teams by arranging the opportunity of video conferences with a neurological expert. Ten selected SAPV teams get equipped with a mobile telesystem. In any time the opportunity is given to ask an expert in neuropalliative care at the specialized center (24/7). A mixed methods design is chosen to address the following questions:

- A quantitative analysis to assess the feasibility of the system and to evaluate the impact of advanced neurological supervision.
- A qualitative assessment using in depth interviews and questionnaires to identify further needs of patients/caregivers and the SAPV teams

**Conclusion:** We think that this system prevents hospitalization and enhances the quality of life for palliative patients with neurodegenerative disorders.

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Palliative Care in an Emergency Department

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Background: Several patients with life-limiting illness visit the emergency department in the last months of their lives. In order to improve care in those patients, we are considering to implement a palliative care support team in an emergency department.

Aim: To quantify the number of patients with life-limiting illness that would benefit from palliative care in the emergency department.

Methods: This is an observational study. The patients in the emergency department were evaluated for four consecutive days, by reviewing medical records. The palliative care screening tool developed by George et al. (Academic Emergency Medicine July 2015, Vol 22, No 7) was used for identifying patients with life-limiting illness and their palliative care needs. Pediatric and maternity ward patients were excluded.

Results: Two hundred seventy-five patients were screened, of which 42 (15.3%) had at least one life-limiting illness; median age was 83 years, (64–99, SD 9.3), 55% were female. The most frequent life-limiting illness found was advanced dementia (24), advanced cancer (8), followed by other clinical situations with high risk of accelerated death like intracranial bleeding (4) or hip fracture (3). Thirty one (11.3%) screened positive for palliative care needs; two or more emergency department visits or hospital admissions in the past six months (22) and uncontrolled symptoms (13) were the most registered items.

Conclusion: One out of every seven patients attended in the emergency department have an advanced disease with short life expectancy; most of them may benefit from palliative care referral. The appropriate care pathway has to be determined for these patients.
An Innovative Multidisciplinary Model of Best Supportive Care for Patients with Lung Cancer in NHS Fife, Scotland: The Role of Allied Health Professionals in Supporting Person-centred, Realistic Care

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Lung cancer is the commonest cancer in Scotland and for the majority it is an incurable illness. Around 40% of patients are unable to receive anti-cancer treatment because they are too frail or their disease too advanced. Such patients are for ‘best supportive care’, although there has been no consensus about what this means in practice. As a result, supportive palliative care provision has been inconsistent, and often reactive rather than proactive. This has precluded anticipatory care planning and realistic goal setting for many. Local data reveals that these patients are typically elderly, functionally poor and live an average of just 73 days. They are at high risk of acute hospital admission and death. Specialist Palliative Care secured funding for a new model of care for these vulnerable patients. To support the aims of this project additional funding was allocated to Allied Health Professionals (AHP’s) in the acute hospital. A specialist Occupational Therapist and Dietician led the initiative, aiming to ensure that all best supportive care patients had timely access to appropriate AHP intervention. This required a redesign of the existing clinical service and leadership, education and support for acute hospital healthcare teams. Supporting the adjustment to deteriorating function and helping to preserve quality of life, comfort and dignity, were key AHP priorities for this frail patient group. A leadership and coordinating role helped expedite appropriate, timely and often complex discharges. An Occupational Therapy ‘end of care summary’, accessible electronically, provided timely communication to colleagues in the community. A palliative approach to nutritional support was also employed, focusing on reassurance, education and realistic nutritional goal-setting. Evaluation data clearly demonstrates significant benefits to patients of the new model of care. Detailed data including patient and carer feedback and health economic analysis will be presented.
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Core Components of Integrated Models of Hospital Based Palliative Care: Results of the Integrate Project

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Background: An integral component of the WHA Palliative Care (PC) Resolution is the development of integrated models of palliative care, yet there is little evidence or agreement as to what this looks like. A variety of hospital based palliative care models exist but more information is needed as to the core components of these models. The Integrate Project aimed to conceptualise & develop models of integrated PC in 12 hospitals, 3 in each country (Kenya, Rwanda, Uganda, Zambia), identifying core components & lessons learnt for scale-up.

Aim: To identify core components of integrated hospital based PC service delivery.

Method: Baseline assessments conducted in 2012 identified existing PC services in the hospitals, if any, how these were delivered & by whom. Over the following 3 years, hospitals were supported to develop & refine their models, ensuring that it was appropriate for their own specific setting i.e. a district, regional or national referral hospital. In 2015, a review of models was conducted & core components identified.

Results: Core organisational & PC care co-ordination & services delivery process components were identified in each hospital. These were built upon foundations influenced by the type of hospital, their vision for PC, hospital leadership & resources. Successful integration required 4 inter-related organisational components:
(a) Senior Hospital Leadership
(b) PC leadership & planning
(c) PC service co-ordination, &
(d) PC service delivery.

3 models of PC co-ordination & service delivery were identified:
(a) Dispersed integrated PC teams,
(b) Dedicated PC team/ individual with integrated support, &
(c) a Specialist integrated PC unit.

Common factors included leadership, local champions, ownership, critical mass, clinical modelling, mentorship and access to medicines.

Conclusion: Whilst no two hospitals had integrated PC in the same way, common approaches & core components were noted that led to successful implementation in these hospitals.
The Impact of Integrated Palliative Care Service Model in Oncology: A Retrospective Study in a University-Hospital Network in Hong Kong

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Objective: The oncological care of advanced cancer patients were provided by multiple departments in a university-hospital network in Hong Kong. One of these departments (clinical oncology department, COD) introduced systematic palliative care training for its oncologists since 2002. The COD was recognized as an ESMO (European Society of Medical Oncology) Designated Centre of Integrated Oncology and Palliative Care since 2009. The study was to review the impact of integrative service on palliative care coverage and outcome.

Method: This is a retrospective study assessing the deaths of top 5 cancers in a university-hospital network in Hong Kong (Hong Kong West Cluster) from July 2015 to December 2015. Patients’ clinical information, palliative care service provision and end-of-life outcomes were reviewed.

Results: A total of 307 patients were analyzed. The mean age of cancer death in the study population was 72 years. Around half of all patients (49.2%) were attended primarily by the COD, and 68.9% of these patients were provided with palliative care service. Those primarily attended by the departments of medicine, surgery and or other units were provided with palliative care in the proportion of 25.8%, 11.3%, and 10.2% respectively. In multi-variate analysis, the age of metastatic diagnosis ($p=0.005$), and the COD being the primary care team ($p<0.001$) were the two predictors of higher palliative care coverage.

Palliative care provision was associated with better end-of-life outcomes with regards to prescription of intravenous chemotherapy ($p<0.0001$), strong opioids ($p<0.0001$), emergency admission ($p<0.0001$), number of AED visits ($p<0.0001$), ICU admission ($p=0.0438$) in the last 30 days of life, as well as documentation of DNACPR ($p=0.0284$), CPR ($p=0.0284$) performed and the place of death ($p<0.0001$).

Conclusion: Systemic training of oncologists and integrative service model is important for palliative care service delivery amongst advanced cancer patients.
How do Lawyers Assist their Clients with Advance Care Planning? Findings from a Cross-sectional Survey of Lawyers in Alberta, Canada

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Background: The medical and legal fields coalesce around advance care planning (ACP). People are as or more likely to seek ACP assistance from a lawyer than a doctor, and as such, lawyers are well-positioned to influence ACP engagement. However, virtually no research has explored lawyers’ attitudes, beliefs and practices in this area.

Aims: To ascertain lawyers’ practices in relation to ACP, perceptions of their professional role, barriers and facilitators to assisting clients with ACP, and resource needs.

Methods: A cross sectional survey of lawyers practicing in Alberta, Canada was undertaken in 2016. An online, anonymous survey was promoted over a four-month period to practicing lawyers by three legal professional organizations through email, websites, e-newsletters and social media.

Results: A total of 133 responses were received (7% of the 1,840 Albertan Wills & Estates lawyers). Most respondents (69%) reported assisting clients with ACP “daily” or “weekly”, and 90% of respondents “often” or “always” bring up ACP as part of broader advance personal planning for their clients. Respondents perceived their role to include initiating ACP conversations, providing ACP information, drafting specific legal documents, and encouraging discussions with others, but not liaising with healthcare providers. Client lack of preparedness to engage in ACP was the top-reported client-centered barrier, whereas lawyers’ lack of information about medical aspects of ACP was the top-reported practitioner-centered barrier. There was greatest need for information about how advance directives and medical orders function together in practice, followed by the development/cataloguing of best practice resources for lawyers.

Conclusions: Lawyers are well-positioned and motivated to facilitate public participation in ACP. Access to high-quality resources and joint continuing education with health professionals is warranted.

Funding: Alberta Innovates Health Solutions
A Community Pilot Project Achieving 96% Patients Dying in their Preferred Place

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Background: A one year pilot project was undertaken in a defined rural geographical area in the South of England. This was developed in response to patient, carer and staff feedback. Interfaces between existing services were unclear so the team was redesigned within one geographical area as a pilot for further development.

Method: A multidisciplinary specialist palliative care team was appointed consisting of part time hours for occupational therapy, social work and consultant plus 3 whole time equivalent nursing staff. This team provided cover 8am-8pm 5 days a week with weekend and overnight cover from specialist nursing staff on call for any patient needing advice or administration of parenteral drugs for symptom control at home.

The catchment population of 33,000 was determined by 7 GP practices and one generalist community nursing team.

Results: 64 referrals were made to the team over a 6 month period

- 96% patients died in the place of their choice
- 2 admissions to the acute hospital
- Relationships with all community staff improved significantly with better whole team working, clear roles and responsibilities but improved communication led to more efficient working, less overlap and shared tasks when workloads were particularly high.

Discussion: £120,000 investment in staffing the team saved an estimated £350,000 in admission avoidance. High numbers of patients died in the place of their choice, patients and carers had clearer lines of communication with community staff and staff themselves had high levels of satisfaction working within a proactive team with the flexibility to respond rapidly, work well with colleagues and the commitment to support each other in tough times. Details of successes and mistakes will be shared – the very practical nature of how the team was structured and developed was key to positive outcomes.
Rating System Proposal for Regional Palliative Care Development across Spain

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Context: Countries with decentralised health systems like Spain might have diverse levels of Palliative Care (PC) development across regions. A rating of development could help visualising these differences.

Aim: To propose a rating system for PC development across the autonomous communities of Spain in 2015, with a similar method to the European Ranking (Centeno, 2016). Data came from the SECPAL directory of PC services (Herrera, 2016).

Method: “PC development” is understood here as a combination of the existence of relevant services in a region (“resources”) and the capacity to develop further resources or improve the existing ones (“vitality”). “Resources” comprise 4 indicators of PC services per population (PC teams, PC units, Professionals, and Paediatric services). “Vitality” is estimated by scoring activity of the regional association, existence of educational, management and research resources and other institutions supporting PC services. The leading community (by raw score) is then considered as the reference point against which all others are measured. Resources are weighted 75% and vitality 25% as decided by an expert committee.

Results: Basque Country, Catalunya, Madrid, Balearic Islands and Castilla y León are at the top of the global rating (66%, 61%, 60%, 60% and 59% of the maximum possible score, respectively). Looking at resources only, Basque Country and Catalunya reach higher scores whereas in PC vitality, Madrid, Andalucía, Castilla y León, the Basque Country and Catalunya are leading.

Discussion: Data are published but have not been audited (The Basque Country reported 7 Basic teams, 5 PC units and 38 physicians while La Rioja reported 1 resource and 8 physicians). The rating system is still in process but permitted a comparison of PC development between communities. Recommendations for improving the rating include improvements in data collection, weights, and other vitality indicators.
Does the Method of Sending a Questionnaire to Assess the Quality of Life to the Patient Influence the Frequency of Answers?

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**Background and aim:** Today communication becomes more internet based. Many people do collect health related information from the internet and the internet is used for communication with patients. Starting in 2016 the time of delivery of normal post has increased with ca. 3–4 days in Denmark.

The aim of the presented work was to investigate if the use of sending a questionnaire about quality of life via post and email or only by post does influence the percentage of answers received.

**Method:** The EORTC QLQ-C15-PAL is a questionnaire developed to assess the quality of life of palliative cancer care patients. It is used widely in Denmark to assess the patients quality of life and actual symptoms. When a patient is referred to the Palliative Care Team (PCT) information about the PCT and the EORTC-questionnaire are send to the patient both via email and normal post. This has become current practice since January 2016 due to changes in the post delivery in Denmark. Before the questionnaire was send by post only. The PCT collected the questionnaires on the first home visit. The percentage of patients who filled in the questionnaire was recorded and the years 2015 and 2016 compared.

**Results:** The period from May to August 2015 was compared with the period from May to August 2016. Between May and August 2015 135 patients were referred to the PCT. 72 questionnaires (53%) could be collected in 2015. In 2016 64 of 105 referred patients had filled in the questionnaire (61%).

**Discussion and conclusion:** After the questionnaire has been send to the patients both via email and normal post the percentage of answers received has raised. One may assume that this can be caused by different reasons. One could be that the use of email lead to raised awareness of the importance of the questionnaire. Another reason might be that the team members were more focused on collecting the data. Future research using a mixed-methods approach including focus-group interviews on this topic is planned.
Patients’ and Caregivers’ Preferences for Services and Support Near the End of Life: Evidence from a Discrete Choice Experiment

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Background: Discrete choice experiments (DCEs) are a useful technique for guiding priority setting, but few have been completed with service users. DCEs require individuals make trade-offs and state their preferences between two or more hypothetical sets of attributes. Their observed choices make it possible to determine if the attributes influence choices, and their relative value. Evidence about the elements of care most valued can support efficient resource use.

Aims: To evaluate and compare preferences for services and supports among patients and caregivers accessing different models of specialist palliative care (SPC).

Methods: The study was carried out in three regions in Ireland. Respondents made multiple choices between combinations of attributes including: access to information; symptom burden; monthly costs; caregiver burden; shared decision-making; place of care; arranging access to services; and access to SPC. The data were analysed using probit and latent class regression.

Results: 75 patients and 69 caregivers were interviewed; 66 (88%) and 69 (100%) participated in the DCE. Patients in all regions preferred barrier-free access to advice, ongoing support from SPC and reduced symptom burden, while preferences differed about place of care, monthly costs and caregiver burden. Caregivers’ preferences varied across regions, with some prioritising support from SPC, access to advice and keeping the patient at home. Unlike patients, caregivers had strong preferences for autonomous decision-making. Two latent classes were identified for patients, three for caregivers. Differences between the latent classes in both perceptions and experiences of SPC were identified.

Conclusion: Priorities differ between patients and caregivers and may be linked to the model of service provision or experience with SPC services. The disparity in preferences between these groups demonstrates the importance of eliciting preferences from patients whenever feasible.
In Reforming Health Care in Romania the World Bank (WB) project included a palliative care (PC) component aiming to develop 90 home care teams, 90 outpatient teams, 29 inpatient units and basic PC through GPs.

**Aim:** Understand current PC provision in the country, volume and quality of services provided.

**Method:** The Ministry of Health (MoH) Working Group for PC developed a questionnaire to collect data on service provision in the country: geographic location, care settings, organization form, equipment, types of beneficiaries, number of admissions, number of patients assisted, number of discharges alive, multidisciplinary team members; staff ratio; staff education, use of assessment scales, protocols and interdisciplinary plans, staff support programs, bereavement services, funding sources, expenditures distribution, real and reimbursed cost/day. WB implementation unit in MoH sent an invitation letter for providers to take part in the survey via local health boards, based on lists obtained from funding authority and professional society. Data were collected online and analyzed.

**Results:** 80 providers with 91 services (74 inpatient units, 9 home-based teams, 3 outpatient, 4 daycare, 1 hospital team) out of 125 services identified; 56.2% services in public sector, 20% NGOs, 23.25% for profit. Patients served: all admit cancer patients, 75.38% neurological patients, 72.31% patients with organ failures, 12.31% HIV patients; 1293 PC beds for adults and children with 10,445 admissions; 4025 patients assisted at home annually (10% of need). Over 95% services have syringe drivers, pressure sore mattresses, adapted bathrooms, use of interdisciplinary care plan, measure pain and performance status; 30 out of 92 services offer bereavement support; 27 services have staff support arrangements. All services have doctors and nurses; psychologist 69.23%; priest 56.92%; volunteers 40%; social workers 38.46%; PC trained staff: 96 doctors, 369 nurses, 10 social workers, 61 others.
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Palliative Care Services across Settings: An Improvement in Patient and Family Well Being

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Background: Patients often encounter discontinuity of care during the last phase of their life. Many are admitted to the hospital in end stage disease, because of inadequate discourse regarding their diseases and wishes.

Aim: To develop a regional transmural (across settings) model of palliative care in order to improve the quality of life of patients and families facing the problem of the end of life or life-threatening illness, whether they are located at home, in a hospital, nursing home, or a hospice.

Method: By talking with and asking commitment of the staff at home care taking facilities in our region, and the hospices and nursing homes, as well with the hospital staff and direction, we developed a transmural palliative care model. In this model, both intra-mural (hospital or other) and out patients questions are first addressed by the nurse practitioner. The nurse practitioner makes a stocktaking of the question and consults who is needed. Both, in hospital and at home, bed side visits are performed if indicated.

Results: An effective collaboration between various institutions. The communication across settings enabled patients to stay at home with adequate care. Nurse practitioner and home care takers visited patients in hospital so they could prepare a proper transition to home care, resulting in less emergency admissions and less crisis’s at the general practice centre. If hospital care was needed it could be given without delay and unneeded interventions on emergency wards. All patients were discussed in a weekly, multidisciplinary consultation, enabling a continuous improvement of the team.

Conclusion: By developing a model of palliative care across settings we contribute to continuity in care during an already difficult journey towards the end of life. In a prospective study, we will evaluate the effect of transmural care on both wellbeing (of patients and family) and the costs.
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A Study of Live Hospice Discharges – Who, Why and How Appropriate?

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Background: In order not to exhaust per lifetime government subvention for a 3 month inpatient hospice stay, hospice patients in Singapore who improve are actively discharged to nursing homes or to their own homes with home hospice support. These planned discharges may not be well received by patients and families, especially those who are not keen for further placement. There is currently no data for live hospice discharges nor appropriateness of discharge planning in Singapore.

Objective: To describe the characteristics and outcomes of patients who were discharged alive from an inpatient hospice in Singapore, comparing with available data from other countries.

Method: A retrospective analysis was conducted on all patients discharged alive from a 37 bedded inpatient hospice over 1 year. Patient characteristics, Karnofsky scores, preferred care plans, reasons for discharge and patient outcomes were studied.

Results: Out of 358 admissions, a total of 61 patients were discharged (17%). Of those discharged, 30 were male (49.2%) and 53 were of Chinese ethnicity (86.9%). Majority were married (55.7%), while the rest were single (16.4%) or widowed or divorced (27.9%). The average length of stay prior to discharge was 43.1 days. Forty two patients (68.9%) were discharged home, while 11 (18.0%) were transferred to hospital and 7 (11.5%) to a nursing home. Of the 7 who were transferred to a nursing home, all except 1 had died 6 months post-discharge. For patients transferred to hospital, the mean time to death was 17.8 days post-discharge for 9 out of 11 patients (81.8%). Analysis of other patient outcomes, patient’s preferred care plans and reasons for discharge are pending.

Conclusion: Based on preliminary data, our live hospice discharge rate is comparable with data from the United States. Median survival for patients transferred to hospital was much shorter than those transferred to home hospice or nursing homes.
Delivering Clinical Interventions at Home – Is This the Future?

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Public policy coupled with patient preference studies promote the need for palliative care delivery in a patients preferred place of care, for the majority of patients this is their home.

In 2014 the specialist palliative care at home project commenced, one of the main components of this pilot was to develop local services to enable the delivery of clinical interventions to patients with palliative care needs in their own home.

To deliver bisphosphonate infusions, blood transfusions and abdominal paracentesis for malignant ascites in a patients home.

Development and ratification of all clinical guidelines, policies and alert cards were needed prior to offering this new service to our patient population. Likert scale questionnaires were developed for patient and carer feedback both pre and post intervention. Additionally, formal interviews have also been conducted with patients and carers.

To date 22 bisphosphonate infusions and 5 blood transfusions have been delivered to patients in either their own home or nursing home. Abdominal paracentesis are being carried out in our local hospice without the need for referral to the acute sector with policies in place to conduct this intervention in the community. Both the formal and informal patient and carer feedback have been positive.

Although preliminary results suggest a very positive experience for both patients and carers the cost effectiveness of this service will influence the decision to commission this service in the future. Comparative studies have demonstrated that receiving a clinical interventions at home is more cost effective than in secondary care. It has been demonstrated that offering an intervention at home leads to an earlier referral to palliative care and that early referral to palliative care decreases the overall cost to the NHS.

Collaborative working to improve the provision of palliative care clinical interventions to our patient population has developed long term relationships between organisations.
Updating a Hospice Community Service within a Context of Increasing Demand and Uncertain Health Economy: Process and Outcomes

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**Aim:** In order to ensure that our Hospice continued to provide an equitable service despite increasing demand within an uncertain health economy, we recognised that our community clinical service required change. Regularly reviewing all patients, regardless of their need, was no longer sustainable. This project aimed to ensure that intervention was targeted to need, empowered self management and clarified processes once input was complete.

**Methods:** A multi-disciplinary working group met regularly and initially analysed the current caseload to demonstrate inconsistencies in clinical service provision. Tools that could be used to improve the effectiveness of the service were identified. Regular meetings with clinicians ensured engagement with the process.

**Results:** Four levels of intervention were used to illustrate the requirements for differing input depending on need: advice only, one-off assessment, a block of intervention or on-going multi-disciplinary input. Phase of illness from the Outcome Assessment Complexity Collaborative suite of measures was adopted. For patients not currently requiring active intervention, Open Access or Discharge status was defined. Guidance for initial assessment, case co-ordination, follow up contact and the Multi-disciplinary Meeting format was developed.

**Conclusion:** This approach has ensured clarity and consistency for patients, carers, external healthcare professionals and Hospice staff. It has allowed our clinicians to perform a specialist advisory role when felt appropriate, empowering both patients and professionals, leaving more time to focus on complex cases. Displaying the Phase of Illness and Levels of Intervention as a grid helped highlight when certain interventions could be most beneficial. Adopting a structured project management approach and reporting to the Senior Management Team kept the project group focussed and helped manage the process of change in the hospice setting.
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**Nurse Prescribing in Specialist Palliative Care – Our Journey**

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The aim of this study was to evaluate the role of two established Registered Nurse Prescribers (RNPs) within a Specialist Community Palliative Care Service in Ireland. The study ran over a six month period, from 1st November 2015 to 30th April 2016.

A dual approach was taken to data collection. A semi-structured questionnaire was used to survey patient, family, doctor and pharmacist experience of the RNP role in the community. Concurrently, the prescriptive patterns of the RNP were examined through a review of prescribing reports, generated from the national RNP database.

There were overall excellent satisfaction ratings from service users and multidisciplinary colleagues (100% for patients and families; 87% for doctors and 85% for pharmacists). Families highlighted the prompt access to medication, convenience in getting to the pharmacy and increased awareness of the use and side effects of medication. Doctors reported on the positive impact nurse prescribing had on their relationship with the patient, family and RNP. They commented on the RNP knowledge base, timely interventions and appropriate actions. Moreover, 100% confirmed their intention to continuing a collaborative working practice with the RNP. Pharmacists gave feedback on their experience of processing prescriptions issued by a RNP, with 100% satisfaction on the completion of the prescription with regard to legibility, demographic detail, written requirements for controlled drugs and the prescribing of generic medicines.

The examination of the RNP prescriptive patterns showed the opiates to be the most commonly prescribed class of medicines. The most common routes of administration prescribed were subcutaneous (71%); rectal (17%); oral (10%) and transdermal (2%).

The study concludes with a recognition that the RNP role is well established and respected with the community by both service users and multidisciplinary colleagues. There is affirmation of the RNP role in enhancing patient care.
“One Patient – Two Doctors” The Cooperation between General Practitioners and Home Hospice Team

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Background: A patient with advanced cancer disease, remaining at home, requires a holistic specialized care and good cooperation between palliative care doctor and GP. Competences both complement each other.

The aim of study was to assess the cooperation between home hospice teams and family doctors evaluated by palliative care doctors. Utilitarian goal was to improve the holistic patient care at the end of life.

Material and methods: Self-made questionnaire of 13 questions was prepared. The questions concerned attitudes, opinions about the cooperation of GP and hospice team, the same as people’s individual opinions and feelings about such cooperation. We surveyed the group of 30 palliative care doctors.

Results: Respondents consider that only half of home hospice patients actively use family doctor care. 80% hospice doctors contacted GP (phone or personal contact) on the patient - 40% on medical transport, 40% on imaging tests and the dosage of opioids. 44% of respondents believe that the cooperation between the hospice doctor and GP is essential, 56% – that’s supplemented with. 64% say that the electronic documentation will facilitate cooperation between physicians. 64% of respondents misjudge their cooperation with GP, the same like cooperation between district and hospice nurse. They noticed the reluctance of family doctors to cooperate and take responsibility for the patient when it is already under the care of home hospice.

Conclusions: There’s a strong need for improving cooperation between family and hospice doctors. Preliminary results show we should use electronic documentation, provide additional training of family doctors in the pharmacotherapy of opioids and persuade them to participate in the patient’s treatment. Further research is required.
Abstract number: P02-105
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**Specialized Outpatient Palliative Care (SOPC) in Cologne**

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Specialized outpatient palliative care (SOPC) in Cologne. How many patient of a region can die at home with the help of specialized outpatient palliative care team? Figures and Data from a specialized palliative care team in the area of the one million inhabitant town Cologne in Germany are presented. SOPC in the region of the right Rhine Cologne was founded in the year 2012 to give people the possibility to die at home. SOPC are multiprofessionelle teams of physicians and nurses which take care of the dying people at home or in old people’s home. Daily visits at home are also part of the concept as well a 24 h emergency services. SOPC is only financed by the social welfare system if the patients have a short life expectancy, a non-curable disease, and severe symptoms, which need specialized care e.g. puncture of severe ascites at home. Research Question Most patients wish to die at home. For this reason, the legislator created the prerequisites to fund ambulatory palliative teams. We investigated how many patients died within a given period of time as part of the care provided by SOPC.

**Method:** All the date of the SOPC Cologne right Rhine were analysed and compared to the official death statistics. The official death data were obtained from the city of Cologne. The patient data have been analysed from the documentation of SOPC team.

**Result:** In the year 2015 902 patients (age range 18–103 years of age) have been treated by SOPC. Of those 119 lived alone, 455 with their relatives and 216 were residents of old people’s home. In this given period of time 684 patient died i.e.18.42 % of all died humans in this region.

**Conclusion:** To die at home is for terminal ill patients and their relatives a strong wish. With the concept of specialized outpatient palliative care teams 18.4 % of all died humans died at home. SOPC avoids unnecessary hospitals stay’s and gives significant help to the families to enable them to accompany their relatives to death at home.
Assessing the Role of Social Media in a Palliative Care Setting

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Background: Social media is a form of electronic communication, which creates online communities and can facilitate the exchange of information and ideas.

Social media in healthcare is a rapidly and constantly evolving phenomenon. Both patients and healthcare professionals are increasingly engaging with social media for personal and healthcare use. Patients are increasingly active online with regards to seeking healthcare information and social support through discussion forums. Patients communicating with their healthcare providers via social media is becoming a popular preference.

It has been reported that social media provides patient empowerment, psychological well-being and connectedness.

Aims: To examine personal and health-related social media engagement in a Palliative Care population.

To assess how social media impacts on patient empowerment, social support and connectedness.

Methods: Cross-sectional survey of patients known to the Specialist Palliative Care service at Marymount University Hospital & Hospice, Cork, Ireland.

A literature review informed the construction a sixteen-item questionnaire, which assessed patient demographics, social media engagement and themes of connectedness, empowerment, psychological well-being. Perceived benefits and disadvantages of social media in healthcare were explored.

Results: Analysis using descriptive statistics is ongoing, however preliminary results convey that social media engagement among the Palliative Care population is prominent.

Conclusions: Social media provides a platform for interactions and information sharing within healthcare for patients and professionals. This study has the potential to develop a social media platform between Palliative Care patients and the Specialist Palliative Care team for symptom assessment and management, including psychological support.
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**Challenges of the Care of Cancer Patients at a Private Hospital in Rio de Janeiro**

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**Introduction:** With the aging of the population, increases the prevalence of chronic diseases, such as cancer. To cancer are attributed 12% of all deaths worldwide and the second largest cause of general mortality in Brazil. In effect, the palliative care, as a multiprofessional approach toward the quality of life of patients and families, become essential. In the face of diseases that threaten the life, palliative care can help in the planning of care, the hospital or homecare. Therefore it is necessary for the whole team of a hospital is prepared with respect to palliative approach, since the number of hospitalizations for cancer amounts and high, one of the items in the plan of care, take a challenge.

**Objective:** Discuss the challenges of hospital discharge of patients in advanced stages of oncological disease, accompanied by the core of Palliative Care, in a private hospital in the city of Rio de Janeiro.

**Methods:** A descriptive study, based on the monitoring during the hospitalization of 35 cases between the years of 2014 and 2016.

**Results:** The diagnosis when performed in an advanced stage of the disease difficult to discharge; twenty of thirty-five patients died, and of these, 12 died in less than 15 days, showing that the approach was performed in phase at the end of life. Fourteen patients were discharged from the hospital, but four returned to die in a hospital environment. Patients and family members were satisfied after a palliative approach.

**Conclusion:** This study showed that the approach palliation solely in the final stage of life, can make it difficult to discharge, since the combination of patient/family is exposed to a degree of suffering and hopes that the hospital care offers greater benefit. Hospital discharge acts in this scenario not only for greater availability of hospital beds but also to bring more comfort to patients and their families, humanization of care among other advantages.
Development of an Atlas of Specialist Palliative Care for Scotland

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Background: Studies of the international development of palliative care have made possible the production of regional palliative care ‘atlases’ for Europe and Latin America, with others in the planning. The global atlas of palliative care played an important role in underpinning the World Health Assembly Resolution of 2014. But to date no attempt has been made to produce an atlas of specialist palliative care delivery and development in a single jurisdiction.

Aim: To create an atlas of specialist palliative care for Scotland.

Methods: Adapting the data collection template of the European Atlas of Palliative Care and using a set of definitions derived from EAPC white papers, we generated a series of questions about the provision of specialist palliative care in Scotland. In 2015 a survey was conducted (by telephone and online) in all 14 Scottish Health Boards as well as among 15 charitable hospices. A detailed review was conducted of policy milestones and related developments, identifying key documents and their location.

Results: A 50-page atlas was produced including maps and figures that describe levels of specialist palliative care provided through different types of services, categorised by each Health Board area along with an organised list of key documents and milestones that capture the development of Scottish palliative care in the areas of policy, education and socio-cultural attitudes.

Conclusions: The atlas has been welcomed by the palliative care community in Scotland and serves as a useful guide to interested stakeholders, including politicians and policy makers. Launched at a specialist palliative care conference in September 2016, it is available online and in print. It serves as a benchmark by which progress on some of the ‘commitments’ in the Scottish Government Strategic Framework for Action on Palliative and End of Life Care (2016–21) can be measured. It is an approach that others could adopt at the country level.
Specialist Palliative Care for Adults with Advanced, Incurable Illness in Hospital – A Systematic Review and Meta-analysis

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**Background:** Physicians from all disciplines are recommended to collaborate closely with specialist palliative care (SPC) services. However, prior to this study, the effect of SPC has not been assessed according to the highest standards of evidence based medicine.

**Methods:** A systematic review (CRD42015020674) and meta-analysis for randomized controlled trials (RCTs) with adult in- or outpatients treated in hospital suffering from any advanced illness was performed. Minimum requirements for SPC included the multiprofessional team approach. MEDLINE, EMBASE, Cochrane Central Register of Controlled Trials (CENTRAL), PsycINFO, and trial registers were searched until July 2016 (handsearch: textbooks, reference lists). Two reviewers independently screened and extracted data, assessed the risk of bias (Cochrane risk of bias tool) and evaluated the quality of evidence (Grading of Recommendations Assessment, Development, and Evaluation system [GRADE]).

**Results:** Of 3967 publications, 12 were included (10 RCTs, N=2454; of these 72% (N=1766) with cancer). No trial triggered SPC integration according to patients’ needs as identified by screening. The risk of bias was unclear or low for most items, but high for blinding in nine studies. Overall, a small effect in favour of SPC was noted (Hedges’ g: 0.17, 95% CI 0.01 to 0.32, N=1223, 6 RCTs, quality of evidence: moderate). The effect was marginally larger for cancer patients (g: 0.21, 95% CI 0.02 to 0.39, N=833, 5 RCTs) and especially for those who received SPC early (g: 0.34, 95% CI 0.10 to 0.58, N=388, 2 RCTs). The impact of SPC on other outcomes was inconclusive.

**Conclusion:** SPC was associated with a small effect on QoL, with most pronounced effects for cancer patients who received SPC early. We hypothesize that SPC could be most effective if it is provided early and if it identifies patients with unmet needs via screening (“SPC as needed”).

As primary outcome, quality-of-life (QoL) was analysed with the random-effects model.
Rural Palliative Care – How to Improve Service?

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Palliative care for patients at the end of life is characterized by multiple and complex problems and challenges for patients, families and health services. Caring for palliative patients at home require competence and interprofessional collaboration between health workers in the local community and collaboration between primary- and specialist health services.

The aim of the study was to gain knowledge about how to improve palliative care in rural areas through better collaboration, according to the perspective of local health workers.

The study was conducted via qualitative focus group interviews; nurses (3), GP’s (2), interprofessionals (5) and 6 individual interviews. 52 health care providers; nurses, physicians, physiotherapist and occupation therapist from 25 municipals participated. Most municipals had between 1000 and 6000 inhabitants. A thematic analyzing process was used.

Some preliminary results and conclusions.
● Many communities are still dependent on “fiery souls”.
● Oncology nurses/palliative nurses and GP’s with a particular interest in palliative care are central for continuity in day-to-day work and development of palliation in the municipal.
● The importance of “talking together” and close collaboration between health care providers.
● A strong wish to succeed; availability, flexibility, and rearranging recourses when needed, including taking care of families.
● Variation in and lack of specialized competence for health care providers, few GP’s have a specialisation in palliation.
● Creating palliative teams when needed.

Fiery souls are still important for continuity, and participating in networks with others in the same situation is important. Physical localization, nearness between professionals seems central. Organizing palliative care in a way that allow a flexibility use of recourses when needed. Improvement in competence for health care professional, both basic and specialized competence. Empowering family members to take part in care.
‘Pending Triage’ Review of the Accuracy of Triage of Referrals to an Urban Community Palliative Care Team

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Background: All referrals to the community palliative care team (CPCT) come on the National Specialist Palliative Care Referral Form (NPCRF). Prioritisation of the patient is dependent on the quality and accuracy of the information provided, and the stated urgency of the referral.

Aims: To correlate the referral urgency scores as assigned by the referrer and those assigned by the interdisciplinary triage team within 24 hours of receipt of the referral with the retrospectively allocated score given at the initial assessment of the patient.

Methods:
• 100 consecutive referrals to CPCT which met the criteria for community specialist palliative care were included
• Referrals were interrogated and triage scores allocated at the above stipulated points in time as per NPCRF
• Extracted data was analysed using Microsoft Excel using descriptive statistics to depict results.

Results:
• GPs referred 41%, the remainder originated the acute hospital sector
• Full correlation of scores in 55%, underestimated urgency 18%, overestimated urgency 15%, missing data 12%
• Highest correlation occurred in the most urgent referrals (n=15) i.e. request for review < 48 hours 73%(n=11) and provided the most accurate clinical information
• GPs triaged patients with the highest level of urgency
• 69% referrals were triaged correctly by triage team, 18% underestimated, 10% overestimated
• There were no urgent referrals from private hospitals & 1 hospital triaged all their referrals as needing review in 1 week
• 12% had no urgency indicated on the referral form, of which half were subsequently scored incorrectly by the triage team.

Conclusion: Pertinent, timely information regarding the urgency of referrals is pivotal in ensuring the CPCT services respond in a timely, responsive manner to those patients in greatest need. However fluctuation in individual patient condition following referral and the subjective nature of triage may confound this process.
The Need to Improve Palliative Care in Nursing Homes – Results from a Questionnaire Based Investigation in Schleswig-Holstein, Germany

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Background/aims: Many people die in nursing homes. Therefore nursing homes are arenas where palliative care and end-of-life care has to be provided on a regular basis. A new law on improvement of hospice- and palliative care has been introduced in Germany (Federal Ministry of Health 2015).

Methods: To investigate the current practice and educational needs a questionnaire about palliative care in nursing homes was sent to all nursing homes in Schleswig-Holstein. Nursing homes were invited to participate by email.

Results: 100 nursing homes responded. 98 of these had routines for end-of-life care whereas only 31 had a concept for Palliative Care. 74 had established cooperation’s with a palliative care Team. 88 stated an interest and need for further education in palliative care. Wishes for education included most frequently pain-therapy, symptom-management and communication.

The following themes were ranked as the most important topics for future education about Palliative Care: pain-therapy 71, communication 46, symptom-control 45, ethics 39, nutrition 36, bereavement 32, cooperation with the relatives 30, wound-management 25, advance care planning 25, spiritual care 23 and volunteers 9.

Conclusions: Although most nursing homes do have written routines for end-of-life care only a third has a concept for palliative care in the nursing home. Most important areas for the improvement of palliative care described by our informants were education and more cooperation with family physicians, Palliative Care Teams and mobile hospice care.

The findings are used to implement educational efforts addressing the needs and wishes of the nursing homes in the whole region.

Literature: Bundesministerium für Gesundheit. Gesetz zur Verbesserung der Hospiz- und Palliativversorgung. 2015 (Federal Ministry of Health. Law on improvement of hospice- and palliative care.)

Abstract number: P02-114  
Abstract type: Poster Exhibition  

A Joint Cardiology and Palliative Care Clinic for Heart Failure Patients with a Novel Approach for Improving Quality of Care across the Primary and Secondary Care Interface

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Background: End stage heart failure is a terminal illness. When a formal palliative approach is not adopted, opportunities for advanced care planning, establishing goals of care and inter-professional communication can be missed, and the supportive element of care overlooked. The aim of this initiative was to develop a collaborative model of palliative care for patients with heart failure, supported by cardiology, palliative care and primary care, within a healthcare system which is part-private and part-publicly funded.

Design: Suitable patients with NYHA III/IV and already known to cardiology complete the Minnesota Living with Heart Failure Questionnaire (MLHFQ) and an Advanced Care Planning document. They attend a shared consultation with a cardiology and palliative care specialist. The patient’s case is reviewed and their goals of care are discussed and agreed. A pre-booked follow up appointment with the patient’s general practitioner (GP) allows further time for management and goal setting. Attending a GP has a charge, therefore an innovative funding scheme has been developed to allow the patient to attend for minimal or no fee, but for the GP to be remunerated appropriately. On-going follow up including repeating the MLHFQ is done by the cardiology department.

Results: An innovative, collaborative multispecialty service has been established. The feedback of patients and professionals taking part is positive – further details will be presented. GPs are empowered to continue managing these patients with the benefit of clear information from cardiology about prognosis and patient wishes.

Conclusion: This new initiative is both feasible and acceptable to all. The shared care goal between primary and secondary services can be improved by increased communication, clear specialist guidance and ascertaining patients’ goals of care. Novel funding streams are an important component of the model that should reduce disparities in who can access primary care support.
Heading toward Integrated Care? Health Care Professionals’ Experiences with Palliative Patients’ Transfers: A Focus Group Study

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Background: Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects to realise continuity of care between all actors involved in palliative patients’ care network. Due to demographic and social changes, palliative care has become more complex. Consequently, transferring patients from one setting to another (hospital, hospital’s palliative care unit, home care and nursing home) is more common. As such, divers professionals from different settings are involved. Continuity of care during patient transfer therefore becomes a challenge.

Aim: To explore:
● health care professionals’ experiences with palliative patients’ transfers.
● how the interprofessional collaboration is perceived.

Methods: Nine focus group discussions with divers professionals (53) from different palliative care settings (hospital, hospital’s palliative care unit, home care and nursing home) were conducted. A grounded theory approach was used for analysis.

Results: The limitation of hospitalisation length was a perceived barrier in complex patient care situations and for organising the required home care before discharge. Specialists’ informing patients on disease stage and prognosis was perceived to happen late and deficient. This hampered open communication on end-of life decisions and a timely transfer to the home situation or the palliative care unit.

Timely and sufficient information flow between all professionals involved was most important. A perceived barrier for interprofessional collaboration was the lack of a shared electronic patient record. Efficient multi-disciplinary team meetings with shared care goals were regarded essential, though often lacking.

Conclusion: Several barriers on divers care levels are to be tackled to achieve integrated care. The availability of a shared electronic patient record can meet the needs of efficient information flow. More training is needed to improve doctor-patient and interprofessional communication.
Palliative Care in Advanced Heart Disease – A Position Paper from the Danish Society of Cardiology


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Introduction: Patients with advanced heart failure are often hospitalized, have poorer prognosis than many cancer patients and have severe clinical symptoms alongside mental, social and spiritual struggles. According to the WHO and the Danish Medical Authority, palliative care must be available for patients with life-threatening diseases including heart failure. In practice focus is on cancer patients. Stimulated by the National Board of Health the Danish Society of Cardiology (DCS) by 2015 initiated a task force to develop a position paper concerning palliative care.

Method: The task force is founded in the Heart Failure working group, and the paper is prepared in collaboration with members from the following specialties: Palliative Care, Psychology, Intensive Care Units, Cardiac arrhythmia, Congenital Heart Diseases, Prevention and Rehabilitation, General Practice and Nursing. Due to major gaps in evidence the paper is based on smaller studies and clinical practice supplemented by knowledge from the cancer area.

Results: The position paper is aligned with the European Society of Cardiology recommendation with focus on the relief of suffering starting in the early stage of the disease parallel to standard care as a supplement to life-prolonging treatment. The Danish statement delivers practical hands-on guidance on clinical aspects and symptom management during the three stages of advanced heart disease. Further the statement focus on the importance of communication and lines out topics to be broached including deactivation of implantable cardioverter defibrillators. Organizational strategies are presented. The paper is available October 2016 in Danish.

Conclusion: Danish cardiologists have acknowledged the important of palliative care. The coming years will reveal how palliative care is implemented in the clinical care trajectory to the benefit of patients and their relatives. The statement might deliver inspiration to other countries.
Person Centered End-of-Life Care: A Transmural Care Pathway

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Aim: The aim of this project is to develop and evaluate a transmural palliative care pathway (TMZP). The TMZP is guided by four key principles: early identification and registration of palliative patients, a timely conversation about end-of-life (identification by surprise question), shared-decision-making and good transmural coordination and communication.

Design, methods and approach taken: The TMZP is pilot tested by 15 GPs, 10 specialists (oncologists and geriatricians) and 9 pharmacists in the Netherlands. The TMZP will be continuously evaluated from December 2015 until September 2017. The TMZP process will be evaluated by means of interviews with relatives of diseased, and focus groups with GPs, medical specialists, coordinators of the TMZP. After each evaluation, findings will be shared with the TMZP project group so process issues can be constantly optimized (action research). The effects of the TMZP are measured cross-sectional (through questionnaires, focus groups and interviews with relatives) by using an intervention group (TMZP) and a control-group (care as usual). Data will by collected on care burden for relatives, health care usage, place of death and quality of dying.

Results: 45 patients are included in the TMZP. Process measures still identify late inclusion; patients die within 6 month after inclusion. Medical specialists and GPs find it hard to communicate about end-of-life in an earlier phase. Although due to communication training they are feeling more confident. Although mentioned barriers, the majority of the health care professionals are positive about the TMZP and find it a useful innovation that will lead to a higher quality of care.

Conclusion / lessons learned: Overall, the TMZP is evaluated as a positive innovation that increases awareness about the palliative care phase, end-of-life communication and specific care needs. End of life communication is still difficult in medical specialist and GPs due to a more ‘cure’ way of thinking.
Leaky Pipeline, Gender Bias, Self-selection or All Three? A Quantitative Analysis of Gender Balance at an International Palliative Care Conference

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Background: The ‘leaky pipeline’ in clinical academia – attrition of women at each step of the career ladder – is well described. Visibility is an important dimension of equality; a paucity of women conference speakers has been demonstrated in several disciplines. It is unclear if the same phenomenon exists in palliative care, where women make up the majority of the workforce.

Aim: We analysed the gender of speakers at the 2016 EAPC World Congress to test the null hypothesis that there is no difference in the proportion of women and men with senior academic visibility in conference programmes.

Methods: The final programme of EAPC 2016 was examined and the gender of each speaker recorded. Presentations were assessed using a three-tier hierarchy of senior academic visibility: Free Communication Sessions, Parallel Sessions and Plenaries (low to high). In cases of speaker substitution we used the gender of the originally planned speaker. At EAPC 2016 five top scoring abstracts were presented as short Plenaries on the main stage. Since the decision to include these was made on the basis of anonymous abstracts, they were analysed with the Free Communication Sessions. As there was only one invited Plenary at EAPC 2016, we examined the gender balance of EAPC Plenaries from 2012–2016.

Results: Most speakers at EAPC 2016 were women (96/130, 73.8%). The proportion of women was highest in the Free Communication Sessions (84/107, 78.5%); 12/22 (54.5%) of speakers in Parallel Sessions were women. In 2016 there was one Plenary speaker (a man). From 2012 to 2016, 6/23 (26.1%) invited Plenary speakers at EAPC conferences were women (Chi-square=25.4, p< 0.00001).

Conclusions: These data reject our null hypothesis and suggest that there is attrition of women along the academic ‘pipeline’ in palliative care. Other factors such as self-selection (that women decline invitations to give talks) and unconscious gender bias need further exploration, alongside action to address this imbalance.

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<th>Women</th>
<th>Men</th>
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<tr>
<td>Free Communication (2016)</td>
<td>84</td>
<td>23</td>
<td>107</td>
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<tr>
<td>Parallel (2016)</td>
<td>12</td>
<td>10</td>
<td>22</td>
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<td>Plenary (5 years, 2012–2016)</td>
<td>6</td>
<td>17</td>
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Chi-square = 25.4, p < 0.00001

(Table: Distribution of speakers by gender)
Building on Firm Foundations: Joining Projects-preparing to ‘Build on the Best’

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Background: Locally in 2014, Transforming End of Life (EoL) Care Acute Hospital & Six Steps for Success (SSS) in Care Homes (CH) were joined to ensure seamless quality care, documentation & standard of education, support & empowerment for staff in all care settings (including community).

Method: Routine data, including GSF registrations, preferred place of care (PPC), future care planning conversations, Rapid End of Life Transfers, place of death, was compared with data collected prior to the creation of the joint Transform Team.

Results: Over 2 years, care of dying training delivered to a number of trust staff equal to 70% hospital clinical staff, 93% DNs & 73% GPs in 93% practices. 89% DNs received training in Future Care Planning, 77% in genograms for family care & 41% co-ordination of care in those approaching EoL.

2% all GSF registrations were triggered by acute trust staff (60% non cancer). 1 in 4 of those recognised likely to be dying in hospital had a conversation about Rapid End of Life Transfer to home, 1 in 10 of all chose it & achieved it, 1 in 100 were failed transfers.

Deaths in usual place of residence (DiUPR) increased to 51% of all deaths from all causes, compared to hospital deaths (43%) (ONS 2015). For all GSF registered patients who died, 31% died in hospital, 86% had documented PPC, of whom 84% achieved it.

Information was known about 667 care home deaths, 40% of which were known to be GSF registered. 68% of all known CH deaths occurred in the CH (UPR) & 32% in hospital, however if CH resident was GSF registered & died, 99.6% died in CH & 0.4% died in hospital for two consecutive years running.

Conclusions: There are many local projects around EoL care, of which Transform is just one. However the collaboration & cross boundary working appears to be making a difference & gives the best foundations on which to build further.
Abstract number: P02-121
Abstract type: Poster Exhibition

The Impact of Pediatric Palliative Care Program on the Patient Care in a Cancer Center: A Qualitative Study

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Purpose: Caring for pediatric patients with incurable cancer is always challenging. Involvement of palliative care team in the care is essential. A pediatric palliative care program was initiated in our cancer center in October 2013. A qualitative research was designed to evaluate the impact of the program on the patient care.

Methods: The nursing staff of the pediatric ward was invited to participate in this study. Utilizing a semi-structured interview format, the third author interviewed the participants after obtaining their written consent. The names of the participants were coded with English alphabets. The verbatim transcription of the interview data was analyzed through content analysis by the first and second authors separately. The main themes generated from the data were compared and discussed until consensus was reached. This study was approved by the IRB of the cancer center in March, 2015.

Results: Between March 2015 and June 2016, five of the seventeen pediatric nurses participated in the research. The data was saturated. Three main themes regarding the impact of the program on the patient care were generated: better psychosocial support to the patient and family, better symptom relief, and provision of palliative care to the patients with terminal illness. The participants felt less stressful when the patients and the families were under better psychosocial support and the management of physical symptoms were optimal. They felt frustrated when the patient’s dying process was full of suffering. The program was essential to both the nursing staff and the patients/families. Enrollment to the program should be early because the members in the palliative care team are new to the patients and their families. Building rapport always takes time.

Conclusion: Implementation of pediatric palliative care program is beneficial to the care of pediatric patients with advanced cancer, for both the patients/families and the nursing staff. Early enrollment to the program is necessary.
Do Compassion Satisfaction and Compassion Fatigue Differ among Health Care Professionals in a Home Palliative Care Unit (HPCU) in Greece?

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Introduction: Health Care Professionals (HCP) working in a HPCU are exposed to many challenges associated with death and dying which may contribute to Compassion Fatigue (CF) and Compassion Satisfaction (CS).

The aim was to explore potential differences among HCP concerning CF and CS in a HPCU.

Material and method: A sample of 12 HCPs completed a demographic/ work-characteristics form and the Professional Quality of Life version 5 (ProQOL-5), Greek version. The ProQOL-5 is a 5 point (1-5) Likert type 30 items instrument divided to three sub-scales: CS, Burnout (B) and Secondary Traumatic Stress (STS). Its average score is 50 (B<50 – STS<50 – CS>50). Additionally, two focus groups (one for nurses and another for all the other HPC) were held to better explore CF and CS.

Results and discussion: Totally 6 nurses/N (50%), 3 physicians/P (25%), 2 social workers/SW (16.7%) and one physiotherapist/Ph (8.3%) participated. N reported less STS (19.5±3.8) and more B (20.5±6.0) than other HCP (p>0.050). P and SW had similarly low STS (24.0±4.2) and B (19.00±4.2). All CS scores were low. The lowest CS was reported by SW (38.5±0.7), followed by N (38.8±4.7), Ph (39.0) and P (41.6±4.7). Focus groups confirmed the results. N and SW reported that caring patients/family was their main source of satisfaction. Additionally, they gained satisfaction by interacting with the same HCP team. P were satisfied by providing symptom control and the availability of a cooperative caregiver. P’ and SW’ low CS was related to insufficient social services, while work related parameters (salary, leaves, out of hour telephone services) were mentioned by P’ and N’. Furthermore, P reported limited opportunities for professional development. Sharing with a teammate (for N and SW same profession, for P closest HPC) was helpful for managing low CS.

Conclusion: All HCP reported low CF and CS, but different factors contributed to CF and CS and slightly different strategies were used to manage their low CS.
Abstract number: P02-123
Abstract type: Poster Exhibition

Baseline Characteristics of Patients Included in the Palliative Randomized Controlled Trial DOMUS

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Background: The DOMUS study aims at investigating whether an accelerated transition from oncological treatment to home-based specialized palliative care (SPC) for patients with incurable cancer results in more patients reaching their preferred place of care and death. The aim of this abstract is to show the characteristics of the patients at the time of inclusion.

Methods: DOMUS is a randomized controlled trial (RCT) with 340 patients with cancer. Included patients were randomly assigned either to:
   a) SPC enriched with a standardized psychological intervention for patients and caregivers at home or
   b) standard care alone.

Patients included were adult incurable cancer patients, with no or limited antineoplastic treatment options left. The patients were assessed at baseline regarding socio-demographics, disease characteristics, The European Organization for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30) and The Hospital Anxiety and Depression Scale (HADS).

Results: Females represented 51.5% of the patients while the mean age was 66 years. Nearly half of the patients had lung cancer or cancer in the digestive organs. The majority were in disease stage IV (85%) and had a WHO performance status of one or two (84%).

Quality of life was 49.8±23.5 measured with EORTC QLQ-C30 and the physical functioning 59.6±25.0. The symptoms fatigue (58.6±25.6), appetite loss (37.4±36.6), dyspnoea (34.9±33.3), and pain (31.6±29.8) were the most prominent symptoms. Further, the patients had a depression score of 8.7±1.7 and anxiety score of 8.5±2.1 assessed with HADS.

Conclusion: The patients included in DOMUS were similar in age, sex, disease stage, and type of cancer compared to previous RCTs assessing SPC. However, the patients in DOMUS had a poorer performance status. The baseline findings indicate that the included population is the target group for SPC interventions, which aim at managing and preventing function deterioration and symptom development.
Abstract number: P02-124
Abstract type: Poster Exhibition

Feasibility Study of the Care Pathway Checklist (CPCL) for Palliative Care Interventions (PCIs) Delivered by Oncologists in Routine Care

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Background: Early specialized palliative care (sPC) documents benefits in nord american settings, but in ressource-variable european countries often lacking a SPC workforce clinical practice tools (CPT) for oncology health care professionals (O-HCPs) may be efficient to address cancer patients (pts) unmet needs for PCIs.

Aim: to develop and test a CPT to screen for and deliver PCIs by O-HCPs.

Methods: Prospective 2-week multicenter feasibility study in out-and inpatient units of consecutive pts (PS 1–3, normal cognition, advanced incurable cancer).

Screening: 6 predefined questions on palliative needs, rESAS (Romanian language).

Intervention: weekly needs-tailored and institution adapted CPCL with defined 7 PCIs (illness/prognosis understanding, symptom management, chemotherapy preference/decision, family care, networking, end-of-life worries, spirituality).

Outcomes: rESAS change in 2 weeks (Paired-samples t-tests), relation of number of CPCL (0–7) and rESAS change (Binary logistic regressions), specific CPCL and individual symptom improvement (Pearson’s Chi-squared tests).

Results: In 81 pts (median age 59, 48.1% female) from 6 romanian centres pain (t76=2.68, p=.009), fatigue (t76=3.40, p=.001), anxiety (t73=2.33, p=.023), depression (t71=3.60, p=.001), dyspnea (t76=2.27, p=.026), appetite (t76=3.30, p=.001) and somnolence (t76=2.29, p=.025) were significantly reduced. Using more CPCL was a significant predictor of improved mood. Improvement (all n=81) of pain was associated with illness/ prognosis (χ²=7.60, p=.001), chemotherapy (χ²=10.42, p=.001), and symptom management (χ²=6.24, p=.012) CPCL; of nausea (n=81) with chemotherapy (χ²=5.26, p=.022) CPLC, and of appetite with symptom management (χ²= 5.56, p=.018) CPCL.

Conclusion: The application of a pragmatic screening and CPCL to deliver advanced cancer pts needs-based defined PCIs seems feasible and effective for symptom control. Further research may explore change of pts needs and a real-world randomized trial.
Palliative Care at Home: An Experience of Private Health System in Brazil

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Introduction: The oncologic palliative care (PC) may be delivered in several models in home health care. Among these models, there is one in which the home visits and telephonic monitoring are made according to the individual risk stratification and clinical status of patients.

Aim: To present a model of PC in home health care created by the partnership of the home health care provider and health insurer, belonging to the private health system in Brazil.

Method: Series of 91 cases selected in the health insurer’s database, between September 2015 and October 2016. After telephone contact, they were confirmed as cancer patients with palliative treatment eligibility and it was scheduled home visit for those who agreed with the program.

The patients were classified in categories A, B and C according to the stratification made by Karnofsky Performance Scale (KPS) and Edmonton Symptom Assessment Scale (ESAS) and indicated for each interdisciplinary support.

Results: 32% men and 68% women; mean age 59.3 years, the oldest, 93 years; 82.4% patients in category A, 15.4% in B and 2.2% C; during the study period 2 patients died at home, 4 in hospital, 55 remain in follow-up and 30 were discharged.

Discussion: The classification in categories A, B and C facilitates clinical management of symptoms and assist in the distribution of resources used for patient care according to their prognosis and needs. The palliative care team can address the multidimensional needs of patients and their families rightly.

Conclusion: This model helped to approximate the home health provider and the health insurer to share decisions and especially to provide the most appropriate care to the patients, according to their needs and the progression of the disease.
A Decade of Excellence in Providing End-of-Life Care to People with Intellectual Disabilities: Overview of Award Winning Practice in the UK

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**Background:** Those providing support to people with intellectual disabilities (ID) who are at the end of life face many challenges, including issues with communication, understanding, decision-making, co-morbidities, complex relationships and complex social circumstances. The Palliative Care for People with Learning Disabilities (PCPLD) Network in the UK has brought practitioners together to share best practice since 1998. Since 2008, the PCPLD Network has given the annual Linda McEnhill Award for outstanding practice in the provision of end-of-life care support for people with ID.

**Aim:** We will look at all nominations that have won the Linda McEnhill Award or that have been highly commended for the award, in order to identify trends in service development and to elicit key elements of best practice.

**Methods:** All winning and highly commended initiatives are described on the website of the PCPLD Network. The presenting author, who has chaired the award’s judging panel since 2008, re-read the full submissions of the award winners as well as the judges’ criteria and considerations for selecting winning initiatives.

**Results:** 13 individuals, teams or collaborations have won the Linda McEnhill Award, and 7 have been highly commended; a total of 20 examples of best practice. Of these, 8 were cases where an individual with ID received outstanding care at the end of life, and 12 were service developments, including sustained collaboration between palliative care and ID services, inter-professional training, and the development of materials and resources.

**Lessons learnt:** Collaboration between various services, professionals, support staff and families is the key to excellence. Award winners demonstrated creativity and sensitivity in ensuring that the person with ID was at the centre of his or her care. There has been a promising trend of service improvements. Our challenge now is to ensure that lessons are learnt and good practice is replicated across geographical areas.
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**Review of Patients who Stay Longer Than 6 Weeks in a Specialist Palliative Care Inpatient Unit**

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**Background:** In light of ever-increasing demands for inpatient specialist palliative care, in September 2016 we decided to review the charts of all long stay patients in the preceding 8 months, to determine if they continued to meet the admission criteria to the unit.

**Method:** A retrospective review of all charts with inpatient stays longer than 6 weeks by senior members of the multidisciplinary team. Criteria reviewed included:
- Length of stay (LOS)
- Source of referral
- Reason for admission
- Discussion at Family Meetings
- Discussion at MDT meetings
- Discharge planning
- Reason for prolonged stay.

**Results:**
- 124 patients were admitted to the inpatient unit, of which 18 patients had LOS > 42 days. LOS ranged from 47 - 139 days+
- Only 2 patients were transferred to palliative care support beds, of which 1 subsequently died.
- 10 patients were admitted from home, 6 from public hospitals and 2 from a private hospital.
- 9 patients were admitted for terminal care, 8 for symptom control and 1 for scheduled respite.
- Following multi-disciplinary discussion, the consensus was that 8 patients did not have ongoing specialist palliative care needs requiring ongoing inpatient specialist palliative care and that opportunities were missed along the way with regards to looking for an alternative place of care.

**Conclusion:** The review revealed that we need to be more proactive in managing patient and family expectations when a patient no longer has ongoing specialist palliative care needs. To that end we have brought in senior medical colleague review once a patient has been inpatient for 4 weeks and collectively as a team being more proactive in seeking transfer to an alternate place of care when appropriate.
Pal@Home: A Rapid Response ‘Out of Hours’ Palliative and End-of-Life Care Nursing Service for Patients and Carers in Two London Boroughs

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Background: A lack of community ‘out of hours’ nursing support for patients with palliative and end of life (EoL) care needs living in two London boroughs (Lambeth and Southwark) was identified. This shortfall resulted in (i) preventable hospital admissions (ii) sub-optimal EoL care for patients managed at home and (iii) inefficient use of the existing on-call community specialist palliative care (PC) nurse skill-set.

Aims: To develop, establish and evaluate a rapid response community nursing team providing practical PC and EoL nursing support from 8pm-8am, 7-days a week. Pal@Home consists of a registered nurse (RN) to triage and a mobile RN and HCA team delivering telephone advice and conducting home visits. Interventions include urgent patient reviews in the last days of life, drug administration and carer support. Pal@Home aims to compliment the work of other community teams e.g. district nurses and enhance efficiency and cost-effectiveness in the out of hours specialist PC teams.

Methods: Standard demographic, disease specific and activity data are collected at referral together with longitudinal collection of validated patient and carer reported outcome measures including the Edmonton Symptom Assessment Scale and the shortened Zarit Burden Index for carers.

Results: From March-July 2016, Pal@Home has carried out 651 home visits (130/month) and made 1700 phone calls (342/month). Provisional longitudinal quantitative data demonstrate the service aids an improvement in symptom severity, carer satisfaction and enables patients to be managed at home. It is also shown to free up specialist PC on call teams to focus on more complex aspects of out of hours PC.

Conclusions: Pal@Home is a rapid response PC and EoL care community nursing service covering two London boroughs. Alongside demonstrating improvements in symptom burden and carer satisfaction, we aim to demonstrate cost-efficiency, vital in our financially constrained UK health service.
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The Quality of End-of-Life Care amongst Advanced Cancer Patients in Mainland China – A Retrospective Cohort of 441 Patients in a New, Public-funded Hospital

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Background: Shenzhen is a rapidly growing city in China with a population of nearly 11 million. The Hong Kong University – Shenzhen Hospital (HKU-SZH) was established in 2012 as a new model of public funded health care in mainland China. The oncology center of HKU-SZH was launched in 2013 with an integrated palliative care service.

Objectives: To retrospectively analyze the quality of end-of-life care amongst advanced cancer patients during their last hospitalization in the HKU-SZH.

Methods: All the advanced solid cancer patients who passed away in the HKU-SZH during March 2013 to Feb 2016 were analysed. Clinical information on cancer diagnosis, anticancer treatments, and the aggressiveness of the treatment during the last month of life was recorded. The discussion on Do-not-Resuscitate (DNR) order with family members was also reviewed.

Results: From March 2013 to Feb 2016, 441 advanced solid cancer patients passed away in HKU-SZH. Around 9.3% (41/441) had received cytotoxic chemotherapy in the last month of life. Younger patients had a high odds of receiving chemotherapy in their last month of life (OR 2.6, p=0.006). Those who had received chemo in their last month of life had a higher odds of admission to ICU (χ²=8.4, p=0.015).

A high proportion of patients’ care-givers (92.3%, 407/441) had documented consented to DNR order suggested by oncologists. The rate of DNR acceptance was higher than most other previously reported series in mainland China. The rate was higher in the oncology center than other departments (OR 5.1, p<0.001). Chemotherapy use in the last month of life did not affect the acceptance of DNR (OR 1.3, p=0.23).

Conclusion: The oncology service of the new public hospital HKU-SZH has yielded a satisfactory level of palliative care in cancer patients. Further studies are indicated to investigate how the financing system and health care management impacts quality of palliative care.
Cohort Feasibly Study on the Use of Video Consultation as a Tool to Augment the Patient Care Experience in a Community Palliative Care Setting

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**Background:** Traditional models of Community Palliative Care offer face to face and phone consultation services to community based patients. A stated ambition outlined by the National Palliative and End of Life Care Partnership, in the United Kingdom, is to embrace technology to augment patient care. Telemedicine is a technology that is garnering recognition in medicine as a means of enhancing patient care. Suggested benefits include improved connections through the visual medium and enriched communication through the use of visual cues. Reports of high levels of acceptability to patients and carers are emerging. Conversely technological challenges have been encountered in studies to date and the cultural acceptability and in the Irish Palliative Care setting has yet to be determined.

**Aims:** To explore the use of video consultation in a community based Palliative Care patient population.

**Methods:** An initial cohort feasibility study is evaluating the acceptability, practicality and efficacy of video consultation. Health care professional initiated consultation using Skype, is offered in addition to standard care. A mixed methods approach will be adopted to explore the stakeholders experience of the intervention, with thematic extraction until saturation is reached. Technical data including call quality and call failure will be captured.

**Results:** Data collection is ongoing. Preliminary results show that video consultation is acceptable to patient and staff and is non inferior to current practice.

**Conclusion:** Introduction of video consultation to augment the remote patient consultation serves to enable the Community Palliative Care Service to adapt to an increasing case load, while responding to a diversifying patient demographic.
Beam Me up, Scotty! Audit of Rapid End-of-Life Transfers

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Background: “If the care planning & rapid discharge arrangements are in place, then a patient can often be discharged to die at home with support that will prevent unnecessary, distressing & expensive emergency re-admission.” (Route to Success 2012). The local Rapid End of Life Transfers (REoLT) system, in place since 2009, audited in 2014, demonstrated that although documentation went with the patient, there were not always complete copies in the hospital clinical record. As a result, a new checklist was introduced & a standard added, that a completed checklist should be available in the clinical record.

Method: Consecutive REoLTs undertaken in 6 month period were reviewed retrospectively against the standards.

Results: (2014) 35 REoLTs organised by 14 different wards during the audit period. 22 had checklist available to view, 21 had copy of an individual plan for the care of those thought likely to be dying developed with patient & family. Only 8 had both. 71% were GSF registered (60%), 75% had non cancer diagnosis (47%). 91% had documented conversations with family (92%); 11% with patient (47%). In 46% the ambulance arrived within 2hrs (50%). 100% had a resuscitation & death certification plans documented (100%), 83% a death in transit decision (100%), 50% discharge medication was collected within 2 hours of prescription. Average length of time from transfer to death was 9.4 days.

Conclusion: Although the number of REoLTs has increased year on year & feedback from bereaved families is generally positive, because it is always done in a hurry, completion of documentation can be poor & copies mislaid. This means that where problems occur it is difficult to trace the reasons. As a result of this audit a new REoLT carbon copy booklet, with detachable top copies to transfer with the patient, will remain in the clinical record to overcome this problem. Reaudit will indicate whether or not this has been successful and results will be available for the poster.
Facilitating the Early Supported Discharge of Palliative Care Patients to Help Ensure They Achieve their Preferred Place of Care/Death

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**Background:** A palliative care patient, from fast track identification to discharge took on average 12 days. The Specialist Palliative Care Team (SPCT) decided to look at how this process could be improved.

**Aim:** To ensure patients are proactively identified earlier and discharge planned in an efficient manner to support preferred place of care/death.

**Method:** Four new posts were created – Consultant in Palliative medicine, Occupational Therapist, Discharge Nurse and an Administrator. These posts work alongside the SPCT to facilitate the Continuing Health Care fast track process and provide earlier identification of appropriate patients through ‘front door’ access (A&E, medical assessment unit and Elderly Receiving Unit. The team provide a holistic assessment and ensure rapid facilitation of equipment. Attend daily board rounds with multidisciplinary teams to identify patients right from admission.

**Results:** A significant improvement in facilitating discharges. The average length from identification to discharge is 5 days. There have been patients ‘turned round’ on the same-day who are in their last hours of life, and achieve their preferred place of death. The team has received positive feedback from families and it has helped in the bereavement process.

**Conclusion:** The discharge process for palliative care patients has improved with earlier identification. Reduced length of stay and lower numbers of readmissions by better advanced care planning.
Physiotherapy in Specialized Palliative Care – Beyond Traditional Approaches?

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Background: Patients in palliative care experience high levels of physical and functional impairments and may greatly benefit from physiotherapy (PT) treatment. However, PT in specialized palliative care (SPC) is often an underutilized resource, and the knowledge of the physiotherapists’ role in the team when treating patients with complex needs is insufficient. Thus an exploration of PT in SPC is highly warranted.

Aims: To explore the variety of activities performed by physiotherapists in specialized palliative care.

Methods: A free-listing approach was used to collect data from 10 physiotherapists in SPC clinics in Sweden. They were instructed to continuously document what they performed during 10 days, as precise and detailed as possible. All activities involving patients and their families either directly or indirectly were documented.

Results: The free-listing exercise generated 504 activities. The activities were analysed and sorted into nine content categories and coded as to whether the activities were directed towards the patient, the family unit or health care staff. Many of the activities indicated an immediate response to emerging needs related to the patients’ sudden change in health status. The activities seems to be adapted during the patients’ palliative trajectory, e.g. from enabling and encouraging physical and functional improvement and independence to providing comfort and relief. Physical exercise and activities were applied to cover not only the patients’ physical but also psychological, social or existential needs.

Conclusion: The preliminary analysis showed a broad spectrum of activities going beyond traditionally described physiotherapeutic treatments. A description of PT in SPC should include the holistic and inseparable nature of what, why, when, how, and with whom the activity is carried out. A more nuanced description of the clinical complexity can clarify, optimize and develop PT in SPC for the benefit of patients and their families.
Multi-professional Palliative Consultant Team in Emergency Care

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Background: Patients with palliative care needs are present throughout the entire health system. Hospitals have deep skills in their own specialties, but in some cases lack palliative expertise and assessment capabilities. In order to better meet an increasing demand for palliative expertise and experience a multidisciplinary team was organized at the Sahlgrenska University Hospital, Gothenburg, Sweden.

Aim: Patients shall receive equivalent symptom relief and medical care, regardless of location and medical condition, and be given advice and support in psychosocial planning. Early detection of palliative symptoms makes it possible to give the patient correct medical treatment at a relevant level. Increase knowledge and awareness among staff in emergency care.

Method: A palliative consultant team was formed with one physician, one nurse and one social worker, after discussion with other palliative consultant teams in Sweden. The team visits hospital wards scheduled, gives palliative advice and recommendations to the regular staff on a consultancy basis. Hospitalized patients can be seen by the team for assessment and symptom evaluation. Professional consultation is also provided by the team, on telephone during office hours. The visited wards are offered education and information in palliative care. A scientific evaluation is planned to be conducted.

Results so far.

The approach has been well received by hospital staff, who feel that the knowledge of palliative care increases.

Conclusion: By advice from the consultant team, the planning can start earlier which means that the patient more quickly can be cared for at a correct care level. Through the multidisciplinary consultant team’s participation, the patient’s symptoms can be paid attention to in several dimensions (physical, mental, social and spiritual).
Palliative Care in the ICU: Complementing and Continuing Care

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Studies have shown the importance of integrating palliative care into ICU care.

Aims: to evaluate the use of a screening tool for palliative care referrals in order to understand the reasons for referral from 4 ICUs in a tertiary hospital.

This is a prospective study, using a screening tool with regular ward rounds to identify patients suitable for palliative care referral. Demographics, progress and outcomes of patients were collected. Descriptive analysis was applied.

Palliative Care Team did regular ward rounds in all 4 ICUs and patients were referred according to a referral criteria. The use of the referral criteria together with regular ward rounds increased the number of referrals from 80 (2013) to 262 (2015) – an increase of 228%. Prospective follow-up of 154 ICU patients referred to palliative care from Jan to Aug 16 was conducted. The most common reason for referral in the 4 ICU is as follows: Cardiac arrest with anoxic encephalopathy (CCU), multi-organ dysfunction syndrome (MICU & SICU), extensive intra-cerebral / subarachnoid haemorrhage with poor neurological prognosis & low presenting GCS (≤6) (NICU). 64 (41.6%) patients passed on in the ICU with the palliative care team’s involvement. The palliative care team provided post-ICU care and transited 36 (23.4%) patients to a Comfort Care Room – a single room specially designed for families to spend quality time with the dying patient. The team also assisted in 4 (2.6%) terminal discharges from ICU to home. Mortality rates were high (78%) with the rest of the patients either discharged to hospice (2%), home (2%) or still in hospital (8%).

ICU-Palliative care collaboration confers important benefits to patients and families and provide continuous support and engagement which extends to post-ICU period where terminal care and care co-ordination become important. The palliative team care complements the ICU team to provide continuous and inter-disciplinary team-based care both inside and outside the ICU.
2016 Palliative Care Inpatient Admissions Re-audit: Are the out of Hours Demands Changing in Palliative Care?

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Background: Local standard at Abertawe Bro Morgannwg University Health Board in South Wales are that 100% of patients are admitted to inpatient units before 3.30pm. Admissions later that 3.30pm are considered out of hours admission (OOHA). This standard allows thorough clerking by the inpatient Palliative Medicine teams in working hours.

Aims: There has been a perceived increase in OOHA since a 2014 admissions audit across the same inpatient units. The aim of the re-audit was to confirm this perception and analyse data to explain increasing OOHA’s.

Method: A prospective audit of all admissions to two inpatient units (Y Bwthyn Newydd [YBN], Ty Olwen [TO]) was completed over a 3 month period. Data capture was completed using a standardised proforma including day/date, referrer profession, mode of transport, mean time of admission, delay in bed availability and admission, and reason for delay. Statistical analysis was completed using Microsoft Excel.

Results: Total number of admissions over audit period: 95. Predominant referrers: community palliative care team (YBN), hospital palliative care team (TO). Mean time of admission: 2pm (YBN), 2.30pm (TO). Total number of OOHA: 31 (33% of total admissions), compared to 14% in 2014 audit. 8% of total admissions were after 7pm, the latest being 1.30am. Overwhelming reason for OOHA: late arrangement of admission, followed by transport (ambulance or inter-ward transfer delays).

Conclusion: There has been a significant increase in OOHA’s in the past 2 years. Majority are due to late arrangement of admissions by community or hospital palliative care teams. The results raise two questions: are OOHA a problem, and if so how to minimise them?

Possible solutions include a ‘cut off’ time for referrals (but against ethos of 24 hour Palliative Medicine service) or adapting shift patterns for on call rota to incorporate the changes. Further discussion and planning is needed following these results.
Changing Roles of Palliative Care Units in Japan

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Background: Palliative care units (PCUs) in Japan have accepted long-term hospitalization of cancer patients to relieve symptoms at the end-of-life. In 2013, the Ministry of Health, Labor and Welfare proposed a comprehensive community system that is designed to promote end-of-life care for the patients at home.

Aims: The PCU in our hospital is the only PCU in a city with a population of about 230,000. Our previous policy was not to promote discharge if cancer patients did not desire early discharge from the PCU. Given the new national policy, we have created a system to promote smooth discharge of patients to home care. The goal of this study is to examine the effectiveness of this new policy.

Methods: The policy change includes support for home hospice care and promotion of a return to home after hospitalization, in order that the patient can receive home care with peace of mind. Within a few days after admission, we hold a conference with a medical social worker and plan the discharge. A request for admission or control of symptoms from a home care support clinic after discharge is responded to at any time.

Results: In 2015, we admitted 186 cancer patients (170 deaths after admission), of whom 43 (23%) were introduced from home care support clinics. We responded to emergency admission requests from home care support clinics for 30 patients who were admitted into the PCU or a general ward. These data show an increase in the level of home hospice care compared to previous years.

Conclusion: The roles of a PCU in the comprehensive community system are defined as follows.
1. Immediate response to an admission request from a home care support clinic.
2. Control of symptoms that are difficult to control in home care.
3. Introduction and promotion of the possibility of home care for a patient.
4. Improvement of approaches to palliative care in home hospice care.

We believe that our new policy for discharge of patients with terminal cancer is meeting these requirements.
Palliative Care Consultation Form (PCCF) at our Comprehensive Cancer Centre

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**Background:** At our cancer centre we provide specialized palliative care (PC) at the Department for acute palliative care (DAPC) and a general PC at all other hospital departments. General indications for specialized PC team involvement are complex and demanding patients/caregivers’ needs. Additional support from specialized PC team to general oncological team at their departments is available upon a written request on Palliative care consultation form (PCCF).

**The aim** of the study was to analyse contents of PCCF and determination of the most common requests stated in PCCF.

**Methods:** We systematically analysed completed PCCF from January to September 2016. Current PCCF is a general consultation form used at our cancer centre for any kind of unspecific consultation and include: patient information, department, physician name, contact, patient history and general question/request for consultation team.

**Results:** There were 135 PCCFs sent to specialized PC team.

Mean patients’ age was 66 years (range 17–93). The most common diagnosis was lung cancer 17.0%, following by gynaecological cancer 11.1%, lymphoma and colorectal cancer 10.4%, melanoma 8.9%, and cancer of central nervous system 8.2%. The most common requests stated in PCCF were comprehensive PC 21.5%, family meeting 20%, help in physical symptoms management 13.3%, admittance of a patient to DAPC 12.6%, follow-up after discharge 7.4%, further care 3.7%, and support in PC management 1.5%. In 20.0% there was no reason listed on the PCCF.

**Conclusions:** According to our analysis we conclude that current PCCF is not adequately formulated for PC team need. To ensure a proper response of our specialized PC team more detailed and PC oriented information in PCCF are needed (precise main problems, active contact information of care-givers/medical staff, urgency). PCCF should be adapted properly and then implemented in daily practice. Further education programs among oncological health staff are needed as well.
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The Development in International Recommendations of Nursing Care in the Care of People with Malignant Fungating Wounds

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Development and organization of services drive the improvement of care practices directed to people. In palliative care, malignant wounds is a prominent issue in clinical practice, but it still lacks strong evidence that underline guidelines to support best practice. In developing countries the highest incidence of head and neck cancers and cervical in addition to breast cancer and non-melanoma skin, makes this the most common type of wound. This research aimed to compare the guidelines of a public hospital specialized in treating cancer in Brazil, with recommendations of professionals from an european entity, for the topical management of malignant wounds. The methodology was comparative case study in the approach of considering the different times and cultures. The findings have shown that there is a difference of seven years between the creation of the materials which were analyzed. They differ in their content for practical actions, assistance service flow, Health Technology Assessment concepts, family approach, and the use of high-technology products. In the materials analyzed there were more convergences than differences identified, showing that similar strategies have been developed by professional groups with different cultures. The use of topical lidocaine 2%, morphine and the use of electrochemotherapy should be subjects of future research, and this may increase the nurses’ work scope in palliative care on behalf of their patients, of their institutions, and the area of palliation. Different publications may be considered milestones in the history of the development of technical knowledge on the topical management of malignant wounds.
Innovative Model and Solutions for Delivering Home-based Palliative Care and Nursing

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The Clinic is probably the only public institution in the country that provides integrated nursing, palliative care and social services to patients at home. The delivery of these services is the result of a variety of multi-disciplinary specialists; doctors, nurses, nursing assistants, social workers and psychologists.

In order to save time and make operations more cost-effective, the Clinic made a decision to optimize home care and communication processes through information technology.

Advanced home-based palliative care improves three key deliverables; quality of care services to patients, shortened health care waiting times, and a significant reduction in the possibility of errors.

The palliative team use mobile devices during home visits, and with the help of the technology all measurements (ECG, SpO2, BP, BGL etc.) and state evaluations can be sent directly to the doctor. Doctors are able to analyze data and advise treatment without leaving the office, and to prescribe drugs online using electronic prescription forms. Prescriptions are then sent to the pharmacy automatically. This delivers a more efficient and convenient process for patients, their families, and medical staff alike.

Digital diagnostic and digital therapy solutions make healthcare far-reaching, and furthermore they enable digital diagnostics options for palliative patients, especially for those most in need of help and unable to get to a clinic. The importance of making process easier and faster for patients in the last stage of their lives cannot be overstated.

A digitalized system does not just mean digital records; our system is also able to streamline the medical care process, as well as giving the ability to co-ordinate all processes and supervise our staff. The system is also able to plan and assign treatment and palliative care procedures for patients. It helped us to diagnose health problems faster, reduce errors and as an added benefit, to provide care at lower costs.
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Abstract type: Poster Exhibition

Identify Patients with Palliative Needs in an Internal Medicine Service with the NECPAL Tool

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Introduction: In our population of 25000 more than 5000 are older than 65 years old. The increase of life expectancy and the prevalence of chronic diseases has led to an increase of medical care needs like the number of admissions, especially at Internal Medicine. Thus, have been recently developed tools (like NECPAL questionnaire) that help to identify patients with palliative needs that benefit not exclusively of a healing approach.

Aims: Detect how many patients have palliative needs in the Internal Medicine Service at our hospital.

Methods: A prospective observational study was conducted during the month of June 2016 in our service applying NECPAL tool at all admitted patients by the designated clinician. We analyzed some parameters as days of hospitalization, response to the surprise question if it would surprise the doctor if the patient died in the next 12 months, discharge destination, if the patient died during admission or 6 months after discharge, existence of chronic disease in advanced stage, readmissions and referral to continuum care network.

Results: In a total of 50 patients the most were male (54%) and 74% had more than 65 years old. 52% of patients were hospitalized longer than 7 days and 6% more than 30 days. 6% of patients died during hospitalization. At discharge 72% of patients were referred to specialist services and 4% were referred to a community care network. 82% of patients lived at home. 36% of patients would not surprise the designated clinician if died in the next 12 months. 60% had palliative needs and these only 14% were oncologic patients. 38% of patients had functional dependence.

Conclusions: It was confirmed that more than half of patients had palliative needs, which requires a great adaptability and versatility of Internal Medicine to meet these needs. It is necessary to invest in health professional training and improve the supply and quality of medical and social services to adapt to this new demographic reality.
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Implementation of Palliative and End-of-Life Care in Non-palliative Care Settings in Hong Kong

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Background: Department of Medicine and Geriatrics in Caritas Medical Centre collaborates with the palliative care team developed a specialized End-of-Life Care Plan which incorporates with different palliative and End-of-life care domains including: verification of Advance Care Plan at different care stages, symptoms assessments and management, psychosocial assessments and interventions, spiritual care, cultural and ritual considerations at end of life, dying scene management and bereavement care.

20-items self-reporting questionnaire after 3-month implementation. Descriptive statistics was used for statistical analysis.

Phone interviews were conducted to 12 bereaved families with whom the deceased patients.

Results: 151 of the staff (81.6%) agreed the care plan was beneficial to patients and relatives. 125 (67.6%) senior nurses (>10 years’ experience) reported the care plan was simple and easy to use; while 13 enrolled nurses (7%) felt it was complicated. Nurses from both acute and rehabilitation settings agreed documentation of cares in the care plan was clear (87.8% and 82.2% respectively).

12 bereaved relatives (7 males & 5 females) were phone-interviewed in October 2014. All of the respondents reported satisfaction on the EOL care. Good response on the timely nursing care to provide comfort and relief. All appreciated on allow private shroud for the deceased, facilitate involvement of families on performing last office like washing face and hands of the deceased, and satisfied with the funeral information and psychological supports by nursing staff at the death scene.

Conclusions: Majority of nurses agree the specialized EOL care plan as a framework to guide their care can enhance their job satisfaction and competence in EOL care. Phone interview revealed the feasibility of quality EOL care in includes facilitate participation in last office and private shroud, provision of private room for families, flexible arrangement of visits and companion of patients.
Aim: When people in Denmark is asked where they prefer to end their life, more than 50 % respond that they prefer to die at home, but it only succeeds for about 22 %. Too many people experience unnecessary admissions in the last three months of their live, and some dies after few hours stay in the acute care setting. The aim of the study is to improve the palliative care towards patients and their caregivers.

Result: The improved efforts needed is:
● Identifying patients who need palliative care
● Hospital and primary sector uses shared terminology; late or terminal palliative care stages.
● Improved communication between primary and secondary sector
● When the patient got ‘a terminal statement’ a palliative home care nurse provides a conversation at home to clarify palliative care needs.
● Screening with EORTC-15 Pal and using conversation guides
● If high symptom burden the nurse is planning a joint visit with the GP.
● discuss and possibly planning for alternatives to ending life at home.

Conclusion: Strongly motivated to meet patients desire to die at home, employees in a cross sectional setting, were able to produce a model of palliative care in 4 weeks.
**International Relations Group: Relations between France and Europe or “The French Connection with Europe”**

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**Aim:** Two years ago, a nurse and a physician wished for France to get more involved in international discussions on palliative care. A year later the interdisciplinary International Relations Group (IRG) was born and is up and running. This communication aims to describe the IRG and its activities.

**Method:** IRG consists of a national network of around thirty English speaking specialists (sociology, documentation, health care, social care, arts, philosophy, etc.) who work in France in palliative care. It is a working group within the French palliative care association, Société Française d’Accompagnement et de Soins Palliatifs (SFAP). One of the principal actions is to build bridges with the EAPC and promote the French touch of palliative care in Europe. To help keep this network alive, the co-founders have created a shared virtual space and facilitate the work of the subgroup.

**Results:** At present France has a low profile on the international stage of palliative care. The IRG creates an opportunity to broaden palliative care networks internationally, and on the one hand is a chance for them to share their palliative care culture and, on the other, a chance for the international community to influence palliative care practice and research in France.

The interdisciplinary knowledge and experience of the members feed into each other whilst sharing a common goal: exporting innovation and expertise from France and importing international practice from abroad.

In one year, the IRG has promoted reflexion and collaborative work on four topics: volunteers, spirituality, advanced care planning and social media. The results of which we would like to present.

**Conclusions:** This young group is dynamic and offers an opportunity for collaborative work nationally and internationally.
Comparative Analysis of the Activity of a Palliative Care Support Team in its Nine Years of Work

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Introduction: The Palliative Care Support Team (PCST) at the Puerto Real University Hospital was founded in January 2007 to provide home care to terminally ill oncology patients. We provide service in a geographically dispersed area with more than 300,000 inhabitants. The PCST was formed initially by a part-time doctor and a full-time nurse but due to its increasing demand since 2014 it comprises of two full-time doctors and two full-time nurses.

Objectives: To compare the activity of the PCST in 2007, year when it started, and 2015.

Results: In 2007 a total of 132 patients were treated, while in 2015 they were 418. This means therewas a 216.67% increase (annual increase graphs will be attached). In 2015 the team made 639 home visits, far from the 74 visits made in 2007. This means a 763.51% increase.

In 2015, 56% of the patients died in their homes, 47% of them died in their homes in 2007. This has been a growing pattern throughout the years (graphs will be attached).

Regarding the average time patients stay in palliative care programs, there has been a 259.4% increase. In 2007 the average stay was 33.8 days and in 2015 it went up to 87.7 days.

Conclusions: The activity of the PCST has sustainably increased since it started in 2007 until now. The rise of the average stay in Palliative Care programs stands out, due to an earlier referral which allows better care planning. This along with higher number of home care visits, can explain the fact that in the first years of our activity the patients died mostly at the hospital, a tendency that has been recently inverted.
Outpatient Palliative Care Growth and Increased Pain Procedural Volumes: Report of a Single Academic Institution’s Collaborative Practice Model

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Pain is one of the most commonly experienced and feared symptoms faced by patients with a serious illness and a common reason for referral to a palliative care service. Palliative care teams are able to control symptoms of pain in most circumstances. However, a substantial minority of patients will have inadequate analgesia and/or intolerable side effects with systemic therapies. For these patients, minimally-invasive interventional pain therapies can be significantly beneficial. Despite these benefits, studies demonstrate a lack of collaboration between palliative care and interventional pain clinicians, resulting in fewer patients receiving potentially beneficial interventions. Lack of mutual understanding about one another’s role & potential benefits and concern about losing patients to one another’s practice have been postulated as potential reasons for this lack of collaboration.

We report on the results of intentional processes put in place since 2012 at a single, multi-specialty, academic institution to enhance collaboration and increase referrals between palliative care and interventional pain clinicians. These include
1. Weekly “Pain Board” meeting between clinicians from both services
2. Educational exchanges between Palliative Care & Pain Medicine fellowship programs.
3. Dedicated weekly “referral” clinician to help with triage of procedural requests & questions.
4. Formation of a cross-disciplinary research team

In the setting of rapid growth of our outpatient palliative medicine clinic (219 visits in 2009 to >1500 in 2015), palliative care clinician referrals for procedural interventions increased over five fold. Procedural volumes for celiac plexus neurolytics blocks & intrathecal drug delivery implantation increased by 90%.

Our experience reveals that targeted collaborations can lead to increased cross-referral between services, reduction of “turf battles” and increased procedural volumes for advanced pain procedures.
When Expected Death Becomes a Matter of Concern: Resolving Practice Issues for a UK Community Hospice Team

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Background: With the development and expansion of the community hospice team three years ago, the extended role of verifying expected deaths for patients known to the hospice who die at home, has been successfully implemented. However, with increased numbers of patients being verified by the team, it became apparent that those who had not been reviewed by the GP within 14 days, or had died of industrial diseases, were subjected to long delays before being seen by the doctor. Some out-of-hours expected deaths were reported to the police, resulting in unnecessary distress. Reviewing themes discussed on an international palliative care forum revealed this was a common problem, without a unified solution.

Aim: To improve the continuity of service, and ability of hospice community nurses to complete verification of expected deaths for patients known to the hospice team, when routine Coroner’s involvement is required.

Approach: The hospice procedure was reviewed in line with national guidance from the RCN, NMC and Hospice UK. The procedure was then discussed with the local Coroner and reviewed with the Coroner’s designated Funeral Director, to find a legal and workable solution to this problem.

Outcome: It was agreed that patients dying an expected death, either from industrial disease, or those who had not been reviewed within 14 days, could be verified by the nurse, and moved to the designated undertaker, until the GP could discuss the situation with the Coroner within working hours. All nursing staff received a teaching update and renewed their competency assessment, to facilitate a smoother process for the bereaved, whilst ensuring the nurses were working within the law.

Conclusions: Sharing this successful solution to a widely reported problem may help other hospice teams extend their services to more bereaved families. This is particularly pertinent at a time when many UK out-of-hours GP services are withdrawing from verifying deaths in the community.
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**The Implementation Opportunities of the Palliative Care Model in Home Care from an Enterprise Belonging to the Private Health System, in Rio de Janeiro City, Brazil**

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**Introduction:** The palliative care (PC) implementation in the home care (HC) model is an opportunity to improve the quality of the service provision, including in a private health system. Despite the challenges, such as the shortage of skilled professionals and the HC features that do not resemble the hospital, as the logistics of medication dispensing and the relationship construction between the patient / family and the professionals, given the aging population and the rise of chronic diseases, the CP implantation in HC can contribute to a better management of resources, reduce the level of anxiety of the patient / family and honor with the patient’s wishes, as providing a dignified death at home.

**Objective:** To discuss the opportunities of the CP integration in the HC model of a company belonging to the private health system in Rio de Janeiro, Brazil.

**Method:** A qualitative study based on the evaluation of 105 cases treated over 18 months by the (PC) core. The initial approach was made through the family conference together with the PC coordination with the objective of family situational awareness in view of the home death.

**Results:** Over 18 months, 38 died at home and 62 in hospital and 5 have still receiving the PC approach, with home visits and afar support via telephone.

**Discussion:** According to the HC manager’s decision, the PC approach can be started since the implementation visit, from the identification of the eligible cases and the family understanding and, from the PC conceptual understanding, then followed until the death, at home or in hospital.

**Conclusions:** Among the opportunities found, include: the family members’ satisfaction and the reduction in their anxiety, a significant percentage of death at home and the paradigm change about the care exercised in domicile concerning the health professionals’ conducts.
Development Level of Palliative Care in Poland

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Background: In Poland, palliative medicine is among the newest fields of medicine undergoing dynamic changes. These changes are associated with aging of the population, the increase in the prevalence of civilization diseases and the advancement in the treatment of many diseases and the introduction of new, effective methods of symptoms management.

Objectives: The aim of this study was to develop national data concerning palliative care in Poland.

Methods: This study is based on the analysis of the national database. Data are collected in the form of questionnaires filled by provincial consultants in the field of palliative medicine.

Results: Patients over 65 years old are the most numerous group of palliative care recipients. The situation related to human resources is satisfactory; the number of educational centers and specialized physicians and nurses increases every year. The availability of individual forms of palliative care is unequal in various regions of the country. Financial resources assigned for palliative care are insufficient. The access to home care is good, the number of inpatient units and the number of beds per 100 thousand of inhabitants is insufficient. Also, outpatient palliative care does not meet the requirements.

Conclusion: The situation of palliative care in Poland is satisfactory. However, financial resources assigned for palliative care seem not to be sufficient.
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Dipping a Toe in the Water: Developing Professional Roles from within

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Aim: Experienced, qualified and unqualified, hospice nurses, desire career progression which is limited within hospice environment. Time and money is invested in education to deliver high-quality palliative care. For nurses to then take those skills elsewhere leaves a huge gap in our workforce. An NHS post is the usual route to becoming a Palliative Care Nurse Specialist (PCNS). If experienced Health Care Assistants (HCA) wants to progress they are currently required to attend university to gain an academic qualification and for many this would prove challenging.

Approach: Local hospice’s professional development was scoped, but revealed no specific models and new roles were bespoke. Two local roles were developed; Hospice Nurse Specialist (HNS), and HCA Therapy Assistant (TA). Roles were clearly defined, with robust job descriptions and person specifications, scope of practice agreed, required skills, competences and boundaries established.

Result: The skilled HNS provides continuity of care for patients and a visible presence provides a vital link between nursing and medical professionals. It has led to a more streamlined admission process for the patient and following completion of the non-medical prescribing module, the HNS works autonomously wherever the patient presents, allowing medical staff to focus on patients with more specialist complex needs. The TA role presented its own challenges as there is no national specifically defined pathway to follow. Specific competencies were developed including input from community equipment suppliers, wheelchair services and by shadowing various therapy teams within hospital and community setting.

Conclusion: This has been a successful ‘dip of the toe in the water’ for role development. Future development include an accredited academic module in Specialist Palliative and End of Life Care, in partnership with the local university and investigating the role of apprenticeships for hospice Healthcare Support Workers and Assistant Practitioners.
Supervision Support – A Progress and Aiming the Progress

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In developing system of palliative care in our country supervision support was seen as a way of controlling someone’s work or as a cost we can’t afford – not understanding benefits of it for either the individuals or the system of palliative care. After starting the project of supervision support to a group of professionals working at different organisations and different palliative, health and social care levels we started to change those prejudices. It all started as an urge need of professionals to get support for their work, it developed as a way of connecting and integrating volunteers and professionals within the health system; and became a way of making progress in palliative care through supporting, educating and networking which was recognized by the participants at the end of the first year of this activity.

This work will show the most frequent issues during the group sessions based on meeting records. It will show participants attitudes about usefulness of the supervision and its goals based on evaluation forms they filled at the end of the first year. Evaluation forms consisted of four parts: general, personal and professional competences, development issues and planning. Also, findings of an external evaluation based on meeting records and evaluation forms will be shown from the perspective of The National Strategy for development of Palliative Care in the context of this supervision contributing to the development of palliative care.

Believing that our patients and their family memebers will benefit from our progress we hope that this example and this work will benefit to the expansion of this kind of supervision support among palliative care professionals.
Parents Experience of their Child’s Care at a Children Hospice

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Aim: The purpose of the survey was to learn about parents’ experience of their stay at the children hospice in order to improve the quality of care.

Method: A survey has been sent to 38 families whose children received care during the previous year (2015) at the children’s hospice. The answers from the survey has been compiled and analyzed.

Results: Thirty families responded (79%) and 10 of those have lost their child, while the others have received respite care. Among the responding parents almost equal numbers were men and women, (44% vs. 56%). A majority of parents, both bereaved and non-bereaved reported being highly satisfied with the care and treatment provided. In addition they reported feeling secure and involved in their child’s care. Parents also reported that they got honest information from the staff and that they had the opportunity to discuss the contents of the care provided. All parents felt that their child and they themselves had been respected during their stay. A vast majority of parents (79%) reported that their children received adequate pain relief, for bereaved parents the number was even higher (86%). Parents were also asked about their child’s treatment for dyspnea, anxiety, nutrition and sleep. Sleep was the symptom most difficult to manage, 10% of parents reported that their child’s sleep was rarely adequately managed. Nearly a quarter of parents (23%) reported that the sibling did not receive full sibling support.

Conclusion: A majority of parents found the care of their seriously ill child satisfying at the hospice. Still there is room for improvement. Sleep was found to be difficult for staff to manage, this may not only impact on the child’s well-being but also on the parents and siblings. Siblings most often are taken care of by sibling supporters yet some do not fully receive this support.
The Palliative Care Team of Southern Jutland – A Model of Good Practice for Specialized Palliative Care in Rural Regions?

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Background and aim: It is special challenge to establish Palliative Care for people living in rural areas. The aim of the presented work was to describe the characteristics of a model of good practice for Palliative Care in a rural region.

Method: The region of Southern Jutland is located in the southern part of Denmark close to the German border. Four communities belong to southern Jutland. These are Aabenraa, Haderslev, Tender and Sønderborg with an area of 3538 km² and 227754 inhabitants. The organization of Palliative Care within the whole region will be described.

Results: Specialized Palliative Care within the region of Southern Jutland is based on a cooperation that includes a mobile Palliative Care Team (PCT) that visits patients in their own home, a nursing home or a hospice; a palliative medicine ward in the hospital with 12 beds and a hospice with 12 places. The multiprofessional Palliative Care team for the region consists of physicians, nurses, priest, secretary, social worker, psychologist and physiotherapists. At any time approximately 130-150 palliative patients are enrolled in a special program with a right for an “open admission” to the palliative care ward in the hospital and the possibility to contact the mobile palliative care team. The team works closely with the family physicians and community nurses and provides the primary care sector with education and supervision. In the period from January 1st 2016 to September 30 the number of patients who received specialized palliative care were: 987 visits of the PCT in the patients home, 2830 patient contact and counselling via telephone, 658 patients were treated on the palliative medicine ward in the hospital and 125 patients received care in the hospice (87 of these died in the hospice).

Conclusion: The above described system for the provision of Palliative Care makes specialized Palliative care treatment available to patients with advanced cancer and other life-limiting diseases in the whole region.
Evaluating the Role of a Band 5 Nurse in a Community Palliative Care Team

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Aim or goal of the work: The nursing workforce is stretched nationally with a 10% vacancy rate with particular shortage of higher grade specialist nurses. Strategies to limit the workload of specialist nurses will potentially allow community palliative care services to meet rising demand. In South London, band 5 nurses were introduced into a community palliative care team to provide support and enable the band 7 nurses to focus on complex cases. We wanted to evaluate the impact of embedding band 5 nurses into a community team.

Design: Case note data was collected retrospectively prior to band 5 nurse recruitment, at 3 months, and again at 5 months. Activity data was collected for a band 5 and band 7 nurse over a 5 day period. Data included the number of patient contacts and specific activities undertaken. Activities were categorised into: visits (to review/ assess symptoms), rapid response contacts (to give an injection, set up a syringe driver, or drop off anticipatory injectable medications) and administrative tasks.

Results: The band 5 nurse had 46 contacts at 3 months and 56 contacts at 5 months, with a 50% increase in rapid response contacts over the 2 month period. Visit numbers remained consistent for the band 7 nurse (13 prior to the band 5 being in post and 18 after), however data found an 84.62% reduction in rapid response contacts and a 38.89% reduction of administrative tasks.

Conclusion: These data suggest that there is a role for the band 5 nurse within the community palliative care setting, particularly in responding rapidly to non-complex requests. This enables the band 7 to focus on complex cases which require more specialist input. These data suggest that the role enables development of the band 5 as indicated by the increased volume and variety of interventions 5 months into the post. This initial evaluation highlights opportunities for modelling services so that we are able to meet the increasing demands for community palliative care in the future.
Model for Basic Palliative Care for Cancer Patients in Romania

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Context: Romania has since 2010 a strategy for developing palliative care (PC) with 3 levels of complexity of the care: support for self care, basic PC and specialized PC. The actual model for basic PC for cancer patients (MBPCC) was fully developed as part of Romanian Swiss partnership project PF05.

Aim: To design and pilot a MBPCC in the community through the GP network

Method: Based on comprehensive research of needs and disparities in care of cancer patients in the community with support of Romanian, Swiss and UK experts the MBPCC was drafted and piloted in 4 counties. Monitoring was done by analyzing patients’ records, interviews with patients and families and GPs. A consensus was run after the first year of implementation to agree the final Romanian MBPCC. Cost per episode of care was calculated. Advocacy is ongoing for national dissemination.

Results: The MBPC has build in educational interventions (online symptom management module, theoretical training, practical placement in specialized PC services, supervised practice, organizational training on using the electronic documentation and continuous support from identified mentors and local coordinators in each of the 4 pilot regions); interventions for care (the MBPCC is applied to cancer patients regardless of stage if PC needs are identified using a 9 items screening tool. Care is differentiating for complex and non-complex patients after an initial assessment) and Coordination and facilitating structures (electronic patients records, telephone help-line, local coordinators/mentors, monthly meetings, local oncologist, access to specialized palliative care services). 168 doctors were trained and 26 were selected to apply the interventions. 280 patients were screened and 146 patients received care in the pilot phase.

Conclusion: The process to develop the model was complex and needed attention not just to the interventions addressed to direct clinical care and education but also to the systemic barriers.
Description of a Tool Used to Identify Patients and Spread the Concept of Palliative Care in a Hospital Environment

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This study aims to describe a tool used by nurses in a hospital where a palliative care consulting team acts. The goal is to identify patients who are eligible for evaluation with a specialized team and instigate the debate about palliative approach in a hospital environment.

**Methodology:** This is a descriptive study which shows a tool built upon the consensual criteria recommended by the Center to Advance Palliative Care (CAPC). Such tool has been used by acting nurses in a large capacity general hospital in the city of São Paulo, Brazil.

**Results:** In 2002, the World Health Organization (WHO) redefined the concept of Palliative Care, making it more embracing. The approach goes beyond the final stages of a terminal disease and aims to see the patient and the family as a unit. Following this concept, the tool presents 8 criteria regarding the patient, the family and the multi-professional team responsible for the treatment. Besides the presence of a terminal disease, symptoms and functionality, the tool considers the of hospitalizations as well as the necessity of aid with complex decisions to be taken by patient, family or team.

Due to a necessity to map the use of opioids and sedatives, guiding a proper use, we have added the criteria: patients with prescription for sedation or analgesics to relieve suffering, creating, thus, more opportunities to discuss the subject of Palliative Care. The tool has been simplified and does not generate system code numbers. The nurse who admits the patient is responsible for enabling the palliative care service after finding two or more criteria in the evaluation. From March 2015 to March 2016, 292 patients were eligible for specialized evaluation service.

**Conclusion:** The tool showed to be useful to identify patients eligible for palliative approach. We realized that from her we did introduce palliative subject more easily, allowing access to palliative care with the active participation of the multidisciplinary team.
Evolution of Consultations in a New Unit of Palliative Care

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Objective: The team of hospital palliative care (HPC) in Rey Juan Carlos Hospital has been recently created (2013). We want to evaluate the evolution of the consultations we receive in a hospital of 700 beds.

Method: We have made a prospective, descriptive and univariant study comparing the consultations of two periods, January-July 2015 and 2016. The significance was established when p< 0.05.

Results: In 2015 we receive 121 consultations out of 7823 admissions that could ask for a palliative consultant (1,5%) vs 155 of 9294 in 2016 (1,7%), p 0.245.

The main characteristics of the 2015 consultations vs 2016 consultations were:

Sex: 49.6% vs 62.6% male (p 0.031), age 80 years (DE 11.7) vs 75 years (DE 12.9) (p 0.001).

Consultation motive: care organization 75% vs 49% (0.001), symptoms control 23.1% vs. 50.3% (0.001)

Consultant ward: Internal Medicine 52.5% vs 51.3% (p 0.856), Oncology 10.8% vs. 13.6% (p 0.482), Geriatrics 11.7% vs 0.6% (0.001), Emergency 7.3% vs 14.3% (0.078), Hematology 4.1% vs 3.2% (0.689), Surgical 3.3% vs. 3.2% (0.970) and others 10% vs 13.6% (0.356); Oncological disease 54.5% vs 71% of non-Oncological (0.003); The non-oncologicals 45.5% vs 41% were neurological degenerative diseases and 45.5% vs 50% organ failure (p 0.637).

Conclusions: As the unit increases we are able to do a bigger number of consultations and assessment of symptoms control. The ward distributions is similar except for Geriatrics due to a change in their organization and Emergency deparment allowing early include patients in program PC. We think that the increase of oncological patients is the result of the settlement of the HPC that ease a multidisciplinary approach between Oncology and us. The result is an optimization of treatment and quality of life of our patients.
Development and Expansion of the Clinical Pharmacist Role Across the Full Spectrum of Palliative Care Services

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Given the burdens of illness, frailty, and polypharmacy borne by Hospice and Palliative Care patients, medication side effects, interactions and cost become central concerns. Palliative care and pharmaceutical care both focus on achieving the best quality of life for patients and families in the setting of their choice. Incorporating a specialty trained palliative care pharmacist directly into the interdisciplinary care of HPC patients across all sites of care is a logical step in the comprehensive management of symptoms in a safe and cost-effective manner. Presenters will describe how clinical pharmacist services can be successfully integrated into the care of patients across the full spectrum of HPC services including inpatient and extended care facility palliative care consult services, an inpatient acute palliative care unit, home based palliative care, a palliative care outpatient clinic and home and long term care based hospice care. The pharmacist serves as a resource for drug information in this patient population for which evidence-based guidelines are limited and where reliable routes of medication administration change frequently. The pharmacist works with physician and nurse members of the inpatient and outpatient services to capitalize on available evidence to develop and revise cost-effective and consistent medication options for inpatient and outpatient symptom management protocols. Central to the pharmacist role is patient, staff, and physician education and collaboration regarding the safe and effective use of medications which may be off-label and outside the comfort level of primary healthcare providers and caregivers. Outcomes presented will include job descriptions, net cost savings achieved, protocols developed, clinical outcomes, and staff satisfaction with the program. Presenters will also advocate for expanding specific HPC training and certification programs for pharmacists.
Bridging the Gap of Palliative Care in a War-torn Nation: A Story of Success from Kurdistan–Iraq

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Background: One of the World Cancer Declaration targets by 2020 was the universal availability of effective pain control measures. Palliative Care (PC) is among the vital elements of cancer treatment and the proper training in this field is crucial. In Kurdistan–Iraq, there is a gap in this field.

Aim: To outline the attempt to bridge the gap in PC in Kurdistan–Iraq.

Methods: Descriptive study of the steps, challenges and provisional outcomes.

Results: After 18 months, a tertiary cancer facility completed its requirements to initiate the 1st organized PC program in Kurdistan–Iraq. External consultants were invited three times to visit and train the local staff about PC. The local team composed of physicians, anesthetists, pharmacists, nurses, and psychologists. The main training course was for 80 hours, concluded with assessment and the team leaders were enrolled in a 6-month diploma-based course. PC program composed of in-patient and out-patient services. Shortage of many elements were obvious including strong oral opioids, invasive nerve block procedures, well-organized wards, district nurses and hospices. Physical, psychological, social and spiritual aspects of symptoms were taken into consideration to achieve the best comfort of our patients, as well as advanced care planning, and other PC measures, including radiotherapy.

Conclusions: Despite the real challenges and hindrances confronting Kurdistan–Iraq to rebuild its human resources, PC program was successfully commenced in January 2016 in Hiwa Cancer Hospital and it promises to help address a shortage of organized PC programs in this war-torn land.
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Developing a Pediatric Palliative Care Unit in a Third Level Hospital. Challenges and Chances


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**Aim:** Since 1991, the Pediatric Palliative Care Unit’s activity has grown progressively in number and quality of attention. Based on the International recommendations a project for a better attention and more services was developed during 2014–2015.

The aim of this study is to describe our project and the impact of it’s development. To analyze the activity and qualitative improvement of it service.

**Design and methods:** To analyze the activity from January 2009 to October 2016 retrospective and description of the projecte developed during 2014–2015 and his consolidation during 2016.

**Results:** From January 2009 we have attended 432 patients, 271 died (131 at home). In 2015 the number of patients attended has growth 9.3% compared with 2014 (Ninety-six in 2014 and 105 during 2015). We support 55 deaths (thirty-nine in 2014). The percentage of oncological and non-oncological diseases remains the same (47% and 53%). Deaths at home increased every year: Twenty-four in 2014 and 23 in 2015 (60% and 42% of total deaths).

During the development of the Project number of professionals increased. Before 2014 the team was conformed by 3 full-time professionals and 5 part-time dedication (2015: Seven full-time and 3 part-time). The bereavement unit was created with parent’s groups. The support is now 24/7 and psychologist and social worker give home care. We also developed a web page to as a tool for patients and families.

During 2016 we have attend 84 patients. Twenty-four patients died at home and 14 in hospital.

**Conclusion:** Following international recommendations it’s possible to give more and better attention to this population.

Twenty-four hour’s attention is essential to support this children and families

Interdisciplinary team is need to give holistic support to the child and the family.

Families grieving after the death of a soon needs support. More resources are need to support children with life limiting and life threatening diseases and his families.
Progress of Palliative Care in Lithuania

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Our aim was to overview the main steps of palliative care development in Lithuania and try to investigate the following directions of its development.

The first steps of palliative care began 1993 (Kaunas Nursing Hospital), 1995 (Lithuanian Palliative Medicine Association), 2007 (A provision of palliative care has adopted by Ministry of Health), 2015 Patients with dementia and Alzheimer’s disease were included in the list of palliative care). Differently from others there are included coma patients. The palliative care is unlimited in time. The necessary team consists of a doctor, nurse and social worker.

Currently, there are one Hospice, 51 palliative care inpatient units, 21 services at home, 2 day centers. Hospice in Vilnius was opened 2012. Psycho-social assistance to cancer patients and their relatives provides St. Francis Oncology Center in Klaipeda. Voluntary Services are created in several places.

Conclusions: We have come a long way to turn it into modern, efficient and well-organised service, nevertheless, certain challenges remain:

- Home care services are scanty and underdeveloped. The solution is strengthening and further developing home care services, so that there is a viable alternative for hospitalization;
- Absence of medicine for controlling outbreak pain (Phentanyl sublingual tablets);
- The underdeveloped spiritual help of palliative care;
- Insufficient education and specialization in palliative care;
- Insufficient number of volunteers in palliative care. This is related to a broader challenge of further strengthening civil society and citizen participation in community life. The positive development is that in the last two years we have seen a certain rise in the number of volunteers in palliative care;
- Underused of methods like music and art therapy, although it is encouraging that Vilnius University started to train specialists in music therapy;
- Insufficient funding.
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Palliative Care Challenges at Home: The Drug Dispensing

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Introduction: In the home care model (HC), the implementation of the end-of-life palliative care (PC) is a challenge under different ways, in particular, the logistics of medication dispensing, mainly the psychotropic, and the family support run by the work team.

Objective: To discuss the challenges of medication dispensing at the end of life, in the HC model in private health in Brazil and the behavior of the family members before death at home.

Methodology: Analysis of a series of 43 treated cases from February 2015 to September 2016. The provision of the services arose from the performed care by health professionals and material and medication supply. In each approach the objectives were: to identify the formal care givers, their doubts about the end-of-life care, the conflicts among the family members and the risks of family claudication; to perform guidance of interventions at the end of life.

Results: During the period were approached 43 patients with 38 deaths at home and 5 are still being followed; 35% men; 79 years average age. There were operational difficulties in the medication dispensing process as late delivery and conceptual understanding by part of the collaborators; family claudication was present in the minority of the cases.

Discussion: Among the items raised in regard to the psychotropic medication dispensing in HC, stand out: i) the need for continuous distribution, mainly in the end-of-life phase; ii) the need to discuss the myths of morphine with professionals and family members; iii) the need for training the medication executor professional.

Conclusion: The medication dispensing may be limited by different HD operational issues, which require a specific organization before the main objectives of attention and Palliative Care models. Yet the family approach requires from the work team a specific skill training such as empathic communication and active listening.
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A Bioethical Framework and Reasoning on Antibiotic Use in Palliative Care: A Systematic Review

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Background: Antibiotic use in palliative raises ethical questions mainly related to the intentionality of its prescription and risk treatment burdens associated with its use in patients nearing the end of life.

Aims: To systematically review the bioethical framework and reasoning on antibiotic use in palliative care.

Methods: Systematic Literature following PRISMA 2009 in PubMed, Web of Science, CINAHL Complete, MEDLINE Complete, Nursing & Allied Health Collection: Comprehensive, Database of Abstracts of Reviews of Effects, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, MedicLatina, Health Technology Assessments, NHS Economic Evaluation Database and EBSCO databases. The keywords were: “antibiotic” and “palliative care” and “ethics”. The inclusion criteria were publications in English, full text and references available. Selected articles were independently reviewed by two investigators.

Results: Of the 38 articles meeting the inclusion criteria, 5 were selected for analysis. Findings show the prevalence of the “Principalism” (Autonomy, Beneficence, Non-Maleficence and Justice) as the main ethical framework informing decision-making about antibiotic use in palliative care. Major ethical concerns appear to be the lack of time to address life-sustaining treatment separately from antibiotic use. The ability to accurately define the prognosis may be a relevant feature in deciding whether or not to prescribe antibiotics to palliative patients.

Conclusions: Ethical issues arise when prescribing antibiotics in palliative care, especially in patients nearing the end of life. Current ethical frameworks seem to be based on the medical ethical principles of Autonomy, Beneficence, Non-Maleficence and Justice. Further empirical bioethics research and debates are needed to ameliorate decision-making processes on antibiotic use in palliative care.

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Religion Based End-of-Life Decision-making

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Background and aims: In Iran, cancer by itself is cause of more than 40,000 deaths every year. Islam is the religion of more than 90% of the population and obviously religious values significantly affect end-of-life decision-making. Critical subjects such as decision of withholding life sustaining interventions in dying patients is merged to the religious believes. Financial burden has non-negligible role in final decision-making that can cause families’ spiritual suffering lifelong.

Method: A structured interview with eight Shiite experts in Islamic studies was organized. The interviews were based on ethical decision-making at the end of life. The Islamic experts should have answered to questions about the criterion for death in religious concepts, criteria for starting or continuing life-prolonging interventions in dying patients, challenges about resuscitation, the patient’s role in refusing life prolonging procedures and more.

Results: From the point of view of Islam life is regarded precious and therefore needs to be saved. On the other hand, life sustaining interventions should not aim at keeping the patients alive only to save their lives. Based on Islamic teachings, people cannot appeal a do-not-resuscitate order, euthanasia, or physician assisted suicide, but in case of no curative treatment, they can decline life prolonging procedures. Final decisions should be made by a team of experts.

Conclusion: Writing a guideline based on Islamic norms on human life and death, purpose of life, God’s will, boundaries of man’s authority, and the physician’s ethical duties and obligations is suggested.

(Based on this study an article was also published in Journal of Medical Ethics and History of Medicine 2014).
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Specialist Palliative Care Nurses’ Perceptions of Assisted Suicide (AS): A New Zealand (NZ) Study

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Aim: Exploration of the viewpoints of NZ Specialist Palliative Care Nurses (SPCNs) regarding the legalisation of AS within NZ.

Background: AS is illegal in NZ under Section 179 of the NZ Crimes Act, rendering it a criminal offence to ‘aid and abet suicide’. Currently, an End-of-Life Choice Bill sits in the NZ parliamentary ballot system. Its intention is to give people with a terminal illness or a grievous and irremediable medical condition the option of requesting AS. If this Bill is successful, it will herald the introduction of AS and change the way end-of-life care takes place within NZ. Despite the significance for NZ nurses, particularly palliative care nurses, NZ nurses have remained relatively uninvolved in this controversial discourse.

SPCNs can be recognised as experts in the care of individuals with complex end-of-life needs. Their intention being to ease any suffering related to death and dying. In this sense, they are in a unique position that warrants exploration regarding the AS debate.

Methods: In 2014, a qualitative methodology used semi structured questions to individually interview NZ SPCNs regarding legalising AS. Thematic Analysis was used to summarise what participants said about topics of interest within participants own words.

Results: The participants identified that AS is a complex issue. They felt that working in palliative affected opinion and that AS did not fit with palliative care nursing philosophy. New issues regarding AS were discovered. For example, concern at AS on youth. The research identified nursing disquiet including reluctance to participate in the act.

Discussion: The study alongside international literature clearly identified that SPCNs have unique knowledge and experience in the complexities of all aspects of end-of-life care. It would be remiss of SPCNs not to act to ensure experienced situational understanding is put forward to inform public awareness of all the issues and options that surround end-of-life care within NZ.
Health Care Providers Becoming as Human Beings in End-of-Life Care – A Tentative Theory Model

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Aim: The aim is to elucidate dimensions in a tentative theory model of health care providers becoming as human beings in end-of-life care.

Health care providers as fellow human beings are vulnerable and caring for patients at the end-of-life is usually something that not goes without a trace for health care providers. The awareness of death can give meaning and understanding of one’s own life. Health care providers’ existential situation has received small extent of attention.

Design, methods and approach: A caring science perspective based on Eriksson’s theory of caritative caring, was used to reveal dimensions of health care providers becoming as human beings. The material consists of two substudies with interviews, one meta-synthesis and three focusgroups interviews with a total of 1635 nurses. In the interpretation of the material a hermeneutic overall approach was chosen.

Result: The theory model indicates that health care providers in a caring communion in end-of-life allows contact with life and oneself as human beings. It is an inner awakening for health care provider as human beings, an inner movement to the awareness to be able to love unselfishly in the caring of patient. When health care providers get contact with life and oneself as human beings they struggle to be reconciled with their own life situations. Becoming, as human beings can be revealed as an understanding of life and feelings of inner strength and happiness as human beings and as health care providers in end-of-life care.

Conclusion: The dimensions of the theory model can give a deeper understanding of health care providers becoming as human being. In caring community health care providers can experiencing difficult situations where there inner as human beings will be touched and existential questions raises about health and suffering, dying and death. Becoming as human beings and health care providers in caring communion is to be at home in ethos, love, charity and reconciliation.
Who is Responsible for their Care? Mexican Illegal Immigrants Returning Back to Mexico with Terminal Cancer

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Illegal immigrants form a large and disputed group in many countries, their existence raises an important ethical question: Do societies have an ethical responsibility to provide health care? Undocumented Mexican immigrants in the US currently represent the majority of all immigrants, they account for 14.6% of the uninsured population and represent the only population excluded from Medicare and the Affordable Care Act. Federal funds for the care of undocumented immigrants are available only through emergency Medicaid. A troubling problem arises in the care of terminally ill patients, as the only access to pain medications is through emergency departments.

Forty patients living in US illegally have been treated at the Palliative Care Service during 2015 and 2016. Most patients were males (25/40); in average: age 45 years; time living in the US 9 years; previous disease modifying treatment in US 42%; treatment with opioids in US, 50%. In Mexico, the average monthly income per family was $US183.00; only 3/40 patients had access to Social Protection Insurance Plan; 37/40 patients had to paid for treatment, including opioids. The average survival time was 90 days.

The abstract ethical question about the responsibility to provide health care for illegal immigrants becomes a concrete political issue between competing goods. Illegal Mexicans with terminal cancer living in the US, often chose to return to Mexico to have quality of death. However, they have become aliens to their families, and to the Mexican Health System an unknown priority.

Remittances are perhaps the most tangible consequence of migration for many households in the country and the second largest source of external finance after oil. Palliative care access at the end of life for the returning workers, should be consider a social, ethical and political responsibility to the Mexican Health system.
**Knowledge and Attitudes toward Advance Directives in Patients with Heart Failure**

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**Background:** Limited studies have addressed the knowledge and attitudes toward advance directives in patients with heart failure.

**Aims:** To assess the status quo of knowledge and attitudes towards advance directives in patients with congestive heart failure and to identify factors that may contribute to the signing of advance directives.

**Methods:** This study used a cross-sectional and descriptive design. 75 patients were recruited from a cardiovascular outpatient department in a medical center in northern Taiwan. The outcome measures included self-designed questionnaire, Charlson Comorbidity Index (CCI), Advanced Directive Attitude Survey (ADAS), Advance Directive Knowledge Survey (ADKS), and M. D. Anderson Symptom Inventory-Taiwan Form (MDASI-T). Data were analyzed by independent t-test, one-way ANOVA, Pearson correlation test, and multiple regression.

**Results:** ADAS and ADKS showed a positive correlation by Pearson correlation ($r=0.265$, $p=0.021$), indicating that disease awareness and attitude towards advance directives have a direct relationship. Multiple regression analysis disclosed that the diploma of college ($\beta=0.256$, $p=0.017$) and time to diagnosis of congestive heart failure ($\beta=0.308$, $p=0.004$) were both ADKS predictive factors; quality of life ($\beta=0.304$, $p=0.006$) and current awareness of advance directives ($\beta=0.259$, $p=0.019$) were significantly correlated with ADAS.

**Conclusion:** This study showed that severity of disease and patient’s self-assessment of quality of life affected the attitudes toward the signing of advance directives; patients and their care-givers were more willing to sign advance directives if the functional status was poor and/or the patient has reached a critical condition. We recommended that if a patient has an uncertain prognosis, palliative care should be commenced, allowing the patient to more actively participate in his/her own medical decisions and decrease the amount of unnecessary suffering.
What Are the Typical Wishes of Palliative Care Patients? Findings from a University Hospital in Switzerland

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Background: Research findings concerning the wishes of palliative care patients are sparse.

Aim: As part of a more comprehensive national project analysing the respect for patient self-determination in palliative care, this study focused on the patients’ wishes. The aim was to identify typical wishes of palliative care patients, as reported in their medical charts.

Methods: We gathered data by extraction from 100 medical records of hospitalized patients seen consecutively from November 2015 by the hospital palliative care team at a university hospital in Switzerland. Data were collected between April and May 2016 and analysed qualitatively using content analysis.

Results: Palliative care patients’ typical wishes during end-of-life discussions were specific and life-oriented, such as post-hospital wishes (to go home, to be transferred to a nursing home, to travel); dietary wishes (to enjoy specific drinks and dishes); relational wishes (to visit relatives, to see pets), and medical wishes (to receive comfort therapy). Death-oriented wishes, like the wish to die, were less frequently documented.

Conclusions: Palliative care patients’ wishes reported in medical charts tend to be specific and life-oriented. The recognition of these wishes can help improve patients’ treatment and support needs. Death-oriented wishes are less frequently documented, though death is imminent for such patients. As a next step our study will explore if death-oriented wishes are more frequently mentioned in direct conversations between physicians and patients. General rules about the extent and manner in which patients’ wishes should be discussed and documented remain to be explored, as well as how these wishes are integrated into the medical decision-making process.

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The Moral Relevance of Metaphors in the Stories of Parents with a Child Suffering from the Neurodegenerative Disease CLN3. An Empirical-ethical Study

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Background: Metaphors are often used within the context of (paediatric) palliative care but have hardly been explored in relation to ethics.

Aim: To describe the moral relevance of a set of metaphors in the stories of parents with a child suffering from the neurodegenerative disease CLN3.

Methods: Semi-structured interviews were conducted with sixteen parents of a child suffering from the neurodegenerative disease CLN3 (8 female; mean age 50.1). The interviews were recorded, transcribed and metaphors were analyzed. The researchers wrote memos and discussed about their analyses until they reached consensus.

Results: The set of metaphors referred to the semantic field of the hands and arms, and consisted of two central metaphors that existed in a dialectical relationship: grasping versus letting go. Participants used these metaphors to describe their child’s experiences, who had to ‘let go’ of abilities, while ‘clinging’ to structures and the relationship with their parent(s). They also used it to describe their own experiences: participants tried to ‘grab’ the good moments with their child and had to ‘let go’ of their child when (s)he approached death. Participants, in addition, ‘held’ onto caring for their child while being confronted with the necessity to ‘let go’ of this care, leaving it to professional caregivers.

Discussion: The ethical analysis of the empirical findings shows that thinking in terms of the dialectical relationship between ‘grasping’ and ‘letting go’ helps professional caregivers to critically think about images of good care for children with CLN3. It also helps them to bear witness to the vulnerable, dependent and embodied nature of the moral self of children with CLN3 and their parents. Such metaphorical reasoning contributes to reaching a reflective equilibrium.

Conclusion: Metaphorical reasoning should be included in bioethical reasoning when it contributes to reaching a reflective equilibrium.

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Bioethics and Nutrition: The Different Faces of Feeding in Palliative Care

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Background: Palliative care refers to a model of attention in health that aims the quality of life of patients out of the healing possibility. In this context, the nutrition sometimes represents a bioethics conflict and exploring the meanings of eating in this population enables that the autonomy principle or the best interest of the patient are respected when a decision should be made by the health professionals.

Aims: To discuss the different faces of nutrition in palliative care from the bioethics perspective.

Methods: An integrative review was performed. The inclusion criteria for searching were: publications up to five years, peer reviewed and title containing the following descriptors: palliative care and nutrition; palliative care and feeding; palliative care and nutritional support.

Results: We obtained 32 articles and from these, 7 were selected because they made reference to the meaning of eating in palliative care. The results were classified into the following themes:

a) eating as a physical benefit: nourish was reported as a way of achieving physical strength and increasing functionality;

b) eating as a bioethics issue: the principle of non-abandonment and the obligation of feeding (nourishing as an ordinary care) were identified;

c) eating to increase survival;

d) eating and hope of improvement: it is being understood as a subjective element on the patient’s life. Keeping feeding symbolizes love and caring for the loved one, even if it does not represent the patient’s best interest. Furthermore, the moral stress could be present when the professional prescribes the nourishment (mainly the artificial one) to meet a family need instead of the patient’s.

Conclusion: The bioethics principles should be incorporated by the members of the family and health care team on. Quality of life was not referenced on these studies, suggesting that the focus of palliative care was not totally integrated on the clinical practice.
Knowledge and Attitudes of Health Professionals about Living Wills in Two Health Departments of Alicante

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Objective: To describe the knowledge and attitudes of health professionals about Living Wills.

Methods:
Design: Cross-sectional survey.

Participants: Of the 1,015 eligible professionals, 329 health professionals agreed to participate.

Variables: Knowledge was evaluated with Champer et al., (2010) questionnaire, which consists of 17 items (5 blocks). Attitudes were assessed with the questionnaire of Simon-Lorda et al., (2008), consisting of 12 items.

Procedure: Electronic questionnaire was sent to professionals following a standardized procedure of 3 e-mails. All participants completed the informed consent.
Analysis: Descriptive and bivariate analysis was performed with the Statistical Package IBM SPSS Statistics 21.0.

Results: The 45% of the sample were physicians, and the rest were nurses, with an overall mean of 13.1 (dt:8.3) years of professional experience. The 67.7% were women and the average age was 38.9 (dt:9.2) years.

The block of knowledge about the “conceptual definition” got the best score (92.50), followed by the block on “implementation of the living will document in practice” (69.33). The block with the lowest score was “procedure and registration” (27.25). The “scale of attitudes” obtained a mean of 75.37 (dt: 11.97; range: 0–90).

The level of knowledge was associated with the subscription of living wills, training in palliative care, the need to report patients, previous experience handling the document and to have read it, all with p < 0.001.

Positive attitudes were associated with motivation to participate in training activities on the living will (p < 0.001) and previous experience in handling it.

Conclusion: Health professionals showed positive attitudes towards the living wills document. The knowledge should improve, especially in the block “procedure and registration”. Knowledge was associated with training and previous experience with living wills, while attitudes were influenced by motivation to training and previous experience.
Decisional Control Preferences in Advanced Cancer Patients in Brazil

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Background: There is still a lack of knowledge on processes and contents of patient’s decision-making (DM) and how to improve communication between patients, families and health care team. In the palliative care setting this issue has a particular concern because the decision-making process regarding disclosure and medical procedures still remains poorly understood. More over, patients and physicians frequently disagree with regard to what the patients’ needs and perceptions of their illness are. Preferences on how to make decisions seems to largely vary among cultures and countries. There are few studies focusing in decision-making process in Latin America or in Brazil as well.

Aims:
a) Primary Objective: To know how Brazilian patients prefer to make their decisions;
b) Secondary Objectives: To know if the preferences vary according to demographic data; To know if the preferences vary according other variables.

Methodology: Cross-Sectional, observational study. Participants were consecutive patients who were attended in the PCU, age 18 and more, with advanced cancer. Demographics and data on Decision-Making Preferences Questionnaire, Satisfaction with the Decisions and Care Questionnaire, and Illness Understanding Questionnaire were taken.

Results: Two hundred, twenty-six patients were enrolled, 62.3% women, 40.3% more than 61 years-old, 70% stage III cancer and 30% stage IV; 66.3% prefer an active DM process, 97.1% were satisfied with information received; 67.8% thought that their cancer was curable, 76.1% believed that the aim of treatment was to eliminate the cancer.

Discussion and conclusion: Although patients preferred a more active model of DM, most of them were aware of their actual condition. The findings suggest incongruence between preferences and communication. More studies on communication are needed.
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The Place of Palliative Care (PC) in Jurisdictions Permitting Assisted Dying

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Background: For the leadership of most palliative care (PC) organisations, including the EAPC, euthanasia and/or assisted suicide (EAS) is doctrinally “incompatible with the very foundations of PC”. Yet, in ever more jurisdictions EAS has been legalised or is on the political agenda. PC workers must reflect on three options for EAS-permissive environments: keep excluding EAS from PC, leave involvement in EAS to individual caregivers’ freedom of conscience or embed EAS in PC as in Flanders, Belgium.

Aims: To inform this debate.

Methods: Review of 1) the essentialistic objections to EAS embedded in PC and 2) the empirical data from EAS-permissive jurisdictions.

Results: 1) The several essentialistic objections are found logically difficult to sustain or contradict the PC tenet of patient-centredness. 2) In the states of Oregon and Washington and in Flanders, over 70% of cases of EAS are preceded by professional PC. In Flanders, EAS occurs three times more often after a PC trajectory than after conventional end-of-life (EOL) care. The Belgian model of ‘integral EOL care’ consists of legally ordained, demand-driven universal access to PC and EAS. It was in 2015 largely emulated in Québec’s comprehensive end-of-life care bill.

Discussion: If in Canada and other future EAS-permissive countries EAS is excluded from PC and carried out only in health-care settings that are less competent for EOL care, patients who want the possibility of EAS may shun professional PC and hence not receive optimal EOL care. Second, EAS will likely be less practiced in a spirit of “total care”. Consequently, the overall quality of all EOL care stands to decline. And ethically, is not the PC tenet of patient-centredness violated when caregivers give priority to their own values over the patient’s?

PC organisations need to confront these practical and ethical issues and duly consider the option of embedding EAS in PC or at least entrusting involvement in EAS to individual caregivers’ conscience.
Legalize it? – Problem Based Learning and Attitude towards Euthanasia in Medical Students in a German Medical School

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**Aim:** Euthanasia is intensively debated in Europe. Different approaches have been undertaken from restrictive (e.g. Italy) to liberal ones (e.g. Belgium). In Germany euthanasia is illegal and since a new bill in 2015 physician assisted suicide is punishable by law if carried out in a regular and repetitive manner.

There is an urgent demand to discuss issues around euthanasia in medical education. However adequate teaching formats are unclear. Complex and differential matters may be taught using problem based learning (PBL). Aim of this study is to assess the effect of PBL on attitude towards euthanasia in medical students (MS).

**Methods:** MS took part in a curricular course on palliative care (PC). At the end a PBL module on euthanasia based on a clinical case was introduced (duration 1.5 hours). MS depicted their attitude towards “euthanasia should be a legal medical procedure carried out by a medical doctor” on a visual analogue scale (standardized 100mm) from “yes” to “no” before and after. Discussion was assessed by participatory observation and topics raised by MS were documented and researched using content analysis.

**Results:** 123 MS participated in the survey. Before the discussion 77/122 (63%) marks were < 50mm (yes), after 60/123 (49%). Means before and after PBL were different (43.0 before and 53.2 after, standard error of mean 2.8 and 2.9, respectively, p< 0.01). Topics discussed (in case of pro legalization) were autonomy, unpalliated suffering, limitations of qualified palliation and quality and transparency and (in case of against) change of heart, patients may respond to an offer in absence of alternatives, autonomy in face of severe suffering, social pressure, family, society, health cost provider and lost opportunities for treatment and research.

**Conclusions:** In nearly 2/3 of MS attitude towards euthanasia is in favour and contrary to common law. Discussing the topic leads to a shift towards “no”. By PBL most relevant topics on euthanasia can be worked out.
Sedation in France Today: Caregivers’ Representations and Legislative Evolution

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Context: In February 2016, a new law (Claeys-Léonetti) was adopted in France on the rights of patients at the end of life. Notably, it outlines the right to a deep, continuous and maintained sedation until death while nutrition and hydration are stopped. Previously, recommendations did not explicitly define sedation and the modalities of this practice had been subject to a medical prescription following collegial discussion.

The social representations of sedation impact the way in which doctors and caregivers experience sedation, because they are confronted with the feedback and remarks from patients’ entourages and because it is the backdrop against which the interaction between patients and their entourages is constructed on this subject.

Aim and method: In this context, we have chosen to explore the representations of caregivers around sedation and the everyday experience of their practice. In order to better understand them and put them in a dialogue with social representations and contemporary ethical debates to make another voice heard, I propose a presentation of the results of a study carried out among young doctors (interns and assistants) in a cancer research centre, a university hospital and an outlying suburban hospital.

This study primarily investigated the indications of sedation encountered, the perception of legislative contexts and the possible confusion with euthanasia “by another name”. The objective is to offer up the reflections of these young doctors as part of the contemporary debate on the end of life in order to insert this debate into a broader plural context. Furthermore, the aim is to propose training and work paths on societal representations to make a considered discussion possible around these questions by mitigating media-driven confusion between sedation and the act of euthanasia.
Advance Directives: The Influence of Quality of Life on Treatment Choices

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Advance directives (AD) should reflect the patient’s wishes for his health care when they will be put to use. It is therefore important to understand the factors that could potentially bias them at the time when they are written. We hypothesized a link between the quality of life (QOL) at the time of their redaction and the QOL restrictions that the patients are willing to accept as expressed in their AD. We introduced the concept of minimum acceptable QOL to define these restrictions.

Material and methods: 201 questionnaires were distributed at the hospital or at general practitioners practices. A score of minimum acceptable quality of life (QVMA) was established for each patient based on clinical situations for which he wished maximum treatment or palliative care. A correlation was sought between the current quality of life score, cultural and religious factors and socio QVMA.

Results: The low life quality group had an average of QVMA 0.55 against 0.61 for the high quality of life (p < 0.001).

The group with a religious practice had an average of QVMA 0.55 against 0.60 for those without religious practice (p < 0.05).

These results confirm the hypothesis of an influence of the current quality of life on the conditions that the patient is willing to accept in the future.

These results ask the DA’s sustainability: they are complex and subject to various influences. Their elaboration should be completed understanding the patient’s important values and they should be revised for patients who have adapted to a significant QOL change.
When you Want to Live

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In 2015, L. F., 52, male, suffered a hemorrhagic stroke by arteriovenous malformation rupture by the level of brainstem that was complicated by severe sepsis, bringing the patient to a vegetative state with no communication, under ventilation support with tracheostomy.

On the February 12th, he joined the Palliative Care Unit because of a nosocomial infection with no perspective of recovery, presenting advanced terminal illness with limited life prognosis and uncontrolled symptoms: neuropathic pain, spasticity, hypersecretion and fever.

During hospitalization, the patient was in a “locked in” state which demanded alternative communication provided by speech therapy and the commitment, dedication and fighting spirit of the patient’s family, who overestimated (appropriately) Mr. L. F.’s skills.

From a vegetative state he became conscious, oriented and able to express his own desires, which created several new issues for the palliative team to analyze.

Goals: Outlining a realistic individual intervention plan, scaled and adapted to the patient’s progression and family needs.

Methodology: Qualitative study using case study methodology.

Results: In interdisciplinary meetings, the Individual Plan was reevaluated, from a symptom control approach focused on the patient’s well-being and comfort and on the family support, to a rehabilitation program based on a transdisciplinary intervention.

This evolution created several ethical issues: do not resuscitate order, end-of-life decisions, principles of autonomy and beneficence and non-maleficence, bringing the palliative team to face the need to change the paradigm of care: from a terminal patient to one with potential of rehabilitation.

Conclusion: Patient cognitive and emotional stimulation with the involvement of the family was decisive for the clinical course of L. F.

This is paradigmatic: the need for a continuous and accurate reflection about the singular circumstances and needs of every patient.
The Undue Influence of Free Treatment: The Case of Seguro Popular Catastrophic Insurance Fund for Testicle Cancer in Mexico

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Low and middle-income countries face double health burden of increasingly prevalent chronic diseases and those associated with poverty. Cancer particularly the testicle cancer is a disease that characterize the complexities and inequities of this epidemiological challenge. Although its incidence and mortality has decreased in Mexico, this type of cancer and it divides the country population in rich and poor. This type of cancer is focused on young men, in productive age when their life projects fracture, physical deterioration, symptoms like tiredness, pain, dyspnea, cough associated with pulmonary metastasis is evident coupled with social isolation leading to suffering and important psychic implications.

At the palliative care service of the National Cancer Institute in Mexico City, most men referred to the service have very advanced disease; live in the nearby states, in poverty. Coming to the hospital represents a huge physical and economic effort. Nevertheless, the Seguro Popular Catastrophic Insurance Fund has improved the treatment possibilities. However, aggressive treatments and invasive procedures and sometimes futile are frequent for alleviate the disease but in contrast palliative and primary care are not included in the Insurance Fund, for example access to pain treatment is only possible paracetamol, not opioids.

Ethics is not unique to patients in palliative care, it must be applied to the whole range of medicine. Physician must have medical training, knowledge and ability for perceive needs as well as sensitivity of the unfavorable evolution and watch their own limits forever seeking the wellness of the patient avoiding harm.

From the bioethical perspective, we question who’s decision is to treat only the disease but not the person. Why don’t we think in the symptoms that this men suffering? Give aggressively treatment, is there an undue influence because of the free treatment?
Pediatric Palliative Care: Perception of Health Professionals in Relation to Bioethical Aspects

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Background: Bioethics reflection on pediatric palliative care has been growing as the quality and quantity of therapeutic intervention possibilities are extended.

Aim: To assess the perception of health professionals on bioethical aspects in pediatric palliative care.

Methods: The study, approved by the local ethics committee for research, included 15 professionals (five doctors, five nurses and five nursing technicians) who work in the care of pediatric patients in a university hospital in the city of Curitiba, Brazil. The professionals were interviewed, using semi-structured interview, and the results analyzed by the Bardin content analysis.

Results: From the reports obtained from the interview, the ideas were awarded in three categories:
1) relationship between health professional and patients and their families, focusing on aspects of truthfulness and confidentiality, psychological support for the family, solidarity and compassion, and importance of spiritual care;
2) training of health professionals in pediatric palliative care, in which health professionals recognize the need for training, mainly because of the difficulties in dealing with the situation of suffering and death;
3) decision-making in pediatric palliative care, with emphasis on competence and autonomy of the patient, recognizing the necessity of the participation of different stakeholders in decision-making and, from the interdisciplinary, promote therapeutic proportionality.

Conclusion: The results reinforce the need for proper training, continuing education offered by health institutions for professionals working in pediatric palliative care, including discussion related to bioethics content that can support the good practice in pediatric palliative care.
Different Opinion of Considering Life-sustaining Treatments for the Patients Lacking of Mental Capacity between Medical and Juristic Professionals: A Delphi Survey in Taiwan

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Background: In Taiwan, Patient Self Determination Act 2016 have endorsed the advance directives (AD) of life-sustaining treatments in limited condition of diseases. For patients lacking of mental capacity but not have had AD, however, the essentials of decision-making for clinical interventions are deficient in the clinical, ethical, legal and social context.

Aims: To develop consensus of clinical decision-making for patients lacking of mental capacity among physicians and jurists, and analyze any difference between two groups of professionals.

Methods: National experts in medicine, law and ethics were invited for a 2-round Delphi survey by E-mail. Experts reviewed a list of proposed statements, based on the domains of medical evaluation and management (EM), patients’ preferences and substitute judgement (PS), social and cultural context (SC), mechanism of dispute resolution (DR), and rated each proposition from 1 to 5 (disagree to agree) with modifying statements or adding propositions. Consensus was achieved when the rating was 4 points or more. The characteristics and opinion from medical and juristic professionals were compared.

Results: 42 physicians and 29 juristic professionals completed the two rounds of survey and achieved consensus on 31 statements categorized across 3 domains: 13 in EM, 8 in PS, 10 in SC. Significant differences of rating between medical and juristic professionals were found only in 3 statements after adjusting for covariates (p<0.05). Physicians had strong agreements with the principle of patients’ best interests for decision-making while juristic professionals had lower rating score (mean = 4.12, 3.52, respectively, p=0.002).

Conclusion: Opinion was similar between medical and juristic professionals, but markedly heterogeneous. Interdisciplinary consensus on practice of decision-making for the incompetent patients provide a strong evidence of developing guidance to clinicians, lawyers, researchers and policymakers.
**What Are Distressing Symptoms of Terminal Cancer Patients for the Bereaved?**


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**Aims:** The main purpose of this study is to clarify the level of distress experienced by families toward the symptoms of terminal cancer patients two weeks before death. The secondary purpose is to clarify symptoms where families feel the need to develop methods for their alleviation through repeated future research and devising solutions.

**Methods:** This study was part of a cross-sectional nationwide survey of bereaved families of patients with cancer, namely, the Japan Hospice and Palliative Care Evaluation 3 study (J-HOPE3). The emotional pain experienced by families two weeks before the death of a loved one was surveyed based upon responses from 805 family members.

The survey items based on the Memorial Symptom Assessment Scale. Thus, nineteen questions were prepared, with responses made on the following 4 points scale:

1. Not distressing,
2. Slightly distressing,
3. Quite distressing and
4. Very distressing, based on the degree of difficulty of the symptoms.

Additionally, triple choice responses were requested concerning “symptoms where families feel the need to develop methods for their alleviation through repeated future research and devising solutions.”

**Results:** In this study, 51.9% of the families reported loss of appetite as a very distressing symptom two weeks before the loss of a loved one, making this the most common response, followed by weight loss (47.9%) and pain (43.9%). Symptoms such as itchiness and fatigue were not distressing. In terms of symptoms for which research was desired, the most common response was pain (47.2%), followed by nausea (29.0%), and edema (24.4%).

**Conclusion and discussion:** While medical professions consider end-stage loss of appetite to be “natural” and “inevitable,” research suggests that it is a distressing symptom for families. Based upon this, while conducting research to find a more appropriate explanation for the loss of appetite, it is necessary to consider the feelings of families.
ALS: Primary Family Caregiver Burden in End-of-Life Care

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Background: Amyotrophic lateral sclerosis (ALS) is a fatal disease with unique demands on patients and carers. Former research has established that burden exists among ALS patient-caregivers and has identified certain challenges that family members find most distressing. Recent research has accented the importance of social support in the study of caregiver burden. Several studies show significant increase of burden and social isolation of caregivers in advanced disease.

Aim: The goal of this study was to determine the experiences and burden of ALS family caregivers in end-of-life care.

Method: Individual interviews with primary family caregivers of ALS patients (n=9) after death of the patient were transcribed and analysed. Burden of care and burden components were assessed with special focus on time after death.

Results: The patients lived between 2 and 8 years with their diagnosis. Family caregivers were interviewed between 5 weeks and 3 years after the patient’s death. All patients had non-invasive ventilation support. Five patients died at home, four in nursing home or hospital. In four cases, the patient got planned terminal sedation following her/his will to take away ventilation support.

The family caregivers reported personal and social restrictions due to time-consuming support and care, patient’s preference for getting help from the primary family caregiver, physical and emotional problems especially during end of life care and challenges according to coping with change and loss after death. Most family caregivers were not prepared to support their loved one with the experienced technical and emotional challenges over years.

Conclusion: The interviews indicated that overall professional support was inadequate and too late to relieve the burden placed on the primary family caregiver. We recommend early professional caregiver assistance including discussion about arrangements for time-limited stay in nursing home or hospital.
How Patients’ and Relatives’ Suffering is Connected? Evidence from a Cohort Study

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Background: Psychosocial Care Teams (PSCTs) in Spain offer support to the existing palliative care services. They provide comprehensive care towards advanced patients and their relatives in regards to emotional, spiritual and social issues.

Aims: The importance of family wellbeing has been considered. The main objectives are to explore the evolution and relation of distress, anxiety and adaptation between end-of-life patients and their relatives. Demonstrating this connection can improve their care quality.

Methods: The evolution of three psychosocial dimensions (distress, anxiety and adaptation) of 8482 patients and their relatives was analyzed by 210 professionals in a quasi-experimental, prospective, multi-centered, one group and pre-test/post-test study for the period 1st July 2014 to 30th June 2015. Dimensions were referred by both patients and relatives in separate visits with the psychosocial team and the global assessment made by the professionals. Differences were performed to correlate patients’ and families’ improvement with respect to the basal visit.

Results: Decrease in patients' distress is positively correlated with decrease in relatives’ distress (corr=0.42, n=4795); increase in patients’ adaptation is positively correlated with increase in relatives’ adaptation (corr=0.37, n=5016) and decrease in patients’ anxiety is positively correlated with relatives’ anxiety (corr=0.40, n=4805). Regression analysis shows a statistically significant relation between one to each other’s improvement for all of the studied variables although causality should not be concluded. Improvement for one without the other is not found.

Conclusions and discussion: Improving relative’s emotional wellbeing helps improving patient’s emotional wellbeing. Thus, the provision of comprehensive care involving family members contributes to ease patient’s suffering. This is in line with current research, pointing to a holistic conception of palliative care provision.
Getting it Right! Understanding End-of-Life Experiences through Engagement with Bereaved Families and Carers in the UK

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‘Getting it right’ at the end of life features in many recent UK reports, but is often reported that it has gone very wrong for many people which tells us that we need to do better. The study aimed to gain an understanding of the actual experiences of end-of-life care to enable the development of end-of-life care initiatives across a UK county with a population of 480,000. A mixed methods approach was developed to capture and measure end of life experience through descriptiveness and generalisability involving engagement with families, carers and professionals. A variety of recruitment techniques were tested out. Data collection methods included interviews, questionnaires (postal and online) and focus groups. All data was scrutinised using an inductive thematic analysis. A three tier framework was designed to explore the different experiences (at individual, secondary and national levels). There were 130 participants, including 57 family members. 12 sub-themes arose, which were located under two overarching themes.

Although there were many similarities and cross-over in types of experiences, families were more likely to identify areas related to the ‘giving of’ care, while professionals were more likely to relate to organisation and structure.

Even though professionals believe they know what is important for end-of-life care, it is not always about structure and physical care. Emotional support, kindness and communication (the ‘giving’ of care) are among the vital elements of what families value. This study also identified ways of engagement for future work.

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<thead>
<tr>
<th>The ‘giving of’ end-of-life care</th>
<th>The organisation and structure of end-of-life care</th>
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[Families and friends............................................. Professionals> > > > > >]

[Themes and sub themes arising]
Expressions of Dignity from the Perspective of Family Members to Patients in Palliative Care

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Background: Living and dying with dignity are fundamental values in palliative care. Family members are often caregivers of the patients and since they are a part of the palliative care they are also care recipients. Hence, their experience of dignity is important to investigate in order to improve palliative care.

Aim: To describe dignity from the perspective of family members to patients in palliative care.

Methods: Qualitative descriptive design. Semi-structured interviews were conducted with fifteen family members of patients enrolled in specialized palliative care. Data was analyzed with latent content analysis.

Results: Several factors were important for understanding family members’ expressions of dignity; a two-headed paradox (wanting to be close to the ill person while simultaneously wishing to escape); reciprocity (mutual bonds); the situation of being a close family member; one’s personality and the organization of health care.

Identified themes were: Being able to keep one’s identity and being acknowledged by telling one’s story, being acknowledged for one’s knowledge and wisdom and maintaining the person you are; Maintaining everyday life by maintaining physical and cognitive functions and receiving desired support; Having connectedness to the family by relational concern for the ill person and good relation to other family members; Working in partnership with the healthcare personnel including home and hospital as the place of care; Being able to envision a future by having a meaning in life, feeling hope and passing memories to the coming generations.

Conclusions: There are a number of factors that needs to be addressed when designing interventions aiming for a dignified palliative care of family members as well as for the patients. This requires a systemic approach, both when designing those interventions and further research, i.e. targeting family members and the patient as a unit.

Funding: The Kamprad Family Foundation, Sweden.
A Process Evaluation of Systematic Risk and Needs Assessment for Caregivers in Specialised Palliative Care

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Background: Caregiving will often be strenuous and it can be associated with adverse psychological outcomes. During the palliative care trajectory, unique opportunities exist for assessing caregivers’ support needs and risk of poor bereavement outcomes. Still, the responsibility of palliative care staff towards caregivers in daily practice is often unclear. Standards for bereavement support exist, but their feasibility has not been tested so far.

Aims: This study tested the feasibility of an intervention based on key elements of the Australian Bereavement support standards for specialist palliative care services.

Methods: A process evaluation of the implementation of the intervention in a Danish palliative home care team was conducted following the UK Medical Research Council’s guidelines. Outcomes included the reach, fidelity and acceptability of the intervention as well as barriers to the implementation.

Results: The intervention reached 76 out of 164 caregivers (46%), interdisciplinary risk assessment and documentation of support plan was conducted for 57 (75%) of the enrolled caregivers, and an electronic medical record was established according to the intervention blueprint for five (62%) caregivers receiving targeted support. Acceptability among palliative care staff was high. Staff recognised that, using this approach, their resources were relocated to the caregiving period rather than after the patient’s death. Barriers to the implementation included caution with asking emotion inducing questions and ethical considerations about establishing electronic medical records for caregivers with no formal disease diagnosis.

Conclusion: The intervention proved feasible and useful. Still, we identified several barriers which can be taken into consideration in the implementation of systematic risk and needs assessment as well as the establishment of medical records for caregivers.

Funding: The Danish Cancer Society and TrygFonden
External Signs of Emotional Distress in Caregivers of Patients with Advanced Illness or at End of Life

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Aims: Assessment of external signs of emotional distress (ESED) in caregivers of patients with advanced illness or at end of life.

Methods: 132 primary caregivers (PC) of advanced cancer patients admitted to different PCU participated in this study. The PC answered the scale Detection of Emotional Distress of Caregivers of patients with advanced illness or at end of life (DED-C) and also demographics variables.

Results: Mean age of PC were 59.69 (SD= 13.3). There was a positive correlation between external signs of emotional distress (ESED) and emotional distress – ED – (r= .566; p< .001). Caregivers who present ED showed more ESED than those no (X²=12.57; p< .001). Of these, showed statically significant difference in “Visible signs of sadness, fear, crying, overflow” (13.76; p< .001); “Difficulty of separating the patient: family refuses to let the patient make decisions and insists care” (X²=4.52; p< .05). The others signs as “Refuses or avoids contact with professionals”, “Refuses or avoids visits from friends or family” or “Difficulties with information (blocks, difficult, minimizes information” did not show difference between caregivers who presented emotional distress than those no.

Conclusions and discussion: The PC who presented ED showed specific ESED easily identifiable by professional and can help them to complement their global assessment of caregivers’ wellbeing. These signs are very important particularly in those caregivers who do not express openly their feelings or the communication is difficult. Our results justify the systematic assessment of these external signs of emotional suffering in the global assessment of the primary caregivers.

Acknowledgements: This study was supported, in part, by the Grant PSI2013-43555-R from the Ministerio de Economía y Competitividad MINECO (Spain).
“What Would Help?”- Exploring Carer Need in Northland, New Zealand

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Aim: In response to anticipated increased need for palliative care over the next 10–20 years with the increasing average age of the New Zealand population, funding for new initiatives that encouraged the partnership of specialist palliative care and primary care services was made available the central government.

It is known that supporting carers has a significant impact on the ability to care for a patient in the community and prevent unnecessary acute admissions to hospital. A joint approach in assessing what would make the most significant difference in the Northland community was undertaken before any new initiatives were considered.

Design and method: After a literature search, questions were agreed on that would assess perceived need of carers and encourage broad thinking as to possible solutions. A web based survey, one-on-one discussions and focus groups were used to gather this information. The broad coverage achieved enabled diverse viewpoints to be captured from primary, secondary and community providers as well as individuals, with focus group meetings providing multiple examples and narrative to elaborate on the key themes. Focus group attendees were predominantly community members currently or previously involved in caring for people with life-limiting conditions.

Results: A total of 193 participants responded or attended. Four key areas of need were confirmed- Access to GP for family meetings; Access to information; Emotional support; Availability of respite.

Conclusion: The needs in Northland are similar to other communities. Better symptom management of patient was not a need. Having confirmed from carers their priorities, a collaborative approach involving the local health authority, specialist palliative care, primary care and community volunteers could be more fully investigated. As a result, a joint specialist palliative care and community carers board is overseeing an initiative through primary care to support carers at home. 
A Qualitative Study to Identify the Needs of Familial Caregivers of Patients with Advanced Dementia Living at Home

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Background: Caring for patients with advanced dementia (AD) at home can be exhausting as they may have high physical and neuropsychiatric needs. Caregiver (CG) factors such as poor physical health and burden are strong predictors of institutionalization. At present, CG of AD patients residing at home have not been adequately studied.

Aims: This study aims to identify the needs of CGs of AD patients living at home.

Methods: 16 CGs of AD patients supported by a palliative homecare service participated in focus group discussions (FGD) where semi-structured questions were asked. The FGDs were audio recorded, transcribed verbatim and analysed thematically. Transcripts were read several times to create codes which were combined to develop common themes. Investigators reviewed the transcripts independently and applied the codes before meeting to check for inter-coder reliability. Discrepancies were identified and resolved with transcripts recoded when necessary.

Results: 4 main themes emerged from 4 FGDs: availability of resources, consolidation of information, policy changes, and increased public awareness. No new themes surfaced on the 4th session. Many CGs require resources to help look after their loved ones in the event of an emergency, such as an affordable help to stand in for care when they are sick or when non-familial caregiver leaves without notice. Currently, information is fragmented. CGs want a centralized database where they can obtain medical information, resources and assistance. Policy changes to increase subsidies for medications and eldercare leave may alleviate their burden. Public education on AD and its caregiving process may remove social stigma and increase understanding.

Conclusion: The FGDs provided insight into CGs’ needs which include available, accessible and affordable resources and understanding from the community about their role and contribution. Structural changes at the national level may be required to meet these needs.
Correlation between Patient’s Sleep Quality and Caregiver’s Sleep Quality and Psychological Well-being among Chinese Advanced Cancer Patients Receiving Palliative Care – PACSSIVE-3

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Background: Poor sleep quality is common among advanced cancer patients receiving palliative care, however, its impact on caregivers’ sleep quality and psychological well-being is unknown.

Method: This is a subgroup analysis of a prospective cross-sectional study involving advanced cancer patients and their family caregivers. Patients and caregivers completed the Cantonese version of Pittsburgh Sleep Quality Index (PSQI). Family caregivers also completed the Psychological Well-being Scale for Caregivers (PWS-C). Chi-square test and Fisher exact test were used to assess associations between two categorical variables. Spearman’s rank correlation were used to assess correlation between two scales. Bad Sleeper was defined as PSQI Global score 6 or greater.

Result: Among 52 family-caregiver dyads, 29 patients (55.8%) and 35 caregivers (67.3%) were female. PSQI were incomplete in 1 subject in each group. Forty patients and 28 caregivers were Bad Sleepers, and the median PSQI were 9 and 7 respectively. Among 50 dyads with PSQI completed for both parties, patient’s PSQI global score was positively correlated with caregiver’s PSQI global score (r=0.454, p=0.001). Patient’s sleep quality was significantly dependent with caregiver’s sleep quality (Fisher exact test, p=0.006). Patient’s PSQI global score was not correlated with caregiver PWS-C total, individual or subdomain score among 51 dyads with questionnaires completed. Patient’s sleep quality was independent with caregiver psychological distress. However, among caregivers who were children of patients (n=27), patient’s PSQI score was negatively correlated with caregiver perceived ability to share feeling (r=-0.430, p=0.028) and PWS-C Social Support subdomain score (r=-0.422, p=0.032).

Conclusion: Patient’s and caregiver’s sleep quality were highly correlated. The poorer the patient’s sleep quality, the higher the caregiver’s distress in share feeling and social support if they were patient’s child.
How Much Care Do Older Patients Get Outside the Formal Health and Social Care for the Last Three Months of Life?: A Mortality Follow Back Study in 3 Countries

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Background: Families and friends often provide informal care but this is rarely quantified.

Aim: To determine and compare the formal and informal care used in the last three months of life by elderly patients who had accessed specialist palliative care in three countries.

Design: Mortality follow-back survey

Setting: 3 countries: UK (London), Ireland (Dublin) and USA (New York City and San Francisco)

Data collection: Postal survey using self-completion questionnaires including the Client Services Receipt Inventory, sent to bereaved caregivers of patients aged ≥65 who accessed specialist palliative, plus extraction of patient record data.

Method: Care costs (formal and unpaid) were calculated, combining service use and unit costs in each country. Lost productivity was measured by the proportion of carers who had stopped/reduced work and by the days off work for 3 months before and after patient’s death.

Results: 721 questionnaires were returned. Patients were: 53% women; mean age 79.9; 46% with cancer; 68% living with someone else; and mean number of carer 2.7. Weekly total hours of informal care varied by country (e.g. 133 in USA versus 148 in UK), but composition was similar. 29% of carers stopped/reduced work by 20 days before and 16 days after death. Substantial unpaid care costs per patient for 3 months were identified: for example, in London $21,843, $23,334 and $16,025 in UK, Ireland and USA, respectively.

Conclusions: Informal care was substantial and varied across the countries. Unpaid carers often reduced or stopped working and this also adds to societal costs. Future economic studies should measure informal care costs.
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Post-discharge Impact on Caregivers of Cancer Patients Move to Palliative Care Units

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Background: The management of terminal cancer inpatients should include an evaluation of several factors: patient’s wishes, status performance, prognosis, family support. Moreover, primary caregivers (PC) background is needed to be considered when transfer from general hospital to palliative medium-long term care settings (MSPCU) is proposed.

Objectives: The study aimed to analyze the post-discharge impact on PC of cancer patients moved to different MSPCU.

Methods: A prospective, multicenter study was performed by Palliative Care Teams in four Spanish University Hospitals from 05/07/13 to 10/27/14 as a part of a multidimensional study about the effectiveness of cancer patient transfer to MSPCU in Comunidad Autónoma de Madrid (CAM). An anonymous questionnaire of 10 multiple choice items was given to PC at the date of transfer and they were asked to complete it at the end of the stay in the MSPCU and return it by mail. Items evaluated included: agreement with the transfer and timing, satisfaction with medical and nursing care, comfort facilities, single room accommodation availability, home to MSPCU distance and overall satisfaction with MSPCU.

Results: A total of 67/132 (50,8%) PC completed baseline questionnaires. This study revealed that 22,4% of PC were unsatisfied with transfer timing. However, 85,1% were in agreement with it and satisfaction with medical (83,6%) and nursing (85,1%) care compared to the hospital, distance to their home (92,6%) and comfort (88,1%) were high. Only 50,7% of patients could have single room accommodation in MSPCU.

Conclusions: In conclusion we consider that in CAM currently PC’s perception supports the management of Palliative Care Teams in terminal cancer patients transfer to Medium-stay Palliative Care Units.

Funding: Instituto Ramón y Cajal de Investigación sanitaria (IRYCS)
Financial Implications of Informal Caregiving for Patients and Families in Palliative Care: A Research Priority Set by Patients and Families through the Palliative and End of Life Care Priority Setting Partnership (PeolcPSP); A National Survey

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Background: Less than 7% of total spent on cancer research is spent for cancer-related Palliative Care and even less is spent for non-cancer conditions. A Palliative and End of life Care Priority Setting Partnership (PeolcPSP) set up by Marie Curie, conducted a national survey, asking patients, carers and clinicians to set research priorities for palliative and end-of-life care. Financial implications of informal caregiving was one of the emergent themes.

Methods: A supplementary qualitative analysis of the free text data from the Palliative and End of Life care Priority Setting Partnership' national survey was performed by focussing on the emergent theme of financial costs of informal caregiving in palliative care.

Findings: They public survey received 1,403 responses. 118 participants (8.41%) provided free-text responses in relation to economic costs and financial support for patients and their families. Participants discussed the financial challenges in looking after a dying family member at home. They argued for a need of financial support for both patients and their families and discussed challenges of accessing the existing support. Equipment and facilities for patients’ homes, carer’s allowance, employment benefit, after death support, lack of guidance and co-ordination of financial resources, and issues of equity across diseases and geographical areas were the main concerns presented by all participants.

Conclusions: The participants confirmed a link between financial constraints and place of care and death, suggesting that palliative care at home is at least partially funded by the patient and the family and hence it might not be viable for deprived communities, or individuals who lack personal resources. Economic costs for the family can have a significant impact on the quality of care at the end of life, given the policy initiatives to move provision of palliative care from hospital to community settings.
Comparison of Care Use, Associated Costs and Carer’s Satisfaction in the Last Three Months of Life among Older People in Three Countries

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Background: Limited evidence exits on how older people are treated and cared for at the end of life, what types of resources and how much of them are used and quality of care.

Aim: To determine and compare the formal care used in the last three months of life by elderly patients who had accessed specialist palliative care in three countries and examine the relationship between care use and satisfaction.

Design: Mortality follow-back survey.

Setting: 3 countries: UK (London), Ireland (Dublin) and USA (New York City and San Francisco).

Data collection: Postal survey using self-completion questionnaires including the Client Services Receipt Inventory, questions on satisfaction, plus extraction of patient record data.

Method: Formal care costs were calculated. Satisfaction, measured by Likert scale, was translated into continuous value. We compared level of satisfaction by place of care (hospital, home, hospice, and care home) across countries along with one-way ANOVA test on country means.

Results: 721 questionnaires were returned. Patients were: 53% women; mean age 79.9; 46% with cancer; 68% living with someone else; and mean number of carer 2.7. Average costs of caring for an older patient for the last three months of life were $15,806 (UK), $32,153 (Ireland), and $33,811 (US). Palliative care, though narrowly defined, comprised roughly 1% of total costs. Overall, bereaved carers were satisfied with the services provided to patients, except the carers in USA with care at care homes.

Conclusions: Difference in care costs across the Atlantic lies in quantities of service use and intensity of care, i.e. more patients used care services more often or used more expensive care services for the last three months of life in USA and Ireland than UK. Carer’s satisfaction has the potential to be used as an indicator of quality of care in the future studies and needs more attention and measurement.
Family Involvement in End-of-Life Decisions: A Nationwide Mortality Followback Study

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**Background:** Almost half of all deaths in Flanders are preceded by potentially life-shortening end-of-life decisions (ELDs) such as limitation of treatment and intensified symptom alleviation. Involving family in these ELDs may positively influence multiple psychosocial aspects for both patients and their family members. To date, little is known about how often family is involved in ELDs.

**Aims:** To investigate the proportion of ELDs in which family was involved and to examine the characteristics of the patients and the decisions associated with family involvement.

**Methods:** A questionnaire survey was conducted in 2013 among physicians attending a large and representative sample of deaths (n = 6,188) in Flanders.

**Results:** Family was involved in 72.3% of all ELDs. In 30.2% of the ELDs that were not discussed with the patient, family was not involved either. In a palliative care unit (PCU), ELDs were discussed with family in 63.7% of cases. Family was more likely to be involved when ELDs were discussed with the patient (OR = 1.34, 95% CI = 1.00–1.79), when the ELD was made in an ICU as compared to at home (OR = 3.02, 95% CI = 1.74–5.21) or in a PCU (OR = 3.81, 95% CI = 1.91–7.61), and if specialized palliative care services were involved in the patient’s care (OR = 1.83, 95% CI = 1.40–2.38).

**Conclusion:** Involving family in end-of-life decision-making does not seem to be standard practice and appears to depend on where these decisions take place and whether specialized palliative care services are involved. Our findings suggest a need for more family-oriented approaches to end-of-life care in a variety of care settings.

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**Family Caregivers of Patients in Advanced Stage of COPD: Relationship between Objective and Subjective Measures of Emotional Wellbeing**

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**Introduction:** One of the main aims of the sanitary attention in end-of-life situations is to promote the wellbeing of the patient and their family. Limonero and Bayés (1995) defined wellbeing as “the global feeling of satisfaction or relief of the needs – physical, emotional, social and/or spiritual. Its main characteristic is its subjectivity, being the patient the one who assesses their own wellbeing and its temporal variability”. On the other hand, the measure of the cortisol levels in hair has been widely used in order to assess anxiety and stress, given the potential of this hormone as a biomarker of stress, and as a mean to support the subjective measures provided by self reports of perceived stress (Russell et al.; 2012).

**Objective:** To elucidate the relationship among the objective and subjective measures of global wellbeing and stress of family caregivers of patients with COPD in advanced stage of illness.

**Method:** Our study is cross-sectional, with a sample of 18 main family caregivers of patients with COPD in advanced stage of illness hospitalized. As a subjective measure of global wellbeing and stress it was used the Questionnaire of global wellbeing of Bayés et al. (1995), and as an objective measure of stress it was used the analysis of cortisol levels in hair of the main family caregiver.

**Results:** Our analysis shows a statistically significant positive correlation between the objective and the subjective measures of stress.

**Conclusions:** Our work provides useful data regarding the relationship between the perception of global wellbeing and the physiological measures of stress, also highlighting the importance of providing psychological support to the family of the patient with COPD in advanced stage of illness in order to reduce their high levels of stress and promote their wellbeing. This work has been funded by the Spanish Ministry of Economy and Competitiveness (PSI2014–51962-R). Ana Soto-Rubio is beneficiary of the Program VALi+d.
Supportive Interventions to Family Members Who Provide Care at Home to People in Need of Palliative Care: A Systematic Literature Review

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**Background:** Care for severely ill persons is emphasised to be carried out at home. Having a severely ill close family member in need of palliative care implies provision of informal care, with family carers’ need of receiving support in one’s own situation. Research overviews about support forms for family carers is sparse and has merely focused experience and context.

**Aim:** The aim was to identify and critically review research on supportive interventions to family members who provide palliative care at home. Research questions: Which type of support is given, by whom and when in relation to the patient’s illness-death trajectory?

**Methods:** Systematic literature searches with combinations of terms related to family members AND support AND chronic illness or palliative care in the databases PsychInfo, AcademicSearch, Cinahl, PubMed, SocIndex, Ageline, ASSIA, WoS, SwePub and Nursing & Allied Health for the period from XXX to June 2016. Studies on needs for support, experience of being a family member, and support targeting children or families with children were excluded.

**Result:** A total number of 66 studies, using both qualitative and quantitative designs, were included. A variety of supportive interventions were identified, from direct interventions such as support groups, to indirect support such as being involved in care provided by professional carers. Most of the support was given when the patient received palliative care at home, while a few focused death and bereavement support. Professionals provided a majority of interventions and consisted of individual support.

**Conclusion:** The interventions identified are reported with positive outcomes, but the level and type of evidence varies. Most of the interventions are reported with the general outline of the intervention and more details might be needed for successful implementations. Most studies come from UK, Australia and Canada. Minority groups are usually excluded.
Place of Death Does Not Determine the ‘Good Death’ for Rural Family Caregivers. An Ethnographic Study

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Background: Achieving one’s preferred place of death (PoD) is often considered within palliative care as a proxy for a ‘good death’. To date, most PoD studies are quantitative and reflect the urban view. In rural settings, relationships between place and one’s self are often stronger than for urbanites, so one would expect that rural people would view dying at home as a major feature of the ‘good death’.

Aim: To explore the concept of the ‘good death’ articulated by dying rural patients, their family caregivers (FCG) and clinicians (general practitioners and nurses) before, during and after the death.

Method: This was an ethnographic study using open ended interviews (one-off and repeated) with 11 rural (town and farm) patients with life limiting illnesses, 16 FCGs (providing care for 15 patients) and six clinicians in a rural region of New South Wales (Australia) over the course of the patients’ dying. Interviews were recorded, transcribed and analysed thematically.

Results: Most patients identified home as the preferred PoD over the course of their illness, yet 10/15 patients moved from their home for end-of-life care and so did not die in their original preferred PoD. For most patients and FCGs, this move from home did not have a negative effect on the quality of dying. The concepts of the ‘good death’ and PoD were narratively constructed by the FCGs after the death. For FCGs, the ‘good death’ reality was sometimes at odds with the notion of a ‘good death’ held by the patient. Terminal restlessness was distressing for FCGs especially within the constraints of rural resources.

Conclusion: Many views are held on the ‘good death’; however, avoiding a ‘bad death’ may be more significant for quality dying. The ‘good death’ can easily be romanticised and the importance of home overdetermined. While efforts to increase the rate of home deaths should be encouraged, PoD does not solely determine the ‘good death’ for rural patients and FCGs.
How to Support Teenagers who Are Losing a Parent to Cancer: Bereaved Young Adults’ Advice to Healthcare Professionals – A Nationwide Survey

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Background: The death of a parent to cancer is considered one of the most traumatic events a teenager can experience. Studies show that teenagers, from the time of diagnosis, are already extremely worried about the consequences of a parent’s cancer but tend to be left to manage this on their own.

Aim: This study aimed to explore young adults’ advice to health-care professionals on how to support teenagers who are losing a parent to cancer.

Methods: This study derives from a Swedish nationwide survey and uses a qualitative approach with a descriptive and interpretive design to obtain answers to an open-ended question concerning advice to health-care professionals. Of 851 eligible young adults who had lost a parent to cancer when they were 13–16 years old, 6–9 years earlier, 622 participated in this survey (response-rate: 73%). Of the 622 young adults, 481 responded to the open-ended question about advice to health-care professionals.

Results: From the pieces of advice provided, it can be concluded that teenagers wish to be seen and acknowledged during their parent’s illness, they want information in order to cope with the situation and prepare for the consequences of the parents illness, treatments and impending death. They emphasize the value of spending time with their ill parent and request tailored support.

Conclusion: This nationwide study contributes hands-on suggestions to health-care staff regarding attitudes, communication and support from the perspective of young adults who, in their teenage years, lost a parent to cancer. If health-care professionals take this manageable advice forward into practice and see each teenager, explain about the disease, its treatments and consequences, encourage teenagers to spend time with the ill parent, and recommend sources for support, teenagers may feel better supported during their parent’s illness.
“It’s a 24-7 Job”: Caregivers’ Perception and Experience of Caring for a Person with Advanced Heart Failure at End of Life

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Background: The prevalence of heart failure (HF) is increasing, with an increased demand and economic strain on HF and palliative care services. The burden of caring, however, often falls to the informal caregiver. Evidence indicates this can be challenging and so it is important to understand caregiver’s experience, in order to seek to address this.

Aim: To explore current and bereaved caregiver’s needs when caring for a loved one with HF at the end of life.

Methods: Semi-structured, face-to-face interviews were conducted with current caregivers (n=20) and bereaved caregivers (n=10). The interviews were transcribed verbatim. Thematic analysis was applied to identify core themes across both experiences. Three researchers verified final themes.

Results: The majority of current caregivers were female spouses, whilst bereaved carers had looked after a parent.

Five key themes were identified. The first three related to the context of the caregiving role, describing the experience as “24-7 care”, with their life being ruled by the condition and their experience likened to an emotional rollercoaster. Two main support needs were identified: the need for improved service provision and the need for information and emotional support.

Conclusions: Caregivers are caring for a loved one 24-7 and are often responsible for making the decision to seek medical assistance, when the patient’s health worsens, yet they lack information about the medical condition, are unsure when to seek help, how and who to contact. Caregivers caring for patients living with HF require additional support and the results from the present study add to the emerging research in this area.
Family Experiences of End-of-Life Care for People Using Alcohol and Drugs

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Family members, friends and carers (FMFCs) play a significant role in supporting people with life limiting illness. Those who have a relative with a substance use problem are likely to have experienced substantial levels of strain over many years, which may be further exacerbated as the relative approaches the end of their life.

This research aims to explore family members’ perspectives of end-of-life care for relatives with substance problems, the extent to which their own needs were met, and how these needs changed as their relative approached the end of their life.

This study comprises secondary thematic analysis of qualitative interviews with adults bereaved through substance use. Interviewees included parents, children, spouses, siblings, nieces and friends in England and Scotland. 23 adults described recognizable end-of-life care for their relative, whilst a further 73 offered additional insights into the end-of-life experience for this group of FMFCs and those who died.

Key findings are that FMFCs experienced extremely stressful lives over many years, stress which could be further exacerbated by the end-of-life experience. The challenges of serious alcohol/drug problems meant that opportunities for identification of end of life were often missed. This meant that conversations about this difficult time were absent or delayed, resulting in inadequate intervention and support by health and social care professionals. This added to the trauma and emotional distress endured by FMFCs – both when their loved one died and subsequently.

In a UK economic climate of serious cuts to health and social services, FMFCs will remain the primary source of support for relatives requiring end-of-life care. This research highlights the critical need for support for FMFCs of people with alcohol/other drug problems facing the end of their lives, and the need to improve the response of both substance use and palliative/end-of-life services in this regard.
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Assessing Families in Palliative Care: An Integrative Literature Review of Available Evaluation Tools

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Background: Families are major contributors in palliative care (PC), but often mask their dynamics and burden on self-report assessments. Understanding tools available to health care professionals, that assess the role family dynamics play, to design a care plan which helps caregivers, is vital. Furthermore, a high number of tools were developed and applied in PC, focusing on patient related outcomes, making it difficult for health professionals to demonstrate their support to family is systematic, effective and has high workload impact.

Aims: This study aims determine what evaluation tools were used with caregivers in PC, and if new ones were developed applicable by health professionals, helping determine how it impacts provision of care.

Methods: Following the publication of a systematic review of family related tools in PC (Hudson et al, 2010), an integrative literature search on online databases PubMed, Ebsco, b-on and RCAAP (open access scientific repository of Portugal) was undertaken, from 2010 to May 2016. MeSH (Medical Subject Headings) descriptors were: PC, caregivers, bereavement, terminal care, hospice, measures, instruments and family caregiver. Articles included were analyzed in a table regarding measurement tools, population studied and primary focus of application.

Results: After exclusion criteria, a total of 31 articles were left, referring to instruments applied, all by self-report. 78% reference pre-existing instruments and 22% mention new ones; of these, 8% reference an update of a preexisting instrument and the validation to other languages and specific PC contexts.

Conclusion: This integrative literature review demonstrates that no new measurement tools were developed for health care professional application, to gain insight into family dynamics. Demonstration of robust caregiver support interventions is needed, hence a possible study field, developing family complexity evaluation instruments in PC, applicable by health care professionals.
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Does Neoplasm Location Matters in Respect of Caregiver Burden? A Prospective Cohort Study in Advanced Cancer Patients

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Background: Caregiver burden increases patients and relatives suffering. Few research has been made about factors related to it, including clinical or biographical.

Aim: To analyse the impact of neoplasm location and other factors on caregiver burden, measured by Zarit Scale.

Methods: A prospective cohort study was developed in a Palliative Care Unit for advanced cancer patients. Inclusion criteria: older 18 years with advanced cancer diagnosis, with a recognizable caregiver, who signed an informed consent. Variables of both patient and caregiver were collected, including biographical items and clinical. The overload was defined by more than 46 or 15 points in Zarit Scale of 22 items (Z₂₂) or 7 items (Z₇) respectively. We also registered and 0–10 scale for overload. Caregiver’s HADS was registered, with more than 10 points in subscales and 16 points in overall punctuation as breakpoints of anxiety or depression.

Results: 38/65 cases were included (58%). 75 and 58 years old were mean ages for patients and caregivers (50% sons or daughters), with digestive location as more often. Most of caregivers worked also out of home, with 58% caring more than 6 months. Means: Z₂₂=46 (DS=15); Z₇=16 (DS=6). Digestive location showed less burden in Z₂₂, Z₇ and 0–10 scale (p=0.048), and lung location was associated with higher HADS-A scores. Patients with delirium, mental health diseases or clinical instability were associated with higher Z₂₂ scores (p< 0.05). Younger caregivers, or patients with cognitive impairment were related to higher scores, almost significant (p values near 0.05). In those with Z₂₂>46, HADS-A and overall punctuation were higher (p=0.006 and p=0.014).

Conclusion: These results suggest that neoplasm location and other clinical variables may be factors related to caregiver burden. And reinforces the association between caregiver burden and mental caregiver’s health (great impact in HADS scores). More research is needed to try to identify better a risk population.
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Informal Caregivers’ Role: A Challenge to Palliative Care

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Aim of the goal: In the region of Catalonia, the Health Department polices have been directed to provided support an care at home in End of life. Palliative Care Domiciliary teams (PADES) provide care and support at home to patients in End of Life and to their families. Recent studies on the informal caregivers profile in Spain and Catalonia reveal new needs to address patients care at home. Informal caregivers, current and future profile needs to be understood in order to readjust care and psychosocial support policies.

Objectives:
- Identify key features of the informal caregivers’ profile
- Assess needs and resources to strengthen the informal caregivers’ role at home.

Methods: Cross-sectional descriptive study aimed at general population, with ad hoc web questionnaire, developed according to literature review. 4 groups of variables evaluated: resources and needs for the caregiver role to be developed, quality of life, care / access to palliative care, prospect.

Results: N=323. Mean Age= 49.76% informal caregivers. Essential Resources: 46% social, 29% economic. 20% specific training as caregiver. 25% Psycho-emotional support. 88% average life quality or lower. Caregiver motivation: 62% moral obligation. 68% relative with palliative needs. 33% Specific referral. 77% High Satisfaction. Prospect: 60% of caregivers think they will not be cared for at home; 63% because of work limitations.

Conclusion: In our cultural context, informal caregivers play this role mainly on moral grounds. To improve the quality of life perception of informal care givers, its necesary increase the training resources and psychosocial support.”Increasing referrals to palliative care teams would improve caregivers’ support. Improving planning and adjustment of resources to current and future needs is recommended.
Differences in Understanding the Patient between Family and Care Givers

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Background: The Swedish Register of Palliative Care (SRPC) started in 2005 and has now collected data of more than 400,000 deaths. This is mainly a retrospective register. 25 questions are answered by the staff just after a patient has died.

Since it is known that staff have a tendency to underestimate symptoms and relatives have a tendency to overestimate we wanted to compare their opinions.

Methods: A subset of the questions used for the staff were chosen. Staff were instructed to give one log in to a representative for the relatives to a webform with the questions. One log in per patient meaning that like members of the staff have to unite on how to answer also relatives have to unite their answers. During the development of this method focus groups taught us that most relatives liked this way of evaluating care and that there should be some time between date of death and being asked to fill in the form. The forms were then connected. The first analysis is made by comparing whether the answers are the same or disagree between family and care givers.

Results: 72 web forms from this year (2016) were analyzed. In 91% of the development group and 92% of the 2016 group family and care givers agreed upon this being an expected death. The agreement was high (more than 65%) also according to iv or enteral tube feeding was used last day in life (83%), presence of pain last week in life (75%), dying with another human present in the same room (76%) and having a conversation between doctor and patient about focusing on End of life care (68%).

The agreement was low (50%) on pain relief good enough, presence of anxiety and presence of nausea.

Conclusion: Family and care givers seems to have the same opinion about obvious and practical things like having a conversation, getting an iv etc. They disagree more about the more difficult questions concerning presence of symptoms. This suggests a more systematic way to work with symptom assessment on a regular basis.
Comparative Study of Advanced Patients’ Relatives Emotional Response along the Life Cycle

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Objective: To Study the differences among advanced patients’ relatives in emotional response and adjustment along the life cycle.

Methods: Descriptive and Retrospective Study of first interviews made to patients’ relatives assisted by Psychosocial Team from the 1st January of 2014 to 31st of December of 2015. Statistical Analysis made with G-STAT Program.

Results: Our sample (n=752) was divided in five age groups. Teenagers (n=10), mean Age: 15.40 +/-5.40 years (12–20) had anxiety on admission mean 6.20 +/-2.69 (0–10), and emotional distress on admission mean 6.33 +/-2.29 (0–10). In Young adults (n=184), mean Age: 36.72 +/-5.78 years (21–44), had anxiety on admission mean 6.07 +/-2.3 (0–10) and emotional distress on admission mean 6.04 +/-2.33 (0–10). In Mature adults (n=343), with mean age: 54.82 +/-5.57 (45–64), were 5.83 +/-2.30 (0–10) anxiety and 5.84 +/-2.22 (0–10) emotional distress. Old age (n=175) with 71.13 +/-3.99 years (65–79), had 5.4651 +/-2.44 (0–10) in anxiety and 5.52 +/-2.23 (0–10) of distress. And Oldest Old (n=40), with 83.30 +/-2.93 years (80–102), had scores of: 5.51 +/-2.30 (0–10) and 5.50 +/-2.31 (0–10).

Most of relatives showed a moderate (46.74%) or good (41.81%) adjustment.

No significant differences was found in emotional response among the five age groups.

Conclusions: Our results show than the age of relatives is not an important factor in their emotional response and their adjustment capacity to the situation of advanced disease. The psychological vulnerability of youngest and oldest has not been proved in our sample.

Probably more Studies are necessary for discover risk factors in relationship with anxiety and distress in care givers at the end of life.
How Does Organisational Context and Staff Attitudes Impact on the Success of Implementing an Intervention to Identify and Address the Support Needs of Family Carers?

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Background: The Carer Support Needs Assessment Tool (CSNAT) intervention identifies and addresses family carer support needs towards end of life. Few studies have investigated how to successfully implement interventions within palliative care despite The Methods of Researching End of Life Care (MORECare) guidance recommending that implementation processes must form a more central part of palliative care research.

Aim: Investigate how organisational context and staff attitudes affect implementation of the CSNAT intervention in palliative care.

Methods: 36 UK palliative care services participated. Staff surveys administered prior to and six months post-implementation included a questionnaire to assess attitudes to the CSNAT and The Alberta Context Tool (ACT) to assess organisational context. Data on use of the CSNAT intervention were collected over six months to determine implementation success; services were classified as ‘high’ or ‘low’ adopters on this basis. Relationships between service characteristics, aggregate data on staff attitudes and organisational context, and level of adoption were analysed.

Results: 157/462 surveys were returned at baseline and 69/462 at six months. Level of adoption depended on service type. ‘High’ adopters had a higher ratio of intervention ‘champions’ to total staff numbers and higher scores for ACT ‘informal interactions’ (e.g. more discussions with colleagues about care), compared to ‘low’ adopters. Both groups had similarly positive attitudes to the CSNAT intervention pre-implementation. By six months attitudes for ‘low’ adopters were significantly more negative, but remained stable or improved for ‘high’ adopters.

Conclusions: An implementation strategy for the CSNAT intervention should be tailored to meet the needs of the individual service. Pre-implementation planning, including an assessment of the context and plans for on-going review to ensure staff remain motivated, is recommended.

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Patients’ Experiences of Care and Support at Home after their Family Members’ Participation in an Intervention during Palliative Care

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Background: Patients who receive palliative home care are in need of support from their family members who take on great responsibility related to caregiving but who often feel unprepared for the situation. An increasing number of interventions aimed at supporting family members in palliative care have been described and evaluated. It is not known whether and how these interventions affect the care or support provided to the patient and this has not been studied from the perspective of the patients themselves.

Aim: To explore patients’ experiences of care and support at home after their family members’ participation in a psycho-educational intervention during palliative care.

Methods: Interpretive description was used for analysis of interviews conducted with eleven patients. The study was a part of a larger project in which the intervention was tested in a randomised controlled trial and proved to be effective in increasing family members’ feelings of preparedness and competence for caregiving.

Findings: The findings clearly point out the significance of supporting family members because the intervention also was beneficial for patients. Patients experienced that their needs were better met and that their family members became more confident at home without risking their own health. Patients felt relieved when their family member was given the opportunity to talk with others in the same situation and hoped that the intervention would contribute to a more honest communication between them and their family member. Further, it was of great importance to the patients that their family members got the attention and were supported by the healthcare professionals. They felt that they themselves and their family member were recognised as a unit of care and that they both had legitimate need of guidance and help from healthcare professionals.

Conclusion: These findings show how an intervention targeted at family members during palliative home care also benefited the patients.
To Think the Unthinkable: Why Not Allow Relatives to Participate in after Death Care when Hospitalized Patients Die?

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Background and aims: As shown in the Greek tragedy Antigone, After Death Care (ADC) has been the relatives’ duty for ages. Nowadays, when patients die at hospital, most often, ADC is effected without their presence. Our research focuses on feasibility and impact of ADC with relatives (ADCWR).

Methods: Four phases are planned
Phase 1: a survey was sent to Palliative Care Units (PCU) nurses exploring their experiences and opinions on this topic.

Phase 2: a semi structured interview investigates feelings experienced by nurses fluent with ADCWR.

Phase 3: a prospective observational study in PCU with ADCWR experience will examine several ratios (proposal ADCWR/total death, accepted/proposed ADCWR) and factors influencing these ratios with multivariate analysis (impact of experience, occurring death number, workload, cultural/religious context...)

Phase 4: a qualitative study (Semi structured interviews) will analyse the relatives’ feelings induced by this experience involvement. The last question to them will be “And if it were to redo?”

Results:
Phase 1: questionnaire survey was send to 190 nurses from 7 PCU:
Responses 127 (67%)
Proposing ADCWR: Never 78 (61%); Exceptionally 39 (31%);
Often 10 (8%)
Have already received at least one request from relatives: 57 (45%)
Have interest for ADCWR idea: 79 (62%)

Phase 2: interviews 10 nurses practicing ADCWR:
Positives experiences 10/10
Have got personnel experience for his/her relatives 5/10
Positive feelings: “For relatives, last occasion to approach the lovely body. Cathartic & peaceful way to take conscience of the death”
Negative feelings: “Need a lot of time”.

Conclusion: Our four steps research aimed to demonstrate that ADCWR must be considered as a practice to encourage. It’s an unbelievable and unforgettable occurrence for nurses to allow relatives bathing and honouring their lovely deceased. At a half way point to this research we want to share our experience, helping altogether to think the unthinkable.
‘We Already Do Carer Assessment and Support’ – Where Is the Evidence?

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Background: As part of our hospice’s strategic review we identified a need to focus on carer support. Hospice clinicians saw carers’ needs assessment and support as part of their role. However limitations in current practice could result in crises and preventable levels of stress for both patient and carer.

Aim: To identify processes of carer assessment and support used pre and post implementation of the Carer Support Need Assessment (CSNAT) Approach in Ayrshire Hospice.

Methods: Three project leads (LC, JM, PB) used a 6 step project management model to guide implementation of the carer led CSNAT Approach. This included identifying existing practice of carer assessment at baseline and review of carer support recorded in a one month period before and after implementation of the CSNAT Approach. The baseline survey was conducted using survey monkey; descriptive statistics used to summarise the data. Hospice records of new referrals in June 2015 (pre-CSNAT) and June 2016 (post CSNAT) were audited for details of carers’ needs and support provided and extracted data summarised.

Results:
(1) Baseline survey: 76 clinicians completed (72% response rate), 68 (89%) said they assessed carers ‘regularly’ but none used a formal process of assessment. Of documented assessments, 69% were in patients’ notes. The most common support was referral on to another service; only 9 (15%) developed a separate action plan for the carer.

(2) Comparison of referral records: data extraction is ongoing. Results will be presented on support needs identified and supportive input provided at both time periods.

Conclusion: Findings indicate that prior to implementation of the CSNAT Approach, clinicians did not ‘already do’ holistic assessment; in practice support for carers was inconsistent and invisible. Implementation of the CSNAT approach has made the assessment of carers’ needs a priority, ensuring the assessment process is transparent and acknowledged and making the carers feel valued.
Using Innovative Distance Learning Approaches to Educate Informal Carers in Outpatient Palliative Care: Findings from a Proof of Concept Trial

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Background: Although we know that family carers often do not have adequate knowledge to enable them to feel confident fulfilling their role, face-to-face and group-based education have a number of recognised disadvantages. These approaches are predicated on carers attending a specialist palliative care unit (thereby leaving the person they care for), learning at a pace set by others and at a time/date controlled by others. Additionally, educational approaches are rarely explicit in their approach to learning.

Aims: To address the inherent inequities in education for informal palliative carers by developing innovative distance learning approaches, to enable learning at their preferred time, pace and location.

Methods: An unblinded one-arm trial with embedded qualitative feasibility and acceptability assessment. The intervention is based on a theoretical framework of self-efficacy theory, whereby the education seeks to impact carers’ belief in their ability to carry out and succeed in caring tasks and situations. Baseline and 6-week follow-up data were collected on four scales from carers (n=23), followed by qualitative interviews. Paired t-tests and thematic analysis and were applied to the outcome measures and qualitative data respectively.

Results: The educational materials on pain and nutrition/hydration will be presented, indicating the innovative pedagogy and androgogical style. Recruitment and retention rates will be reported, compared with published data on face-to-face group education for similar cohorts. The impact on self-efficacy outcome measures will be described, alongside reflections from interviewed carers and recruiting specialist palliative care staff to report the feasibility and acceptability of this approach.

Conclusion: Distance learning technologies and theories have untapped potential to reduce inequities for carers who do not live in urban centres or close to specialist palliative care units.
Is Empathy a Good Candidate Theory for Family Meetings in In-Patient Specialist Palliative Care? A Mixed-method Exploratory Study

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Background: Family meetings are increasingly being used within palliative care settings and are a recommended component of family support. Research on family meetings has to-date been a-theoretical, with assumptions that they operate to enhance communication between clinicians and patients/family members.

Aim: To examine relational empathy as an explanatory theoretical basis for positive outcomes from family meetings.

Methods: Mixed method study, comprising pre/post quantitative measures and qualitative interviews. The measures were the Clinical and Relational Empathy (CARE) Measure, a 10-item tool measuring relational empathy, and the 20-item Family Inventory of Need questionnaire. All adult family members of in-patients were invited to participate in the study. Fifteen family members of consecutive meetings were interviewed after the family meeting about their experience of its impact on perceived staff empathy. T-tests were applied to the quantitative data, and narrative analysis to the qualitative data.

Findings: Empathy is a helpful construct and candidate theory to consider in the conduct of family meetings. However, not all family meetings produce positive outcomes for families. Scenarios where there is pre-existing family conflict require a different approach to published guidelines. The interviews identified a number of important considerations in setting up and conducting meetings, such as preparing the family prior to the meeting, consideration of existing family conflict, and the significance of feeling heard.

Conclusion: This study contributes to theoretical understandings of family meetings; and as such an essential precursor to designing complex interventions which include such meetings. The findings contribute to facilitating clinicians to provide empathic support to patients and families.
Comparison of Lived Experience of Family Caregivers of Patients with Cancer with Those of Patients with Dementia in Indonesia

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**Background:** Dementia, even more than cancer, demands long-term care. In Indonesia, one of the Asian countries with a strong family and community bond, the family plays a major role in caregiving. However, although people in Indonesia are familiar with caregiving for their relative with cancer, dementia is still considered ‘a normal condition,’ getting little attention.

**Aim:** We aimed to compare the lived experiences of family caregivers of patient with cancer with those of family caregivers of persons with dementia (PWD) in Indonesia.

**Method:** A qualitative design was applied for the current study. In-depth interviews were conducted with family caregivers of patients with cancer and family caregivers of PWD in two outpatient clinics one of a tertiary hospital in Yogyakarta. A constant comparative method was applied to analyze data. Analysis took place with the help of Atlas.ti software.

**Results:** Thirteen family caregivers of patients with cancer were interviewed and twelve of PWD. Three themes were identified: beliefs on caregiving, problems with caregiving and dealing with issues. These themes present a framework of lived experience in caregiving. Most codes were applicable for both groups of family caregivers. However, only family caregiver of patients with cancer were concerned with the quality of the service, financial aspects and hiding emotions as well as diagnoses. Only family caregiver of PWD were concerned on managing the loss of their relationship.

**Conclusion:** Many commonalities and some differences were identified. The findings pointed out some strategies of family caregivers in Indonesia in looking after a relative with cancer or PWD, how they are struggling to care and managing to find some positive values on their personal life.
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Social Health of Family Caregivers of Patients with Cancer or Dementia

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Background: The social health of caregivers of patients with cancer or dementia is likely to be influenced by caregiving characteristics. Social health represents caregivers’ capabilities as related to the social and environmental context. This context and culture differs around the globe. However, most caregiving research focuses on Western countries. We used the opportunity to learn from the Indonesian culture in which care for ill family members is obligatory. The aim of our study was to explore the role of social health in the lived experience of family caregivers of cancer or dementia patients in Indonesia.

Methods: A qualitative design was used, in which data were collected by face to face in-depth interviews with family caregivers of patients with cancer or dementia in two outpatient clinics in Indonesia, as part of the CAPtAIN study [CAregiver PAlliative INdonesia]. A constant comparative method was applied to analyze data. Atlas.ti software was used.

Results: Thirteen family caregivers of patients with cancer and twelve of patients with dementia were interviewed. Six out of twelve categories found in the analysis were linked to the social health concept. These categories included hiding (e.g. hiding own emotions in front of the patient in order to prevent burdening the patient) and social support (sharing the caregiving tasks with other family members and making neighbors informal guards).

Conclusion: The data reflected the interconnection of family caregivers with the patient and other social network members during the caregiving process. The cultural Indonesian background, being one of strong family ties, might have influenced the lived experience.
Detection of Psychopathology in the Main Family Caregiver of Cancer Patients at the End of Life

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Introduction: To stand by the side of a beloved one who is in an advanced stage of illness is considered one of the most stressing events in life. People in this situation frequently present symptoms of distress, such as anxiety, sadness, recurrent thoughts; and physical symptoms such as muscular distress, digestive problems, sexual dysfunction, and sleep disorders. These symptoms might be normal adaptive responses to the situation of lost that the family caregiver is going through. Nevertheless, it is important to do an adequate follow up of the clinical symptoms that the family caregiver present in order to assess the risk of psychopathological complications (in average, 10–20% of family caregivers are in risk of developing a clinically significant psychopathology).

Objective: The main aim of this study is to identify the presence of psychopathological symptoms in the main family caregiver of patients in advanced stage of cancer.

Method: Our study is cross-sectional, with a sample of 28 main family caregivers of cancer patients in end-of-life stage hospitalized. Data was collected using the short version of the Symptom Assessment Scale (SA-45).

Results: Our data point at the presence of clinically significant symptoms of emotional distress in the main family caregiver of oncological patients at the end-of-life stage, specially in the somatization, depression and anxiety dimensions of the scale, and the global score of psychopathological symptoms.

Conclusions: Our results provide useful data regarding the psychopathological symptoms experienced by the family caregivers of oncological patients at the end of life, highlighting the need of implementation of psychopathology prevention programs and interventions aiming to promote the psychological wellbeing of this population.

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How to Help Children Coping the Other Parents Death?

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The aim of this intervention was to find a meaningful way to support families with their children at the situation where the other parent had fallen ill with an incurable cancer. It changes the life of the whole family (Anttonen 2016). Despite the good patient care it is not clear, how family members participate in the process. Especially talking with parents about their children is a challenging task (Rauch & Muriel 2003). Still, it is important to ask the patient, if there are children as family members. There is evidence that if the patient’s situation traumatizes the children’s normal growth, it may increase their need for psychiatric care (Niemelä 2012).

Method: The Finnish Association for Mental Health has developed a two phase intervention “Let’s talk about Children” (LT) including 1) LT-discussion and 2) LT-networking. It takes only little time in the clinical practice to assess in the present situation, how to strengthen the protective factors in child’s everyday life. The intervention is used in daycare, schools, and now in palliative care.

Educational intervention: The Hospice Terhokoti trained 23 nurses to use LT-intervention in 2015. Three days education was given to learn a method, how to strengthen the parents to discuss with their children about the current situation and carry them on when they understand the sickness and upcoming death. Between the education days nurses trained the method in a real situation. They introduced the method to the parents and gave them time to take a closer look before making the decision, whether to take part in it or not. If parents found this as a useful procedure, conversation started. At the moment 123 families has taken part in the LT-intervention.

Conclusion: This method seems to relieve tension between family members and increase the opportunities to support each other and grieve together. Pilot research is needed to evaluate, how permanent the findings are in this context.
Caring during Serious Illness
http://CaringDuringSeriousIllness.com

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Aim: Patients who live with serious illness (and their family members) will typically need to make a number of important decisions about the kinds of medical treatment that is provided as the patient approaches the end of life. Unfortunately, patients and their family members are often left to make decisions in crisis situations, and with little information. This website was developed to provide patients and their loved ones with advice about these decisions, offered by clinical advisors whose unique perspectives derive from devoting their professional lives to caring for patients with serious illness.

Design: Video interviews were conducted with doctors and nurses who specialize in hospice and palliative care, and spiritual caregivers who provide support for patients and families.

Results: Fourteen in-depth interviews were conducted with specialist in end-of-life care. Interviews were edited down into 113 video clips on the following topics:

Decision-making:
- Caregiver preferences (what do caregivers want for themselves at the end of life)
- Changing course from cure to care
- Denial
- Family roles

- Symptom management
- Resolving family conflict

Rescue medicine: Costs and benefits:
- CPR
- ANH
- Mechanical ventilation

Care options:
- Palliative care
- Hospice
- Spiritual care
- Bereavement support

The process:
- Setting priorities for care
- The dying process: What to expect

Training/policy: (for doctors and nurses)
- How to have THE Conversation
- Improving training
- System reform

Conclusion / lessons learned: Caregivers talked passionately about the value in focusing on care and quality-of-life while setting limits on medical interventions as the end-of-life draws near. The importance of patient-centered goal-setting to guide end-of-life care was emphasized.
Family Carers’ Perspectives on Palliative Home Care – A Phase Model

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Background: Family carers play a key role in palliative home care for persons with advanced cancer. Research has shown numerous burdens and strains of family caregiving, nevertheless families are dealing with terminal illness at home day-to-day. There is limited evidence on how carers experience home care of a palliative patient over time.

Aim: The aim of the study was to identify and describe family carers’ experiences and self-management strategies in palliative home care in the course of time.

Method: The study employs a qualitative longitudinal design. Data collection consisted of serial in-depth interviews with family carers during ongoing palliative home care and after the patient’s death, applying a purposive sampling strategy. Finally, a total of 29 interviews and field notes provided data for analysis and comparison of 11 trajectories. The analysis was subject to case reconstruction methodology.

Results: From the perspective of family carers, palliative home care is an unstable and unpredictable process. We developed a phase model with six different phases referring to the degree of stability within the trajectory: crisis situation, re-stabilization, stable, unstable, dying, and transition to grief. The experience of instability results in uncertainty. The aim of the family carers is to maintain control in this dynamic process and to remain capable to act. Their strategies include taking on responsibility, becoming experts in medical aspects, creating daily routines and balancing family relationships. The effects of nursing interventions are also described in this process.

Conclusion: The phase model can help to understand the dynamics of palliative home care from the perspective of family carers. Each phase encompasses specific challenges and demands different tasks. Nursing interventions should focus on family carers’ efforts for control and provide flexible support.
Importance of Talking to Dying Patients: A Survey of Bereaved Family Members

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Background: Family members feel helpless when facing a dying patient. Some caregivers encourage them to talk to the patient even as the patient loses consciousness. They explain that the patient can hear till the end; this explanation is given to make the family realize that they are not helpless, but that they can indeed do something for the patient by talking to them.

Aims: Although patients tend to respond to talking, the literature on this subject is sparse. This survey analyzed whether talking to a dying patient could help improve caregivers’ interaction with families and caregivers’ awareness.

Methods: The subjects were 142 patients who were attended by the author and died as inpatients in 2013–2015. The questionnaire was mailed to bereaved family members. Problem cases and cases with inadequate information on bereaved family members were excluded. The questionnaire was anonymous and patient information was protected.

Results: Responses were obtained from 60 patients’ family members (42.3%). In all, 80% of respondents recognized that the sense of hearing remained despite declining consciousness and that talking is important. The most frequent source of this information was the ward nursing staff (45.8%), followed by family and relatives (35.4%). A total of 89.8% of families actually talked to the patient; in 69.8% of cases, the family sensed some response; 96.6% of families wanted to believe that their voices were heard; 93.2% of them expressed the desire to be talked to if they were in the same situation; and 96.6% said they wanted to instruct their families and friends to talk to them in that situation.

Conclusion: Though 69.8% of patients responded to talking, this could not be considered as an entirely physiological response. The caregivers need to believe in the possibility that hearing does actually remain and nursing plays a critical role in talking. Explaining the importance of talking using specific numbers and raising nurse awareness is crucial.
Satisfaction and Self-care: A Logotherapeutic Intervention to Care for the Caregiver

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**Background:** Formal caregivers in palliative care (PC) are exposed to situations that may affect their health and their personal and professional development. This in turn, affects the people they care for and their families.

**Aim:** This study analyzed the effect of an 8-week psycho-educational logotherapeutic group intervention to promote caregivers’ satisfaction and self-care and to prevent or decrease their compassion fatigue.

**Methods:** This study was a quasi-experimental pretest - post-test with waiting list control group design that took place in Quito, Ecuador, from September 2016 to January 2017. Follow-ups will be made up to 9 months. 88 formal caregivers of different institutions participated voluntarily and were divided into experimental or control groups depending on each institution’s time convenience. The intervention had a total of 8 1-hour sessions (once a week for a period of 8 weeks).

**Results:** Partial results show a change in resiliency characteristics, professional quality of life, job engagement, perceived stress, cognitive-emotional regulation, and general health status. The first main statistical analysis will finish in February 2017. Descriptive, correlational, and t-test analyses will be done using SPSS 23 to measure the differences between and within groups.

**Conclusion:** This intervention might be an effective strategy to care for formal caregivers in PC, promote their satisfaction and decrease their fatigue.

**Discussion:** Programs to care for formal caregivers should take place not only for people already working in PC, but also into undergraduate and graduate training. This study might have other practical applications in future research in the medical, clinical and counseling fields inside and outside PC.
From Hospital to Home: Supporting Family Caregivers at End of Life

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Background: The work undertaken by family during discharge to home/nursing home for end of life (EoL) care can make or break the sustainability of discharge and subsequent quality of care. Whilst there is good evidence about family caregivers’ needs and how best to support their caregiving after discharge, less attention is given to their support needs during discharge.

Aim: To implement best evidence to support family members’ EoL discharge work. The study will design and assess the usability of a brief supportive intervention for family caregivers and construct a service model to support implementation in hospital services.

Methods: The study design is guided by Normalization Process Theory (NPT), a rigorously tested sociological implementation theory, using Participatory Learning and Action (PLA) methodology. Each PLA cycle addresses a phase of NPT implementation. This paper focuses on the first two cycles, the theoretical and clinical modelling of a brief intervention. Using the active ingredients of tested support interventions, identified from analysis of systematic reviews and meta-analysis of support for caregivers in palliative care, the intervention was modelled theoretically on Family Sense of Coherence (FSoC), and clinically for contextual suitability. We worked with experienced palliative care practitioners from three acute NHS hospital settings.

Results: The intervention theorises that supporting family members in their discharge work influences family resilience after discharge. The intervention consists of conversational prompts addressing meaningfulness, comprehensibility and manageability, the conceptual components of FSoC. Clinical modelling suggests the intervention can be integrated into everyday practice.

Conclusion: The next two cycles of implementation will systematically assess the use and acceptability of the intervention through qualitative evaluations with practitioners and family members who have engaged in the intervention.
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**Weekend Plan**

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**Background:** Weekend is the time when there are more relatives at home, and the primary home care team does not provide cover. It is the ideal period for educate family after the hospital discharge. And is when the patients and family can feel overwhelmed.

**Aim:** To train and help relatives and carers over the weekend in their homes.

To reduce anxiety when faced with queries which can be easily resolved at home, over the phone or using WhatsApp. Prevent visits to the emergency department during the weekend.

**Design:** At weekends, the nurse from the hospital support team goes to the homes of patients who were discharged during that week, and to the homes of the most fragile patients who were discharged in previous weeks. Monitors the situation at home.

Provides training for relatives and carers. Administers medication if necessary. Contacts the palliative care doctor by phone if necessary. Has a mobile phone with data to resolve queries.

**Results:** 212 patients were visited from January-October 2016. 322 telephone interventions (calls or WhatsApp), independent of the scheduled visits. Compared with the same period the previous year:

- Number of readmissions reduced by 48%.
- Number of readmissions at weekends reduced by 56%.
- Decrease of visits to the accident and emergency department during the weekend of 62%.
- 28% more people died at home compared to the previous year. Families expressed great satisfaction. Primary care team highly satisfied as a result of the coordination.

**Conclusion:** The weekend is the ideal time to train families and carers at home. New technology is introduced, using WhatsApp to clarify doubts over the weekend.

Resources are optimised, reducing the number of readmissions and people attending at emergency department. This training enables more people to have the choice of dying at home. The nurse from the hospital support team who dealt with the patient during admission is the ideal person to carry out this continuity of care.
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Needs of Families in Perinatal Palliative Care and Proposing a Model Training Questionnaire

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Introduction: Perinatal palliative care is a biopsychosocial and spiritual approach to sustaining and improving the quality of life of patients and families facing the problems associated with limiting and / or life-threatening diseases that start in the context of the perinatally, in a broad sense, even when the disease and / or death occurring later.

Objectives:
A) To describe the family’s needs and coping resources.
B) To develop a model of questionnaire for interviewing families.

Method: A descriptive review of our records over a five-year period.

Results: The records of 379 families were reviewed (use relative frequency) and here de most frequent results are displayng.
A) - NEEDS OBSERVATION:
a) PHYSICAL: Discrepancy between resources and basic needs.
b) EMOTIONAL: WOMAN: Feelings of guilt, anxiety, instability, differences with the couple, tendency to exclude other members of the family, self-esteem disorder. MAN: anger and difficulty expressing feelings.
d) SPIRITUAL: Rethinking beliefs, search for meaning, mother fulfill project, achieve transcendence of child.
e) SOCIAL: ignore resources avaible.

- COPING RESOURCES OBSERVATION:
a) POSITIVE: family ties, social networks, empathic nursing, adequacy of information and palliative care.
b) NEGATIVES: lack of family ties; previous unresolved grief and / or prior psychopathology.

B) DEVELOPMENT OF A MODEL OF TRAINING QUESTIONNAIRE: each group of questions investigate a different needs or coping resources.

Conclusions: The needs of the families proved to be complex.
Based on these observations, the authors proposed a training questionnaire.
“It Is What It Is”: How Informal Carers Experience Providing Bladder and Bowel Care to Palliative Patients Compared with Palliative Community Nursing Staffs’ Perception of that Experience: A Qualitative Two-phase Study

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Background: Around 90% of palliative patients spend their final year in the community. An estimated 55% of their care needs are provided by informal carers (carers). One element is bladder and bowel care (B&BC) which most palliative patients require at some point. However, B&BC can be difficult for patients and carers and there is a paucity of research about carers providing it.

Aims: To explore carer’s experiences of providing B&BC to palliative patients and how they make sense and meaning of their experiences. The views of palliative community nursing staff were explored to facilitate a deeper understanding of the phenomena.

Method: A two-phase qualitative design:
Phase one: Interpretative phenomenological analysis of semi-structured interviews with carers purposively selected from the community service of a large, London hospice.
Phase two: Thematic analysis (Braun and Clarke), of a focus group of nurses selected from the same study site. Predefined criteria ensured sample breadth.

Results:
Phase one: Five interviews with mothers of terminally ill daughters were analysed. One overarching theme, It is what it is, and three superordinate themes emerged: Whatever my daughter needs, Mum knows best, and Coping with caring.
Phase two: Six participants attended. Three themes emerged: It’s not normal, B&BC is a huge challenge, and Even for us it’s not simple.

Differences were identified between the views of carers and nurses. Nurses saw B&BC as abnormal and best when carried out by professionals. While carers agreed B&BC was challenging at times, situated within the context of their daughter’s disease, it was not a major concern. Instead it engendered feelings of closeness and the opportunity to provide better care than most felt professionals could.

Conclusion: This study is the first to explore the experiences of carers providing B&BC to palliative patients. These findings have implications for how nurses see the carer role and the support and guidance they offer.
Facilitating Successful Implementation of a Person-centred Intervention for Carer Assessment and Support: The Key Role of ‘Champions’

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**Background:** The Carer Support Needs Assessment Tool (CSNAT) intervention identifies and addresses family carer support needs towards end of life. This person-centred approach involves a change in practice from a practitioner- to carer-led assessment process. The Promoting Action on Research Implementation in Health Services (PARIHS) framework was used to guide development of an implementation strategy for the CSNAT intervention in which internal facilitation by intervention champions is key.

**Aims:** Investigate what components of facilitation are needed to successfully implement the CSNAT intervention across palliative/end-of-life care.

**Methods:** Qualitative: Interviews three and six months post-CSNAT implementation with 38 practitioners acting as intervention champions (internal facilitation) in 32 services. Researcher field notes collected from teleconference support sessions with champions (external facilitation).

**Results:** Successful implementation was associated with support from senior management from the outset and a teamwork approach to facilitation in which the ‘lead’ champion had a leadership role in the service e.g. team manager. Champions had higher levels of success if they (i) had good communication skills and authority to make changes, (ii) presented a clear rationale to why a change in practice was needed, providing legitimacy for the practice change, (iii) carried out on-going review of progress and made changes to overcome any identified barriers.

Organisational changes e.g. budget cuts, and a culture focused on the patient hindered facilitation efforts. In addition, the need to establish a new carer record placed demands on champions.

**Conclusions:** Facilitation needs to be a team effort and the selection of champions requires careful consideration. To help ensure implementation success, champions require protected time for pre-implementation planning and for the on-going audit and review of progress.

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Translation and Pilot-testing of the Norwegian Translation of the Carer Support Needs Assessment Tool (CSNAT)

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Background: The Carer Support Needs Assessment Tool (CSNAT) is a 14-item self-report tool, for assessment of carers’ support needs in end-of-life research and practice. The tool focuses on family carers’ (hereafter: carers) own personal support and their needs to enable provision of care for the patient.

Aim: To translate and pilot-test the Norwegian CSNAT translation.

Method: Forward and backward translation and pilot-testing were done according to the EORTC guidelines. Pilot-testing was done in 2015. Carers were approached by research assistants and asked to complete CSNAT prior to a structured interview, asking if any item was difficult, confusing or upsetting, if they would have worded it differently, and about relevance. Free comments were encouraged.

Results: Eighteen carers of advanced cancer patients (mean age 61, range 36–91, 6 males, 12 females) participated; 11 partners, 4 adult children >18 and 3 girl-friend/friend/sibling. Fifteen carers (83%) gave spontaneous comments in favor of using CSNAT, perceived relevance and simplicity with a few exceptions. Some reported questions to become more relevant when the illness progressed. One respondent found the introduction somewhat long. Two respondents commented that question 3 (Q3) lacked precision since “medicines” are mentioned as an example of the patient’s symptoms, but no other aspects i.e. emotions. Several respondents commented that the Norwegian words used for “belief”, “spiritual” and “concerns” in Q10 “…your beliefs or spiritual concerns?” lacked clarity and precision. The results were discussed among interviewers and with G. Grande (CSNAT developer). It was decided not to change the wording with one exception; Q10, to make it less ambiguous.

Conclusion: The Norwegian version of CSNAT proved relevant and easy to understand. One question was rephrased. CSNAT is now available for use in carers of advanced cancer patients.
Dying at Home or Not. Which Social Factors Influence on the Place of Death

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Background: Even if home is the preferred place of death among advanced cancer patients, data available shows that a growing number of those patients do not achieve this goal. Factors other than those related to diagnosis and symptoms are present and its identification play a crucial role when discussing the most appropriate place of death between patients, relatives and the palliative care team. The main objective of this study is to identify the social factors identified through an interview carried out by the social worker in a home care team.

Methods: Descriptive and retrospective study. We reviewed clinical files of all patients attended on 2015 by our home care team. Sociodemographic (patient and main career) and clinical data are evaluated. For the social evaluation we used the E-CAP (software used in the primary health system in Catalonia), to evaluate the social risk we used the TIRS scale and the ZARIT scale to assess caregiver’s burden.

Results: A total of 499 advanced cancer patients were followed-up by the home care team in 2015. 191 of them (38, 28%) were discharged because death. From those, 109 (56, 7%) died at home while 20 (10, 47%) patients required admission to a palliative care unit (PCU). All patients got a social evaluation; 70% of them presented social risk on the first evaluation while this risk was present in the 100% of patients that required admission to the PCU. Main factors detected were social burden in 90% and social isolation in 80% of the cases.

45% of patients finally admitted to the PCU expressed their desire to die at home, if possible.

Conclusions: The main social risk factor detected was main social burden. Social isolation and the lack of an effective career was the second.

A correct social evaluation can lead to detect those factors not related to the diagnosis or clinical symptoms and thus help to indicate the most appropriate place to look after advanced cancer patients in our area.
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Carers of Advanced Cancer Patients – Experiences, Needs and Suggestions for Improvement of Care

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Background: Caring for advanced cancer patients (ACPs) is associated with considerable burdens and has been reported to negatively affect family carers’ psychological and physical health, social life, and bereavement outcomes. In a rural district in Mid-Norway integrated cancer palliative care services have been developed and offered to patients and carers since 2012. The present study aimed to investigate how carers of ACPs experience these services, and how carers prefer health care providers (HCPs) to support them.

Method: Qualitative, semi-structured, individual interviews with adult carers of ACPs admitted to the cancer outpatient clinic in Orkdal (O) or to the cancer clinic at Trondheim University Hospital (T) were recorded, transcribed and analyzed using systematic text condensation. Two authors read and analyzed all interviews independently.

Results: Fourteen carers were interviewed, 11 in O, 3 in T; men 7, women 7; mean age 59. The carers were overall satisfied with the care offered by multiple professions. However, some report insufficient information about the severity of the illness. Lack of routines for family consultations and assessment of carer support needs was reported. Carers value HCPs having a personal relation to carers, are available and give clear information about the illness to adults and children. Carers value cancer nurses doing home visits, assessing patients’ and carers’ support needs and coordinating treatment and care. Carers want pastoral care, i.e. counseling in illness and bereavement for adults and children, but some did not access pastoral care due to lack of information.

Conclusion: Carers of ACPs report important support from HCPs, but the present study revealed that there is a lack of systematic care for and information to the carers. The findings may contribute to further development of the established cancer palliative care services for patients and carers both locally and nationally.
The Support In Brazil to the Elderly Caretaker of Elderly People under Palliative Care

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Introduction: Elderly patients under palliative care at their homes are frequently dependent, needing home care, often by caregivers that are also elderly, who need support.

Objective: To understand the instruments of support to the elderly caretaker of elderly patients under palliative care.

Method: A qualitative study, in which the participants were identified through the records of the elderly patients registered on the base of a public program for home care (PAD) in Salvador, Bahia, Brazil. The interviews were performed in the homes after the second visit, by means of semi-structured instrument, and the results analyzed through content analysis according to Bardin.

Results: Eight elderly caregivers participated of the research. Ages varied between 61 and 84 year, six were of the female gender, four were spouses, one ex-wife, two daughters and one son-in-law. Three exercised the role of main caregiver, having only the support of the PAD; three had, apart from the support of the PAD, the informal support of a housemaid; and two had the support of a professional caregiver. Five caregivers stated that they did not have any knowledge of having any health issues and the others revealed the existence and/or background of diseases such as breast cancer, arterial hypertension, osteoporosis and arthrosis. The categories for analysis were formed through these discourses. Formal aid as an instrument of support to the elderly caregiver; Religiosity and Informal support offered by the family to the elderly caregiver.

Conclusion: The elderly caregivers, despite receiving the visit of the program, feel a lack of support by the PAD, receiving assistance also from housemaids. They turn to religion to overcome the difficult routine, feel overburdened due to the situation of palliative care of their loved ones and to their limitations, requiring visibility and support.
Assessment of Knowledge of Relatives of Cancer Patients about Palliative Care

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Background: For patients with advanced chronic diseases, palliative care (PC) is a specialty that focuses on symptom management, psychological and spiritual support, providing the best possible quality of life for patients and their families, but very few people benefit from them.

Aims:
● Assess the prevalence of knowledge in caregivers about PC as a complementary discipline that relieves suffering and supports the best possible quality of life for patients with advanced oncological illness.
● Determine the relationship between the collected variables.
● Demonstrate the existence of differences regarding age, gender, previous information or experience.

Methods: Prospective cross-sectional study to assess knowledge about PC of relatives of patients with advanced cancer who accompanied them to the oncology consultation. A closed questionnaire was provided after signing informed consent, for a month, ensuring compliance with the inclusion criteria and none of exclusion.

The project was approved by the Ethical Investigation Committee. Data was analysed with SPSS.

Results: During the study, 36 caregivers agreed to take part in it. Higher participation was found for women (56%) with an average age of 52 ± 13 years old, predominantly spouse or offspring. The data showed that 39% had received previous information from healthcare staff and 50% knew someone that had benefit from PC. Caregivers with previous information knew that PC isn’t only for terminal or elder patients (0.015).

A high percentage did not believe that spiritual support is important (0.032). As caregivers with prior knowledge or contact with PC, up to a quarter of them believed that the objective of the PC was to cure patients.

CONCLUSION: There is an elevated prevalence of people without enough information about the existence or competences of PC. This might be affecting the number of requests for assessment and the actual effectiveness of the services. Information management should be an area of improvement for physicians.
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Leading an Intervention for Family Caregivers. A Part of Nursing in Palliative Care

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Background: Interventions that focus on supporting family caregivers in palliative care have increased over the last few years and many of them have been led by nurses. Previous research from group interventions in palliative care have demonstrated that professional leaders played an important role in how family caregivers experienced participating in the interventions. However, few studies have exclusively focused on the experience of leading interventions provided to family caregivers.

Aim: The aim of this paper was to explore nurses’ narratives about the role as group leader in a psycho-educational group intervention for family caregivers in specialized palliative home care.

Methods: The intervention consisted of three sessions that focused on the informational, emotional and practical needs of family caregivers. Eleven nurses from eight palliative care settings that delivered the intervention accepted to be interviewed about their experiences as group leaders. Data were analyzed with interpretive descriptive methodology.

Results: Three themes were identified in the analysis:
Embracing the leading role, Developing qualities as a group leader and Professional and personal development. It was generally considered positive that the intervention was nurse-led, as the nurses felt that they were most familiar with the family caregivers. Being a group leader was considered a new and challenging role that the nurses gradually grew into while they developed their qualities as leaders. The participants stressed that they achieved an increased repertoire in how to address the needs of family caregivers and a better confidence in their ability to give support in their regular work, with a greater mandate within the palliative care team as a whole.

Conclusion: Leading interventions may be considered something that could contribute to the development of the professional and personal skills of nurses in caring for people and families in need of palliative care.
Family Members’ Experiences of the End-of-Life Care Environments in Acute Care Settings – A Photo-elicitation Study

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Acute care hospitals are the place of death for many people, although they are not primarily organized for end-of-life (EoL) care. Research shows that the hospital environment is of importance for safety, communication and how stressful the experience may be. A less researched area is family members’ experiences of the environment during on-going EoL care in acute care hospitals; the aim of this study was to explore this.

This qualitative study is part of the research program “DöBra” in the research line “Space and place in end-of-life care”. We used photo-elicitation, an approach where participant produced photographs was used to stimulate a follow-up interview. Nine family members’ of patients in a palliative phase of a life threatening disease were purposefully recruited via acute hospitals and two units specializing in lung diseases. Participants took 3 pictures each of aspects of importance to them in the care environment. Data was analysed by interpretive description. In the presentation, we will show photographs to illustrate the findings.

Participants illustrated experiences related to sight and sound through photographs depicting furnishings, art, color, fabrics, light and technical devices. These were described as supporting or hindering family members’ feelings of safety, comfort and distress. Photos of patient rooms and public areas triggered discussions of space for privacy and social relations as important but not always possible in this context. Encounters with staff contributed to the atmosphere and ultimately the degree to which the environment was experienced as safe, supportive and hospitable. Aspects in the care environment were associated with feeling welcomed or in the way and could promote conversations, rest and wellbeing.

These findings point out important aspects of EoL environments in acute care hospitals, which have potential to both add to and diminish family members’ distress in a difficult life situation.
Ready for Use? Translation and Cultural Adaption of the CSNAT for German-speaking Countries

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Background: Although support for informal carers has been on the agenda for a long time, no specific tool in German language is available to assess informal carers’ needs in the palliative home care setting. The Carer Support Needs Assessment Tool (CSNAT) has been shown to be valid and effective in several studies. It represents a novel, carer-led approach to empower family carers to express and prioritise their support needs.

Aim: The aim of the study was to translate and culturally adapt the CSNAT for a German-speaking context and to assess comprehensibility and acceptability.

Method: Following ISPOR guidelines (Wild, 2005) and with support of professional translators, forward and backward translations were performed and discussed in a consensus meeting of the scientific team. Further steps included cognitive interviews (n=15) with current and bereaved carers in Germany, Austria and Switzerland, applying “think aloud” and prompting techniques. A second consensus meeting was informed by content analysis resulting in the first German version. Additional input was obtained from the CSNAT developers in the UK.

Results: A number of terms and grammar issues had to be adapted carefully after testing alternatives for some phrases. Two terms did not fit the Swiss context perfectly and were adapted. Upon request of the carers a comprehensible German name for the tool was searched. KOMMA, an acronym for “communication with carers” turned out to work best. The final version was found feasible and easy to understand in all three contexts.

Conclusion: The German CSNAT (KOMMA) was validated linguistically and culturally and is now ready for use to assess content validity and feasibility. For translations into other languages a team approach, including professional translators, is recommended, in close cooperation with the CSNAT’s developers in order to make sure that what is being translated is an accurate reflection of the original intention.
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Loading the Primary Caregiver of Pediatric Cancer Patients in the Cuban Institute of Oncology and Radiobiology

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Objective: To describe the sociodemographic and clinical variables and assess the burden of the primary caregiver of children and adolescents hospitalized in the service Oncopediatrics the National Institute of Oncology and Radiobiology of Cuba (INOR).

Materials and methods: exploratory, observational-descriptive study during January to December 2015 in the INOR. The universe consisted of all primary caregivers of pediatric patients who were admitted in the mentioned period, an intentional sample (248 caregivers) depending on the availability to participate in the investigation was taken. Summary measures for qualitative variables were used: absolute and relative frequencies and for evaluating the objective burden Zarit method was used. The analysis was performed with SPPS, version 21.0.

Results: there was a predominance of women with college degree education by caregivers. An intense overload mostly related to physical overload of carers in 89% was obtained.

Conclusions: Overloading may be closely related to both the impact of care, the complexity of the actions, time care, coping resources, physical and emotional state of the caregiver.

Keywords: caregiver burden, pediatric patients, cancer
In investing in family carers: A model for practice implementation of carer assessment and support within palliative care (plan, pilot, train, sustain).

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Background: The Carer Support Needs Assessment Tool (CSNAT) intervention ensures a person-centred approach to carer assessment and support within palliative care. In response to national and international demand, an online toolkit has been developed to provide palliative services with more accessible preparation and support for implementation of the CSNAT intervention.

Aims: To test the feasibility of an online implementation toolkit to assist services to plan, pilot, train and sustain a person-centred approach to carer assessment and support within palliative care.

Methods: The Plan, Pilot, Train, Sustain model has been developed from the on-going CSNAT research programme; based on feedback from 89 organisations using the CSNAT intervention. This model underpins the implementation toolkit developed within a multi-disciplinary team including expert input from practitioners and an online developer. The toolkit consists of two learning components: (i) to train practitioners in the person-centred approach used with the CSNAT and (ii) to assist services to plan, pilot and sustain implementation of the CSNAT intervention. Five services will be recruited in January 2017 to the feasibility study. Up to 20 practitioners will provide feedback on toolkit content and online user experience via an online survey and qualitative interviews.

Results: Feasibility results will be reported: how informative and useful the content is, and how suitable it is for use within existing resources of palliative care services (e.g. time to complete, IT resources). This will enable refinements to toolkit content and instructions.

Conclusions: Palliative services are under increasing pressure to assess and address family carers’ support needs. The implementation toolkit will provide organisations with accessible and structured guidance on how to implement evidence based comprehensive carer assessment and support and ensure embedding into practice.

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Patients and Relatives: Target of Treatment. Also in Palliative Sedation

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**Background:** Palliative sedation is a therapeutic maneuver used to control a refractory symptom. It is a highly complex clinical situation. It generates demands on relatives who need a specific attention owing to the clinical context.

**Methods:** Retrospective, descriptive study. Data collected of clinical records of patients who were sedated along a year in the Palliative Care Unit of Hospital Puerta del Mar of Cádiz. We analyzed in relatives the number of visits, anxiety degree and discomfort degree (quantitative scale from 0 to 10), adaptation (qualitative scale: excellent, good; moderate and poor). The main fears were also collected.

**Results:** Total 61 cases, eight of them could not conduct the interview. Average of visits 3.5. In 86% the score of anxiety degree was five or less. In 77% of cases the discomfort degree was five or less and in 90% the adaptation was good or moderate. The main fear was a poor control of symptoms (30%). Up to 35% did not show any problem with a good acceptance of the situation.

**Conclusions:** The clinical situation of palliative sedation needs a special attention with a higher number of visits to get better levels of anxiety, comfort and adaptation. The main fear communicated by relatives is an inadequate control of the symptoms.
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The Psychosocial and Economic Effects of Caring for Terminally Ill Patients: The Case of Hospice Africa Uganda

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Background: Care giving at the end of life can be a challenging and confronting experience. The responsibilities of care giving may include executing complex physical and mental tasks including financial planning, decision-making, emotional support and coordination of care.

Aim: To identify the psycho social and economic effects of caring for terminally ill patients attending Hospice Africa Uganda.

Methods: This was a cross sectional both qualitative and quantitative study. The source of data was restricted to care givers of terminally ill patients attending to Hospice Africa Uganda. Sampling was simple random and patients who were scheduled for review on any given day during the study period had their files randomly selected. The care givers whose patients had their files picked were invited to participate in this study.

Results: Results from this study showed that care taking had statistically significant effects on the psycho social well being of caretakers as shown by the p values (< 0.05). Particularly their relationship with God (p< 0.05), getting enough time to attend social gatherings (p< 0.05) and the care to their children (p< 0.05). Fatigue and exhaustion as a result of giving prolonged care to the terminally ill (p< 0.05) was as well reported.

Results also show that providing care for terminally ill patients had minimal effects on the economic livelihood of care givers. Care giving only had statistically significant influence on the changes in income of caregivers (p< 0.005), and the fact that caregivers could not find an alternative job alongside caring for the patient (p< 0.05).

Conclusion/ lessons learnt: Care giving has a statistically significant effect on the psycho social well being and economic livelihood of caregivers. This study recommended that caregivers and their families be given ongoing support to help them provide adequate care to the patient and family which should be initiated early in the disease trajectory.
The Impact of Family-centered Care in Reducing Stigma and Discrimination in the Management of HIV/AIDS in Children

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PASADA is a community-based health and social services agency providing holistic care to people infected and affected by HIV and AIDS. Services offered by PASADA include: Voluntary Counseling and Testing (VCT), Care and Treatment (C&T), Home-Based Palliative Care (HBC) and Support to Most Vulnerable Children.

Stigma has been one of the major barriers for HIV+ children in accessing medical care. Discrimination occurs when a distinction is made against a person that results in his or her being treated unfairly or unjustly on the basis of their belonging, or being perceived as belonging, to a particular group; this may worsen the stigma and lead to poor family support, denial, failure to disclose of HIV status, denial for social support, experience loneliness, depression and increased rate of HIV transmission.

A case study of an HIV positive male child aged 11 years old whose mother died from AIDS when he was 3 years old: his father abandoned him after discovering his HIV status. The child has been suffering from multiple skin infections, chest infections and generalized body weakness. Currently he is living with his grandmother.

Through Family-Centered Care which enabled the involvement of the whole family, care and treatment plans were established. These included: home visits, psycho-social support, return to schooling and enrollment in the antiretroviral therapy program.

Currently the child’s health has significantly improved; he has returned to school and has attended grieving sessions as part of psycho-social support.

Family-Centered Care plays a pivotal role in the management of children living with HIV and facing challenges of stigma and discrimination. It is easier to address the issue of stigma by involving the whole family.
What is “The Strength of Cancer Survivors to Get through Life”? Based on the Narratives of the Experienced Care Givers for Cancer Survivors

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Background: In recent year, cancer survivors due to the aging population in Japan are increasing. In Europe and the United States, there are consecutive supports for cancer survivors but they are not enough in Japan. Then, before we examine a support program for cancer survivors to live by their own strength, we must explain “the strength of cancer survivors to get through life”; the ability to live by own strength from when they newly diagnosed with cancer until they lead to the end of life, and the caring to support it.

Aims: To examine “the strength of cancer survivors to get through life” and the caring to support it.

Methods: We did the unstructured interview with four experienced care givers who are cancer survivors, at second step, and nine experienced care givers who are many type of occupation, and analyzed the data using the phenomenological methodology.

Results: We found out that “the strength of cancer survivors to get through life” was the process that contains three core elements, meaning for a change produced because of newly diagnosed with cancer, adaptation to the change, and growth as deciding a new their self and making self-advocacy possible. The medical professions and non-medical staffs have different way to support “the strength of cancer survivors to get through life”. In the case of medical professions, the relationship between care givers and cancer survivors is different by their occupation. The experienced care givers who are cancer survivors thought it is necessary for cancer survivors to live better.

Discussion and conclusion: These results suggest it is necessary that care givers who are multidisciplinary team which contains peer-support support “the strength of cancer survivors to get through life”. And we suggest that to support “the strength of cancer survivors to get through life”, the caring need to have a purpose not only to solve problem but to support for cancer survivors to live better.
Family Attitudes towards Wishes and Values of Patients with Chronic Conditions (PCC) and Patients with Advanced Chronic Conditions (PACC). End-of-Life Discussions

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Background: When the patient cannot communicate, family is central to decision-making at the end-of-life (EOL). Go Wish card game(GWG) is a tool developed to facilitate conversations about EOL.

Aims: To identify the wishes and values of PACC and PACC through conversation with family using GWG to talk about the EOL.

Methods: Patients’ family admitted to the in-patient unit of intermediate care and long-term care were recruited. Sociodemographic data were recorded. We asked relatives and physicians their projections of serious complications in the next 12 months. The GWG was used to speak about EOL. Relatives were asked about patient’s wishes in a EOL conversation. Families categorized these wishes as important or not important; after that we asked for the 10 most important. The utility and appropriateness of the interview were asked.

Results: 4 men and 15 women, average age was 59.47 ± 11.8. PACC (73.7%); PCC (26.3%). Couples 21.1%; Children 68.4% Brothers 5.3%, Others 5.3%. 42.1% of relatives would be surprised at complications in the next few months while 89.5% of physician’s wouldn’t be (p< 0.05). The ten wishes identified as most important by relatives were: to have my family with me (84.2%); to be free from pain (78.8%); not dying alone (63.2%); to have human touch (52.6%); not being a burden to my family (47.4%); to die at home (47.4%); to be able to know my family and Friends (47.4%); to maintain my dignity (47.4%); not being connected to machines (42.1%); to have close friends near (42.1%). The less common wishes identified were: to be able to talk about what scares me (94.7%); to take care of unfinished business with family and friend (89.5%). The interview was useful (89.5%) and appropriate (89.4%).

Conclusion: The relative’s perception of future complications was lower than the physician’s. To have my family with me and to be free from pain were most important for the patients. The GWG was useful and appropriate for the conversation about EOL.
Multiple Nation Originality, “A Challenge in Managing a Child with HIV/AIDS”

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There are a lot of Challenges in managing an HIV child with multi-nation originality. A child with multiple nationalities refers to an offspring of parents of different races.

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. So far in Tanzania, no documentation has been made showing challenges of managing HIV positive children with multi-national originality.

This paper discusses a case study of a 14years old child living with HIV AIDS with ‘three Nationalities’ (Chinese, Tanzanian and Kenyan). Both parents died with HIV/AIDS 11 years ago. He currently lives with a Kenyan grandmother. Late father and mother were Chinese and Tanzanian respectively.

Before enrolment in family centered care, he had history of recurrent infection, poor drug adherence (> 1month) and poor attachment. This was due to poor social relation of the grandmother to the Tanzanian relatives. The child has faced difficulties in tracing relative for support. Language barrier of the guardian has led into poor adherence to Medication and general health hygiene. Through family centred palliative care mode of service delivery, the issue of disclosure, proper attachment, adherence to drugs, nutrition and hygiene were addressed.

Within six months of intervention, the child has shown; improved adherence to medication, clinical presentation, good link with the family, academic improvement, reduced racial segregations, improved link with the community where the child has secured more assistance from the Tanzanian/Germany community organization.

Family centered care (FCC) is a teamwork program. You need to take heart in working with children with multiple problems. Involvement of the family and patient help them to be more responsible in taking care of the patient.
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Families, Care Givers

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Assessment is the prerequisite to effective care planning. Assessment of patients and family must take into account physical, psychological, social, spiritual and cultural needs. On identification of patient and needs, a plan of care can be drawn up by the inter-disciplinary team. Significant demands are being placed on the informal caregivers of chronically ill patients, including those suffering from cancer. Health care professionals need to be aware of these demands, and they need effective tools to assess the impact these demands place on the caregivers.

Caregivers completed a 28-item semi-structured questionnaire developed by the researchers. Demographic information and caregiver problems with symptom management, time spent giving care, hospice services utilized, other sources of support and assistance were assessed. Open-ended items asked about caregivers’ stress levels and about problems that were not resolved by hospice. The study found that the distressing symptoms caregivers found most difficult to manage were constipation, confusion, and anorexia. Caregivers identified lack of mobility and loss of bladder control most frequently as unmanageable symptoms. A majority of respondents identified the hospice nurse as their main source of information regarding care and resource needs and often cited the nurse as a source of emotional support. Sixty-four percent reported that they provided care 12–24 hours per day with some respite from family members. Results of the study indicate that caregivers spend a large amount of time with the hospice patients despite use of hospice services and assistance from family members. This can lead to high stress levels and exhaustion. There is a need for more respite care for caregivers. Hospice provides caregivers with needed support, both emotional and with the care itself.
Challenges in Transferring Information in Palliative Care Contexts: Findings from an International Study (InSup-C)

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Background: Patients receiving palliative care often have a multiple agencies involved and communication between these groups, the patient and their family carers is complex but crucial. There is a range of ways in which information sharing takes place but how effective are these methods and what are patient and carer views on this?

Design: 157 patients with advanced cancer, COPD and chronic heart failure, with prognosis of < 12 months, were recruited through clinical services in five European nations: Belgium, Germany, Hungary, the Netherlands and UK. Semi-structured interviews were carried out at baseline and at 3 months focussing on how services responded to patients' needs and problems. A transnational comparative analysis was conducted using a qualitative thematic approach. 19 group interviews were held in the five countries with staff from the clinical services. Data about information exchange were extracted.

Results: The majority of services relied on paper transfer of information. This created problems for patients when information was unavailable for crucial meetings. Patients reported this led to serious delays in changes in medication and increased their anxiety. Team meetings were common but often limited to staff from one clinical setting with community staff travelling to meetings. Hand held notes and telephone calls were also seen as useful. One site had a well-developed electronic notes system which all care providers could access. Patients found this useful but some noted that the system was only as good as the information put into it.

Conclusion: Commonalities across the participating nations about the impact of poor information sharing were apparent. Examples of effective practice were notable including systems for electronic transfer of information which other palliative care initiatives could learn from.

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**Comparison of Patients with Malignant versus Non-malignant Disease Referred to an Inpatient Palliative Care Consult Service in Ontario, Canada**

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**Background:** In Canada, individuals aged 65 and older make up 15% of the overall population. An increasing proportion of aging Canadians will be diagnosed with chronic non-malignant illnesses; non-malignant illness already leads to malignant disease as the major cause of death. As population demographics shift, delivery of palliative care in developed countries must evolve to meet the needs of the changing population.

**Aims:** To characterize differences in demographics, symptom burden and referral reason between patients with malignant versus non-malignant disease, and to determine if there is an increase in number of referrals to palliative care for patients with non-malignant diagnoses over time. The study also investigates timing of referral to palliative care between the two groups.

**Methods:** Retrospective data analysis and comparison between patients with malignant vs. non-malignant illness for patients referred to an inpatient palliative care consult service between January 1, 2010 and December 31, 2014 in Toronto, Canada.

**Results:** There was a greater proportion of patients with malignant disease referred for consultation overall (65 vs 35%). The proportion of patients with malignant disease referred over the five years increased, but the number of patients with non-malignant disease remained stable. Patients with non-malignant disease had lower PPS scores at the time of referral, but longer time to death. Patients with malignant disease had higher ESAS scores for pain and constipation, whereas patients with non-malignant disease had higher scores for dyspnea.

**Conclusion:** Canada is facing an increase in the number of patients with terminal non-malignant conditions. Despite this, their access to palliative care services remains low and occurs when functional status is already significantly impaired. The palliative care needs of patients with non-malignant disease are complex and require specialist collaboration and mixed model palliative care to improve access.
Length of Hospital Stay in the Last Year of Life Explained by General Practitioners’ Home Visits and Palliative Care Support Team Involvement per Palliative Care Network Zone

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Background: A Care Pathway for Primary Palliative Care, aiming to improve GPs’ role in palliative care, was rolled out in the action zones of five palliative care support teams (PCST) in Belgium, supporting primary care teams to perform high-quality palliative care. The primary outcome was a reduction in hospitalization rate and length of hospital stay.

Aims: To explore the association between length of hospital stay, and the frequency of home visits by GPs and involvement of the PCSTs, per cluster.

Methods: Health care consumption data have been collected retrospectively by the InterMutualistic Agency for all people domiciled in the research clusters, having died a ‘non-sudden’ death during the study period, at least 45 years at the time of death. A zero-inflated negative binomial model was used for analysis, with SAS 9.4.

Results: This data set includes 46,581 patients from five clusters: zone 1 (22%), zone 2 (15%), zone 3 (18%), zone 4 (23%), and zone 5 (19%). Males dominate the population (53%).

Averagely in the last year of life, patients spent about 6.03 (s.d. 25.79) days in the hospital. Both PCST involvement and home visits by GPs had a significant decreasing effect on length of hospital stay (-27.9% and -2.3%, resp).

All zones differed significantly overall from reference zone 5, with zone 5 having the shortest mean length of stay and zone 4 the longest length of stay with a regression coefficient in log being +0.32 (s.d. 0.02).

Compared with zone 5, there was a significant difference in the PCST effect in zones 1, 2 and 4. Zone 4 had the smallest PCST effect on lowering length of stay (+0.14, s.d. 0.05).

Compared with zone 5, there was a significant difference in the effect of home visits by GPs in zones 1, 2 and 3. Zone 4 had the biggest GP effect on lowering length of stay (-0.05, s.d. 0.03).

Discussion: The dynamics of primary palliative care differ significantly between PCST zones. This calls for reflection on possible underlying mechanisms.
Care of Advanced Cancer Patients in the Australian Emergency Department: A Quantitative Study of Health Care Providers

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Background: While patients with advanced cancer commonly present to hospital Emergency Departments (ED), many palliative care providers view this as an undesirable outcome. The views of ED providers caring for this patient cohort are poorly understood.

Aims: To understand the views of ED health professionals around providing care for patients with advanced cancer.

Methods: Building upon exploratory qualitative work, a nationally distributed, cross-sectional electronic survey of doctors and nurses working in Australian EDs was undertaken.

Results: The sample (n=681, response rate 14%) comprised 444 ED doctors, and 237 nurses, from all Australian states (metropolitan and regional). Most (84.2%) felt comfortable providing care to the dying and found it to be rewarding (70.9%), but some (n=123, 20.6%) felt that the ED was not an appropriate place for such patients to present for acute care. While 83.8% found caring for the dying a reasonable demand on their role as clinician, 83.8% also agreed that the ED is not the right place to die, with overcrowding, noise, lack of time and privacy cited as barriers to care.

Over half (n=338, 55.1%) felt sufficiently skilled in cancer pain management, however 64.5% reported that futile treatment is frequently provided in the ED often due to a lack of clear documented care plans.

Conclusion: ED clinicians in Australia are generally supportive of patients with advanced cancer presenting to ED, and find providing their care rewarding. Nevertheless they are cognizant of the limitations in the care such patients will receive in the ED environment.
Comparing and Explaining Variation in Technical Efficiency of Long-term Care Facilities (LTCFs) in 6 EU Countries

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Background: Societies in the EU are aging, leading to higher needs of long-term institutional care at the end of life. At the same time, healthcare costs are rising while resources are limited. Therefore, there is an urgency to extend our knowledge on factors affecting efficiency and quality of care in LTCFs. This study, as part of the EU PACE project, aimed to investigate and explain variation in technical efficiency¹ of LTCFs in 6 EU countries.

Methods: A number of 305 LTCFs in 6 EU countries (UK, BE, NL, FI, PL, IT) participated. Data on health and nursing services provided to patients in the last month of life were collected. To investigate efficiency, an output oriented data envelopment analysis (DEA) approach incorporating quality of life (EQ5D) and of dying (QOD-LTC) as output was performed. Bias-corrected DEA efficiency scores were generated for each LTCF, followed by truncated regression analysis with explanatory and casemix variables, such as country, status (public vs. private), LTCF type (availability GPs and nurses) and disease severity.

Results: Only 186 LTCFs were suitable for our analyses. Technical efficiency of LTCFs varied considerably. The UK appeared significantly more efficient than other countries. Moreover, variation between LTCFs was associated with LTCF type – LTCFs with offsite nurses and GPs are significantly more efficient than other LTCF types (p = 0.007). Disease severity as measured by the BANS also had a significant impact (p < 0.001). Other variables did not significantly influence efficiency.

Conclusions: Technical efficiency of LTCFs was associated with disease severity and LTCF type. The significant variation in efficiency between LTCFs, with UK being most efficient, indicates that substantial efficiency improvement might be realized.

¹ effectiveness with which a given set of inputs is used to produce an output

Source of funding: EU 7th Framework Program.
Monitoring of Patients’ Needs, Professional Triggers and Delivered Basic Palliative Care Interventions in Routine Inpatient and Ambulatory of Advanced Incurable Cancer Patients: Phase I Complex Intervention Study

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Background: Evidence is increasing about effects of early integrated specialized palliative care for cancer patients, but few systematic work addresses the delivery of palliative care interventions (PCI) by oncology health care professionals (O-HCPs).

Aim: To develop components of a clinical practice toolbox (CPT) for oncology professionals.

Methods: 3 Focus groups (FGs) of O-HCPs explored the if, when, by whom and how of 7 Key PCIs (EAPC 2016). Deductive content analysis was used for FG1 amended by open inductive codes, between FGs peer-consensual codes were compared and interview guide adapted. Formulated final statements were rated by FG participants (anonymous Delphi survey (aDS#1)) for agreement. aDS#2 presents revised statements amended by CPT components to all oncology professionals (37 senior oncologists / fellows, 6 leading nurses, 7 other professionals) until predefined consensus.

Results: 19 physicians, 9 nurses, 1 psychologist participated in 3 FGs. Variability about the assessment and delivery of the agreed 7 PCIs concerned by whom (multi-professional collaboration), how (vulnerability) and when (triggers). aDS#1 (16 doctors, 6 nurses, 1 psychologist) revealed agreement on:

- a) all 7 PCIs are important (3 early, 2 intermediate, 2 late phase)
- b) basic communication skills are required to assess patient’s hints for palliative needs using an individual approach,
- c) oncologists and/or nurses shall primarily capture needs for PCIs,
- d) cancer disease and service utilization related triggers for PCIs require further clarification

(2) CPT will encompass: patient booklet, screening and monitoring sheet, structured education of oncologists. Currently statements are reformulated to perform aDS#2 in 11.2016.

Conclusion: Oncologists, nurses and Palliative Care specialists of a centre of integrated oncology agreed on importance of 7 PCIs. A CPT should be pragmatic, allow adaption to specific setting and react dynamically to individual patient needs.
Hospital Admissions in Palliative Care: Benefit or Burden?

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Background: Despite increasing attention in how hospitals are used in palliative and end-of-life care, little is known about the benefits and burdens of hospital admissions from the perspectives of patients during a period of acute illness.

Aims: To explore the benefits and burdens of hospital admissions in palliative care and how these influence preferences for place of care during a period of acute illness.

Methods: A sequential multi-phase mixed methods study.
Phases 1: review of international literature and policy on the role of the hospital in palliative care
Phases 2: qualitative study using semi-structured interviewing with patients admitted to hospital with palliative care needs
Phases 3: survey of 116 patients admitted to hospital with palliative care needs. Data was analysed using independent t-test, ANOVA and multi-variate analyses.

Results: This presentation will focus on findings from phase 3. The decision to come to hospital was made by the participant or family in 50% of cases. Although 84% perceived a good relationship with their general practitioner (GP), only 1% presented to their GP prior to admission. Home or hospice was chosen as the preferred place of death by 52% of participants yet 84% expressed a preference to come to hospital if they became unwell again. Being able to choose their place of care was considered important by 78% of participants. All perceived some benefit and burden being in hospital. Multivariate analysis will be presented to demonstrate associations between perceived benefit and burden and key clinical and socio-demographic factors.

Discussion: Findings suggest that hospitals have a role in providing palliative care that extends beyond the medical treatment patients receive. Further research is needed to explore why patients prefer to come to hospital during periods of acute illness despite experiencing burden associated with that hospitalization and how the benefits they experience may be extended to other care settings.
What Factors Are Associated with Consultation of a Palliative Care Team in Dutch Hospitals?


Background and aim: Palliative care team (PCT) involvement in hospital-based care for patients with advanced cancer positively affects patients’ quality of life, symptom burden and satisfaction with care. In this study we investigated which factors are associated with consultation of a PCT in hospital.

Methods: This study was performed in 9 Dutch hospitals with a PCT. We included patients who were hospitalized with cancer for whom the attending physician would not be surprised if they would die within 12 months. Physicians filled in a questionnaire and medical records were investigated to collect data on PCT involvement, medical treatment and end-of-life decisions. Logistic regression was performed to investigate factors associated with PCT involvement.

Results: Univariable analysis showed that patients’ age, sex, type of cancer, comorbidity and time since the primary cancer diagnosis were not associated with whether or not the PCT was consulted. Patients for whom a PCT was consulted had a worse prognosis and WHO performance status as compared to patients for whom the PCT was not consulted. Involvement of a PCT was also associated with unplanned hospitalisations, having no more options for anti-tumor therapy, not currently receiving chemotherapy, having a wish for active hastening of death and decisions to withdraw life-prolonging treatment. In multivariate analysis only worse prognosis (OR=0.91 per month, p=0.03) and having no options for anti-tumor therapy (OR=2.18, p=0.01) were associated with PCT consultation.

Conclusion: In Dutch hospitals, PCTs are more often consulted for patients who have a poor prognosis and patients who have no more options for anti-tumor therapy. This indicates that PCTs are involved relatively late in the disease trajectory. Patients with advanced cancer could probably benefit from early integration of PCT consultation in oncological treatment. More awareness regarding the benefits of early PCT involvement is desirable.

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No Place Like Home? Palliative Discharge from Hospital in Patients with Impaired Decision-making Capacity

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Background: Achieving preferred place of death is a central component of good quality end-of-life care. When mental capacity is impaired, hospital discharge for end-of-life care can be complex, and may constitute a deprivation of liberty if a patient fails to die in their preferred place of care. Impaired decision-making capacity is common at the end of life, but little is known about the impact this has on discharge outcomes.

Aim: To compare discharge outcomes, in particular change in residential status, between patients with mental capacity (C) to make discharge decisions and those felt to lack capacity (NC)

Methods: Retrospective analysis of ‘Fast Track’ continuing healthcare funding applications approved in a clinical commissioning group over one year. All patients were terminally ill and nearing the end of life.

Results: 125 notes were analysed. 32% of patients lacked capacity to consent to discharge planning. Change in residential status was more common in the NC group (72% v 40%, \(X^2 = 8.205, p= 0.004\)). Rate of discharge to an institution was significantly higher in the NC group (\(X^2 =14.429, p= 0.001\)). A logistic regression analysis examined the effects of capacity on change in residential status adjusting for age, family carer, and functional ability. The model was statistically significant (\(X^2=30.524 p < 0.001\)). Lack of capacity was the strongest predictor after presence of a family carer for a change in residential status. Age and functional scores were not significant predictors. Mean length of discharge process was longer in the NC group (6.21 v 4.65 days) but this did not reach statistical significance.

Conclusion: Lack of capacity is a strong predictor of change of residential status after hospital admission toward the end of life. Given the likelihood of impaired capacity, advance care planning discussions should focus on how to ensure wishes regarding place of care are followed if patients lose the ability to decide this themselves.

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Dying Where We Choose: An Analysis of the Coordinate My Care

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Background: Over half a million people die each year in England and Wales. Enabling patients to achieve their preferred place of death is considered a marker of quality. However, little is known of the determinants of achieving preferred place of death across diagnoses and age groups.

Aims: We aimed to determine the proportion of patients achieving their preferred place of death as well as the determinants of achieving preferred place of death.

Methods: Co-ordinate My Care (CMC) is an online platform which allows patients to have their medical details and care wishes recorded. We used CMC’s registry of 33,882 patients with incurable disease in London, U.K. We analysed all patients who died between 1st March 2011 and 31st September 2016 with a recorded place of death and preferred place of death. We compared the characteristics of those who did and did not achieve their preferred place of death, before building logistic regression models to explore the determinants of achieving preferred place of death, adjusting for patient case-mix. These analyses were performed on the full cohort, as well as the cohort divided by age group and diagnosis.

Results: Of the 8,841 patients analysed, 77% achieved their preferred place of death. A greater proportion of those who achieved their preferred place of death were elderly with a poor performance status. Resuscitation status was the only statistically significant modifiable predictor of achieving preferred place of death. Patients with a recorded do not resuscitate order were 71% more likely to achieve their preferred place of death (OR, 95% CI: 1.71, 1.46–2.00) whilst those who were recorded as for resuscitation were 31% less likely to achieve their preferred place of death (OR, 95% CI: 0.69, 0.51–0.95).

Conclusion: Discussion of resuscitation status between patients and their healthcare professionals has emerged as a potential opportunity to institute care planning to ensure end-of-life wishes are met.
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Abstract type: Poster Exhibition

‘Frankly, I Do Not Yet Like to Pass Away…’

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Background: In patients with life-limiting conditions and a history of migration, a higher risk of not dying at home and limited access to palliative care services has been reported.

Aim: To explore the views and end-of-life preferences of migrants, a qualitative study was performed.

Methods: Two-armed study using l’entretien compréhensif interview method and grounded theory approach. Both migrant and non-migrant adult patients receiving palliative care in Upper Bavaria were included. Thematic content analysis was applied using MaxQDA 12 software.

Results: The 36 interviewees (19 native Germans, 17 patients from Europe and the U.S., Israel, Turkey, and Indonesia) expressed the following themes:
(1) The feeling not yet to be in a ‘palliative’ situation; the duty not to give up; and a wish to prolong life
(2) Fear of suffering at the ‘end of life’, wish for hastened death
(3) Wish to manage everything alone, lack of strength, personal need for assistance
(4) Having ‘everything arranged’ making oneself calmer. Advice regarding advance care planning, financial matters, and funeral arrangements is needed
(5) Importance of family and friends vs. family as a burden
(6) Feeling ‘safer’ when staying in an inpatient facility, but being tired of treatments
(7) Awareness of disrupted identity, not feeling as a migrant
(8) German skills as prerequisite to ‘survive’, yet, mother tongue ‘touches the heart’
(9) Longing for home, but feeling safer in Germany and getting better healthcare.

Conclusion: Patients gave their opinion on topics critical for palliative care. Most participants were reluctant to discuss ‘end of life’ as this term implied suffering and loss of autonomy, while the concept of ‘palliative care’ remained unclear. Moreover, individual attribution of ‘migrant status’ was often not clear-cut. Potential barriers to access should be addressed, and categorization of migrants has to be avoided.
Abstract number: P02-268
Abstract withdrawn
What are the Most Common Unmet Palliative Care Needs in Cancer Patients in Indonesia According to Cancer Stage? A Descriptive Study

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Background: Indonesia has been improving palliative care since 1992 however its development has been slow. Meanwhile, the dramatic increase in cancer incidence underlines the urgent needs of palliative care provision within the country. The fulfillment of palliative care needs is indeed critical to improve quality of life as the main target of treatment. These needs are greatly influenced by cancer stage and modified by cultural background.

Aims: To evaluate the most dominant unmet palliative care needs of cancer patients in Indonesia in terms of cancer stages.

Methods: This study was a cross-sectional study using consecutive sampling in Cipto Mangunkusumo Hospital, a tertiary, national referral hospital in Indonesia, between September and December 2015. The population was cancer patients in outpatient and inpatient settings. The inclusion criterias was cancer patients aged 18 years old or more who signed the consent. The exclusion criterias were cognitive and/or affective disorders and weak general condition which did not allow the filling of questionnaire. The unmet palliative needs was evaluated using validated Problems and Needs in Palliative Care-short version questionnaire. Top five of the most common unmet palliative care needs are compared between advanced (stage 4) and early (1–3) stage.

Result: In the end of study 329 subjects completed the questionnaire, 45.3% of which were in advanced stage. Despite the similar unmet physical needs between early and advanced stage (pain 75.6% vs 81.8% and neuropathy 79.1% vs 80.5%), there was a trend of shifting in other domains. Unmet social and psychological needs were more prominent in the earlier stages while unmet spiritual needs (the meaning of death, 90%) was the most common unmet needs in the advanced stage.

Conclusion: To better fulfill the unmet needs, early stage patients require more attention in psychological and social needs while advanced stage patients demands most of the attention for spiritual needs.
Challenges of the Introduction of a Randomised Controlled Trial (RCT) of Early Integration of Specialist Palliative Care (SPC) within a Tertiary Cancer Center in the Czech Republic

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**Background:** Little is known about barriers which might jeopardize successful implementation of new early SPC initiatives within existing cancer care programs.

**Aim:** The aim of this contribution is to identify barriers to referrals of patients to a RCT of integration of SPC conducted in a large tertiary cancer center.

**Method:** PALINT is a RCT comparing standard oncology care + early SPC to standard oncology care alone in patients with advanced solid tumors treated with palliative antineoplastic therapy. The SPC intervention consists of consultations with palliative care team every 6–8weeks. The endpoints are quality of life, level of anxiety and depression and symptom burden, structure and cost of health care provided in the last 3 months of life and the place of death. We report results and experiences of the enrollment process during the first 12 months of the project with analysis of barriers in referring patients to the study from attending oncologists’ point of view.

**Results:** 57 patients have been screened, 43 (75%) patients have been enrolled. The number of screened and enrolled patients (n= 57) represent only 20% of all eligible patients (n=291) treated in our cancer center during the first 12 months of the study. The recruitment rate was much slower than planned. Semi-structured interviews made after 6 months from the start of the study with 10 attending oncologists caring for eligible patients revealed two main reasons of reluctance to referral:
1/ early referral to palliative team may distress patients on active oncological therapy;
2/ some oncologists are uncomfortable with the palliative care physician „supervising” their work.

**Discussion:** The introduction of a clinical trial of SPC service integration may be challenging and has to develop a „marketing” strategy to address and overcome prejudices and misunderstandings among other specialties. Supported by Ministry of Health of the Czech Republic, grant no. 15-33590A. All rights reserved.
Resource Use during the Last 6 Months of Life in Patients who Died with versus of Alzheimer’s Disease

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Background: Alzheimer’s disease (AD) is a progressive incurable disease with a protracted course and gradual loss of cognition and function. Because of its protracted nature AD is often seen as a predisposing or contributing factor, rather than a primary cause of death. This could result in a differentiated nature and intensity of palliative care depending on whether people die of AD rather than with AD.

Aim: The aim of this study is to describe resource use during the last 6 months of life of those who died of AD and those who died with but not of AD (‘died with AD’).

Methods: We performed a full-population retrospective descriptive analysis on linked healthcare, population and death certificate data of all 107,448 Belgian decedents in the year 2012. Those who died of AD were selected based on the primary cause of death recorded on the death certificate. Those who died with AD were selected using a validated algorithm based on medication and clinical activities.

Results: 11,410 patients died with (8804) or of (2606) AD. Both groups differed only marginally in terms of age and sex. Those who died of AD had less hospital use in the final 6 months of life compared to those dying with AD (40.5% vs 61.1% was hospitalized and 2.0% vs 8.8% had an ICU stay respectively). They were less often admitted to a palliative care unit (1.2% vs 2.3%) but received palliative home care services slightly more often (7.0% vs 5.6%) and for a longer median period (53 vs 28 days). Those who died of AD had comparable use of physiotherapy, invasive and non-invasive ventilation, medical imaging, CPR, sedatives, oxygen and opioids as compared with those who died with AD.

Conclusion: During the last 6 months of life, those dying of AD use less intensive resources than those dying with AD, which could point to the recognition of an end-of-life phase. Still these patients receive rather rarely palliative care, which may point to the need for more efforts to encourage palliative care in AD patients.
Abstract number: P02-272
Abstract type: Poster Exhibition

Care Provided to Cancer Patients in their Last Month of Life: A Retrospective Study in Patients Who Died in Dutch University Hospitals


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A quarter of all patients die in a hospital. Insight into their received care can provide important information.

Aim: To describe the care provided in the last month of life to patients with cancer who died in an university hospital.

Methods: A retrospective chart review was conducted within all Dutch University Medical Centres. The Dutch Cancer Registry was used to identify 150 deceased patients per centre. Only patients who died in the hospital due to cancer were selected. Trained data managers derived 38 preselected items from the patient file. Whether a patient was admitted to the hospital during a palliative care trajectory was retrospectively assessed by an oncologist (AR) and a specialized nurse (ML).

Results: Data of ninety-four patients were included; mean age was 64 years and 63% were men. Most common diagnoses were lung cancer (29%) and gastrointestinal tumour (16%). Upon admission, 47% of the patients were in a palliative care trajectory, 19% were treated with a curative intent, 28% were admitted pro diagnosi and for 6% it was unknown.

Patients in a palliative care trajectory less often underwent invasive procedures than patients in a curative or diagnostic trajectory.

Conclusion: This retrospective chart review shows that a large proportion of cancer patients who die in a university hospital receive anticancer treatment and diagnostic interventions in their last month of life. However, the majority of those patients were in a diagnostic or curative trajectory upon admission.

<table>
<thead>
<tr>
<th></th>
<th>Total (n=94)</th>
<th>In a palliative trajectory (n=44)</th>
<th>Not in a palliative trajectory (n=50)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care characteristics</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Received chemotherapy</td>
<td>22%</td>
<td>27%</td>
<td>18%</td>
<td>0.281</td>
</tr>
<tr>
<td>Received radiotherapy</td>
<td>7%</td>
<td>11%</td>
<td>4%</td>
<td>0.175</td>
</tr>
<tr>
<td>Underwent an invasive procedure</td>
<td>40%</td>
<td>25%</td>
<td>54%</td>
<td>0.004</td>
</tr>
<tr>
<td>Consultation specialist palliative care team</td>
<td>15%</td>
<td>18%</td>
<td>12%</td>
<td>0.401</td>
</tr>
<tr>
<td>Diagnostics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CT scan</td>
<td>78%</td>
<td>70%</td>
<td>84%</td>
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</tr>
<tr>
<td>MRI scan</td>
<td>18%</td>
<td>20%</td>
<td>16%</td>
<td>0.576</td>
</tr>
<tr>
<td>PET scan</td>
<td>6%</td>
<td>7%</td>
<td>6%</td>
<td>0.871</td>
</tr>
</tbody>
</table>

[Care and diagnostics in the last month of life]
**Advance Statements in End-of-Life Care: Requirement of the Public in Norway**

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**Background:** In the past two decades there has been an increasing awareness of the poor knowledge and documentation of patients wishes and hopes according to end-of-life care. An advance statement gives the opportunity to express wishes on future care options and is the basic for advance care planning. Existing limited evidence suggests that it improves service users’ satisfaction with treatment.

**Aims:** We explored the preferences regarding to advance statements and their documentation among a sample of the public in 9 municipalities in our district. A further question was if these preferences are influenced by gender, age or level of education.

**Methods:** A structured paper survey with 20 closed questions was send to a sample of the public in Romsdal, Norway (n=530). A descriptive statistical analysis was used for preferences and attitudes of the individuals. The Chi-square test showed to which degree gender, age and level of education affected the respondents’ preferences.

**Results:** The response rate was 63 % (n=335). 88 % off the responders would like to talk to professional care givers about wishes and care preferences in case of serious illness with an estimated lifetime of one year. 90 % are open to document preferences in an advance care plan.

90 % wish to be informed about prognosis, 96 % want to know something about possible symptoms and problems, 99 % require information about possible future health care providing. The results showed a trend where women, young and highly educated people were more inclined to want information, participation and documentation.

**Conclusion:** The participants strongly support advance statements and information about disease and prognosis in case of serious illness. Documented advance statements, although not legally binding in Norway, are important for further treatment decisions in end-of-life care. Integration into an advance care plan strengthens the collaborative process between service users and health care professionals.
Is Specialised Palliative Care Associated with Use of Chemotherapy at the End of Life in Patients with Cancer? – A Population Based Cohort Study

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**Background:** The use of chemotherapy during the last months of life can often be considered futile and even harmful. However, survival prognostics are uncertain, which makes timely discontinuation difficult. Knowledge about the use of chemotherapy close to death is sparse and mostly described in small studies with proportions ranging from 11.5% up to 33.3%. Specialised palliative care (SPC) might affect decisions about treatments at the end of life such as chemotherapy, but it is unknown how or if SPC might impact the use of chemotherapy.

**Aims:** To investigate the use of chemotherapy in the last month of life in patients with cancer and the association with the provision of SPC.

**Methods:** This was a register-based cohort study with data from The Danish Register of Causes of Death, The Danish Palliative Care Database and The Danish National Patient Register. Patients ≥ 18 years who died from cancer from January 2010 to December 2013 in the Capital Region of Denmark were included. Chi² test was applied to compare the use of chemotherapy in patients in SPC and patients not in SPC and to compare the use of chemotherapy by patients provided with SPC by a hospice or by a hospital-based palliative care unit (PCU).

**Results:** During the study period, 17,246 persons died from cancer and 5,735 (33%) received SPC – 2798 from a hospice and 2937 from a PCU, respectively. In the last month of life, 1,557 (9%) patients received chemotherapy – 451 of the patients in SPC and 1,106 of those with no SPC (8% vs. 10%, \(p=0.0002\)). Six percent (n=164) of patients in the hospice group and 10% (n=287) of the patients in the PCU group received chemotherapy during the last month of life (\(p=< 0.0001\)).

**Conclusion:** A low proportion of patients received chemotherapy in the last month of life (9%). SPC was associated with a lower use of chemotherapy but when separating the providers of SPC, in fact only the hospice group had a lower use of chemotherapy.
Abstract number: P02-276
Abstract type: Poster Exhibition

Healthcare Utilization of Advanced Dementia Patients in an Integrated Palliative Homecare Service

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**Background:** Symptoms are prevalent in advanced dementia (AD) patients at the end of life resulting in frequent hospitalisations. As the prevalence of dementia increases with an ageing population, healthcare resources may become severely strained. Program Dignity (PD), a multidisciplinary palliative homecare service was piloted to care for AD patients at home.

**Aim:** To determine healthcare utilisation of AD patients supported by PD.

**Methods:** Patients with FAST (Functional Assessment Staging of Dementia) Stage 7A and beyond with at least one of the following: serum albumin < 35g/L, tube feeding or pneumonia were recruited into PD. Healthcare utilisation data post enrolment was collected prospectively. Data pre-enrolment and data of a matched historical cohort not receiving any palliative homecare support admitted into the hospital 1 year prior to the start of PD were collected retrospectively by chart review. Within group comparisons used Wilcoxon Signed Rank and McNemar’s tests while between group comparisons used Mann-Whitney U and Chi-square tests.

**Results:** Median number of emergency department visits, hospital admissions and hospital bed days reduced significantly post enrolment into PD (Md=0, 0, 0; n=218) compared to pre-enrolment (Md=2 (IQR 1–4), 2 (1–4), 10 (6–15)), Z=−11.9, −11.7, −10.6, p< 0.05, r=0.57, 0.56, 0.51 and the historical cohort (Md=1 (IQR 0–1), 2 (1–3), 11 (10–20); n=233), U=14332, 2906, 4255; p< 0.05, r=0.44, 0.80, 0.75. The proportion of patients readmitted within 30 days of discharge was also significantly lower post enrolment (10.1%) compared to pre-enrolment (35.3%) and the historical cohort (44.2%), χ²(1, n=451)=63.7, p< 0.05, phi=−0.38.

**Conclusion:** An integrated, multidisciplinary palliative homecare program for AD patients reduces healthcare utilisation, relieving the strain on healthcare resources significantly. Future health economic analysis will determine the cost benefit for patients and the nation which could be substantial.
Do-not-Resuscitate (DNR) Orders and Intensive Care Unit (ICU) Utilization over Time in a Developing Country

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Background: There is frequent ICU utilization in end-of-life patients in developed countries. However, little is known about the rate of DNR orders and ICU utilization in hospitalized end-of-life patients in developing countries, even though ICU resources are more scarce in this setting.

Aim: To describe the prescription of DNR orders and ICU utilization over a 33-month period in a tertiary hospital in Brazil.

Methods: Data was retrospectively collected from electronic medical records of all in-hospital deaths in a tertiary hospital in Brazil, from May, 2014 to September, 2016. We analyzed the rate of DNR orders and ICU admission over this period.

Results: In the period of the study, there were 48732 hospital admissions and 1071 in-hospital deaths. Deaths were preceded by a DNR order in 276 (25.8%) cases and an admission to the ICU occurred in 814 (76%) cases. DNR orders were prescribed in the wards in 199 (72.1%) cases, in the ICU in 63 (22.8%) cases and in the intermediate care unit in 14 (5.1%) cases. Patients with DNR orders died in the wards, in the intermediate care unit and in the ICU in 222 (80.4%) cases, 9 (3.3%) cases and 45 (16.3%) cases, respectively. Patients with DNR orders were less likely to die in the ICU than patients with no DNR \( \text{OR}(95\%CI) = 0.06 \) (0.04–0.09). There was a trend of increased prescription of DNR orders over time in the study period (chi-square for trend, \( p< 0.001 \)), but not of ICU utilization (\( p=0.901 \)), DNR prescription outside the ICU (\( p=0.929 \)), or death outside the ICU for DNR patients (\( p=0.298 \)) (figure 1).

Conclusion: There was a high rate of ICU utilization in patients dying in the hospital, but patients with DNR orders were less likely to die in the ICU. Moreover, there was a trend of increased prescription of DNR orders, but no apparent changes on ICU utilization or deaths outside the ICU.
The Need of Palliative Care among Cancer Patients in Brazil: Analysis of Data from 2008–2014

dos Santos C.E.\textsuperscript{1,2}, Peixoto Caldas J.M.\textsuperscript{3,4}, Barros N.\textsuperscript{1}, Serafim J.A.\textsuperscript{5,6}, Flamarion G.\textsuperscript{4}, Filippi M.R.\textsuperscript{7}
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Background: Cancer figures among the leading causes of morbidity and mortality in Brazil, with approximately 576,000 new cases and around 200,000 cancer related deaths in 2014. According to the Brazilian National Oncological Policy, cancer control must include health promotion, prevention, diagnosis, treatment, rehabilitation, and palliative care, following the National Health System (SUS) principles: **Universality, Equity and Completeness of health care.** However it is necessary to estimate the needs, resources and specify parameters to structure and tailor an adequate modality of assistance in palliative care.

Aims:
1) Outline the hospital admissions for treatment of clinical intercurrences of cancer patients in the National Health System (SUS) between 2008–2014;
2) Estimate the number of cancer patients with palliative care needs in the population.

Methods: This is a cross-sectional study using death certificate and hospital admissions data related to treatment of clinical intercurrences of cancer patients.

Results: Yearly an average of 1.1 million deaths were reported to the Brazilian Mortality Information System, being 15.9% of these related to people living with cancer. Between 2008 and 2014, there were almost 4.5 million hospital admissions (4,431,685) of patients with cancer in Brazil. Of all the hospital admissions of cancer patients, 1,189,908 (26.85%) were related to complications of the disease and/or treatment, with hospital mortality rate of 21.4% (252,522). Around 90% of the hospital admissions in the procedure “Treatment of Clinical Intercurrences of Cancer Patient” were related to palliative care for terminally ill patients. In this context we can conclude that yearly around 153 thousand cancer patients need palliative care at the end of life.

Conclusion: We need to estimate the needs, resources and specify parameters to structure and tailor an adequate modality of assistance in palliative care.
Abstract number: P02-280
Abstract type: Poster Exhibition

Rehabilitation Goals in Hospice Palliative Care: What Matters to Patients with Advanced Progressive Disease?

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1Cicely Saunders Institute, King’s College London, London, United Kingdom, 2St Christopher’s Hospice, London, United Kingdom, 3St Joseph’s Hospice, London, United Kingdom, 4Marie Curie Hospice Hampstead, London, United Kingdom, 5Royal Trinity Hospice, London, United Kingdom, 6Cicely Saunders Institute, King’s College London, London, United Kingdom, 7Cicely Saunders Institute, Kings College London, London, United Kingdom

Introduction: Rehabilitation is a key component of multidisciplinary palliative care that aims to maximise function irrespective of diagnosis or prognosis. Goal setting, a core part of rehabilitation practice, can be used to understand what patients want to achieve and direct rehabilitation in a manner that values patient priorities.

Aim: To determine the timescale and nature of patient identified rehabilitation goals within hospice services, according to the WHO International Classification of Functioning, Disability and Health (WHO-ICF).

Methods: Adults with advanced progressive disease attending 4 UK hospices set SMART (specific, measurable, attainable, realistic, timed) goals with hospice staff who had received standardised training. Two independent raters mapped goals onto ≥1 WHO-ICF codes, and categorised goals according to a primary focus on impairment, activity or participation in work, social life and society. Codes were ranked by frequency counts.

Results: 68 patients (mean (SD) age 68 (15) years, 48 (74%) cancer, 36 (53%) outpatients) took part and set 120 individual goals (median (range) per patient 2 (1–4)) that mapped onto 181 WHO-ICF codes, spanning 12 of 30 possible WHO-ICF domains. Goals had a median (range) timescale of 21 (3–84) days and most frequently related to mobility (code d4, n=54), general tasks and demands (d2, n=29), mental functions (b1, n=24), community, social and civic life (d9, n=23), and self-care (d5, n=13). Twenty-five goals (21%) had a primary focus on impairment, whilst 68 (57%) focused on activity and 27 (22%) on participation.

Conclusions: Patients receiving palliative care, through hospice services, are able to engage in setting functional goals that can be mapped onto the WHO-ICF in a manner consistent with other rehabilitation areas. Most goals have a short timeframe (days or weeks) and focus on retaining independence in life activities and situations, often by managing symptoms and emotions.

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<tr>
<th>Rank</th>
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<th>Description</th>
<th>Count</th>
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<tbody>
<tr>
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<td>d4, Mobility</td>
<td>Mobility</td>
<td>54 (30)</td>
</tr>
<tr>
<td>2</td>
<td>d2, General tasks and demands</td>
<td>29 (16)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>b1, Mental Functions</td>
<td>24 (13)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>d9, Community, social and civic life</td>
<td>23 (13)</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>d5, Self-care</td>
<td>13 (7)</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>b4, Functions of the cardiovascular, haematological, immunological and respiratory systems</td>
<td>12 (7)</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>d6, Domestic life</td>
<td>8 (4)</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>b2, Sensory Functions and Pain</td>
<td>8 (4)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>b7, Neuromusculoskeletal and movement related functions</td>
<td>4 (2)</td>
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<tr>
<td>10</td>
<td>d7, Interpersonal Interactions and relationships</td>
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</tbody>
</table>

[Goal mapping ranked by WHO-ICF code, domain (n,%)]

Poster Exhibition (Poster Set 2)
Palliative and Health Care Needs of Key Populations in Zimbabwe

Hunt J.1, Harding R.2, Bristowe K.2

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Key populations suffer human rights violations due to legal and social conditions and have significantly lower uptake of health services than the general population. Currently and particularly in Africa, little is known about the palliative care needs of these populations.

A study of the health and palliative care needs of sex workers, lesbian, gay, bisexual, transgender and intersex persons in Zimbabwe was undertaken on behalf of the Open Society Foundations in 2014/15.

A qualitative design employing focus group discussions and in-depth interviews recruited 72 participants from 4 sites around Zimbabwe. Participants comprised key population members, representatives of support agencies, palliative care providers and private medical practitioners.

The study confirmed that key populations are discriminated against by health workers, receive lesser health care than the general population, care at the end of life is most likely to be offered by sexual identity groups and a painful, undignified death is common. Health workers demonstrated stigmatising attitudes often based on the belief that key populations deserved their fate. Key populations considered they needed to sexually ‘conform’ in order to access care. Health and palliative care and support was determined by personal attitude rather than professional ethics and standards.

Training of pre- and post-graduate health practitioners is required to enhance sensitive interviewing skills to honour human rights, facilitate disclosure and ensure effective health support. Further research is required into attitudinal change programs to inform policy change, reduce stigma and effectively implement equitable health care.
Advance Care Planning for Cancer Patients: A Retrospective Chart Review in Patients Who Died in a Dutch University Hospital

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Advance care planning helps to ensure appropriate palliative care that is in line with the wishes of the patient. A minority of patients dies in a university hospital, insight into the documentation and practice of advance care planning for this high complex patient population is important.

Aims: To assess how often advance care planning and end-of-life decisions are documented for patients who die from cancer in a university hospital in the Netherlands.

Methods: A retrospective chart review was conducted within the 8 Dutch university hospitals. Data of the Dutch Cancer Registry were used to identify 150 oncological patients who died between Oct 2013 and Feb 2014. Those patients who died in the hospital due to cancer were selected. Outcome measures were derived from the patient file by trained data managers. Whether a patient was admitted to the hospital during a palliative care trajectory was retrospectively assessed by an oncologist (AR) and a specialized nurse (ML).

Results: Data of ninety-four patients were included. Of those patients, 47% were in a palliative trajectory upon admission to the hospital. In 66 patients (87%) the approaching death was discussed during the last week of life. Do Not Resuscitate orders (DNR) were recorded in the patient file in 80% of the patients, in 33% a Do Not Treat order (DNT) was noted and in 10% an advance euthanasia directive was recorded in the file. In 18% of the patients the life expectancy was documented and in 18% the preferred place of dying was documented. For patients admitted to the hospital in a palliative care trajectory, DNR orders (93% vs. 69%, p=0.004) and DNT-orders (44% vs. 23%, p=0.035) were more often documented for patients in a curative or diagnostic trajectory.

Conclusion: Although the majority of patients were not in a palliative care trajectory, advance care planning items were recorded in patients’ files in most cases. Information on preferences regarding place of death was less often present in the patient file.
Partners in Hospice and Palliative Care Networks: Who They Are and How They Cooperate

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Background: The Bavarian State Ministry of Health and Care fosters the establishment of regional hospice and palliative care (PC) networks in Bavaria, Germany. Little is known about the different network partners and their cooperation strategies. This study aims to investigate the various actors of hospice and PC networks in Bavaria and their patterns of collaboration.

Methods: Data were collected in several study phases: In the context of a status quo analysis qualitative interviews with 10 coordinators of 10 Bavarian hospice and PC networks were conducted (March-June 2015). Data were enriched by an online survey. Requirements for partners were discussed with 8 coordinators in a workshop (November 2015). 7 semi-structured interviews (February-April 2016) added information on factors impacting cooperation. Interviews and workshop discussions were audiotaped, transcribed verbatim, and analysed with the qualitative data analysis software MAXQDA. The online survey was analysed with IBM SPSS Statistics 21 using response frequencies.

Results: Hospice and PC coordinators report that 192 key partners of 36 different categories are represented in 12 networks, ranging from specialised community PC teams to PC units, general practitioners, hospice societies and regional authorities. Relationships between central network partners were rated on a verbal scale (loose/not formalised [n=52], rather loose/rather not formalised [n=47], rather formalised [n=52], very formalised [n=41]). Moreover, the 12 networks draw on 186 associated partners. A definition of qualities and characteristics of network partners was developed: Network partners should share the same goals and provide resources. Central cooperation themes regard cooperation agreements and network coordinator.

Conclusions: Network partners tangibly described the different actors in hospice and PC networks and their cooperation strategies. The present data will foster the development of a best practice recommendation.
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The strengths of and Challenges for Palliative Day Care Centres. An Interview and Focus Group Study in Belgium

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**Background:** Palliative day care centres (PDCCs) are a marginal service within the palliative care landscape. However, relevant empirical research to study the potential and added value of this service model is virtually non-existent, and PDCCs may therefore be underappreciated.

**Objective:** To examine how representatives of Belgian PDCCs perceive their strengths and added value, as well as the biggest challenges to their survival.

**Method:** We performed a qualitative study based on 7 individual, semi-structured interviews and an overarching focus group (6 participants) with professional representatives of the five existing PDCCs in Flanders, Belgium. The data collection ran from December 2014 until April 2015. NVivo software was used to extract relevant themes from the verbatim transcripts.

**Results:** Five distinct strengths were identified:
- 1) a unique care model;
- 2) contact with peers in a non-clinical environment,
- 3) a reliable and competent multi-professional team;
- 4) care tailored to the individual;
- 5) respite for family caregivers.

The most significant challenges were:
- 1) optimizing government funding schemes and
- 2) achieving sufficiently high occupancy and referral rates.

According to the interviewees, this latter challenge was due to the low visibility of the service to health care professionals and the general public, to unclear criteria for referral and to the high psychological threshold for referral among patients and professionals alike.

**Conclusion:** PDCC representatives in Belgium see significant potential for added value of their service for patients with advanced illness. However, negotiating adequate funding and raising referral rates by changing current perceptions are paramount to unlocking this potential. Scientific analysis of cost utility and patient outcomes associated with PDCC use is highly recommended.
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**Exploring Palliative Care Researchers’ Experience of Using an Evidence-based Model for the Transfer & Exchange of Research Knowledge**

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**Background:** Research can result in health outcomes if adopted. Palliative care has built up a strong evidence base and it is important to explore the most effective ways of transferring this evidence into practice. The authors developed the Evidence-based Model for the Transfer of Research Knowledge (EMTReK) from a systematic review of articles in health services research. Initial analysis of the model suggested that its core components were equally evident in palliative care and general health services research identified as part of the systematic review.

**Aims:** The aim of this research is to examine the relevance of the EMTReK model in palliative care by exploring the experiences of palliative care researchers using the model to inform their knowledge transfer activities. Therefore, a key aim of this presentation is reflect on the application of the model in practice by researchers.

**Methods:** A series of case studies have been developed in which palliative care researchers (early career and experienced individuals) working in different settings (academic and non-government organisations) agreed to develop and implement a dissemination plan informed by the model. Researchers involved in the four case studies were interviewed before and after using the model to explore their experiences. In addition the research team used the model in their own dissemination and reflected on the process.

**Results:** Preliminary analysis of data collected suggests that the core components of the model are relevant to researchers in palliative care, however there was evidence of variation in the way in which researchers were influenced by the model. One area for learning is the nature of messages that may be disseminated by researchers at different stages of the research process.

**Discussion /conclusion:** The EMTReK model offers guidance as to effective ways of translating research knowledge to multiple stakeholders and has clear implications for researchers in palliative care.
Hip Protector Device: An Observational 12-month Study of Compliance and Effectiveness among Participants of Senior Citizen Housing Society of NCR India

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In elderly, hip fracture is a major cause of disability, functional impairment and even death. Hip fractures are related to both falls and osteoporosis. The most common indicators of an imminent falls are gait abnormalities and imbalance. Fracture treatment is expensive and good preventive method is a hope of alleviating the huge social burden of hip fractures by a suitable design of a wearable device.

Objective: A new microcellular polymer based Hip Protection Device (HPD) is developed and patented at IIT Delhi. In order to assess the efficacy and efficiency of the developed device, this study was proposed with the following:
1. The compliance among the elderly Indian population in the National Capital Region (NCR).
2. Comfort & confidence level 3. Fall incident and Acceptability by the target population.

Study design: The study is based on free distribution to 75 elderly.

Methods: The study consisted of male and female above the age of 65 with or without hip fracture. All participants possessed high risk of fall.

Results: The study shows 73% used it during walking and 27% used at walk, home and during sleep also. Out of 75 subjects wearing the hip protective device, 4 fell down in a span of 12 months. Maximum number of participants i.e. 90% and above felt the use of new device comfortable and 97% compliance of its usage was reported. The participants level of confidence in walking improved and few who were afraid to walk in their room, started morning walks for 4–5 km a day wearing the device with a smile. 15% of possible fractures were prevented by the device in a limited time study; this percentage of prevention can go up in long term study in further follow up.

Conclusions: Novel HPD of IIT Delhi is effective in reducing chances of hip fractures among the elderly and can be a cost effective solution of futuristic palliative care. The study shows confidence in the normal life & finally arrival of low cost, light weight hip protective device.
The Real Story: Palliative Care Patients’ Experience of One Acute Hospital

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Background: In order to deliver high-quality, patient-centred care at the end of life that is safe and efficient, it is imperative for service providers to understand what patients think about the care they receive (NPELCP 2015). This is in accordance with overarching principles of the NHS Constitution and UK National guidance in end-of-life care (DH 2013, NICE 2015). Engaging with service users can also inform ongoing service improvement strategies.

Aim:
- Explore patient experience of being in hospital, receiving support from the Hospital Specialist Palliative Care Team (HSPCT)
- Make recommendations to the acute trust regarding improving patient experience

Method:
- Narrative Interviews – with recently discharged palliative patients; Thematic Analysis undertaken
- Case note review – key documentation from recent inpatient episode

Results: 20 interviews completed.

Positive experiences were described by many patients:
- Care delivery that was compassionate and responsive
- Patients feeling at the ‘centre’ of care delivery
- HSPCT involvement had therapeutic impact; not just symptom control but holistic wellbeing
- However challenges were evident, with less positive experiences also described:
  - Over stretched staff and resources
  - Task oriented focus of care delivery
  - Pain assessment and control was a concern for many

Conclusion: Study findings contribute to a greater understanding of the inpatient experience within the acute hospital setting. Findings enabled recommendations to be generated for the acute trust, rooted in ‘real’ patient experience, promoting local change and improvements to care delivery.
From Concept to Practice, Is Multidimensional Care the Leading Principle in Hospice Care? An Exploratory Mixed Method Study

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Background: Hospice care aims to optimize the quality of life of patients and their families by relief and prevention of multidimensional suffering.

The aim of this study is to gain insight into multidimensional care provided to hospice inpatients by a multi-professional team and identify facilitators, to ameliorate multidimensional hospice care.

Methods: This exploratory mixed method study with a sequential quantitative – qualitative design was conducted from Jan-Dec 2015.

First a quantitative study of 36 patient records (12 hospices, 3 patient records/hospice) was performed. The outcomes were multidimensional care, clinical reasoning and assessment tools.

Second, multidimensional care was qualitatively explored using semi-structured focus group interviews with multi-professional hospice teams.

Both methods had equal priority and were integrated during analysis.

Results: The physical dimension was most prevalent in daily care, reflecting the patients’ primary expressed priority at admission and the nurses’ and physicians’ primary focus. The psychological, social and spiritual dimensions were less frequently described. Assessment tools were used systematically by 4/12 hospices. Facilitators identified were interdisciplinary collaboration, implemented methods of clinical reasoning and structures.

Conclusions: Multidimensional care is not always verifiable in patient records however it is experienced by professionals in daily practice. The level of multidimensional care varied between hospices. The use of assessment tools and a stepped skills approach for all dimensions are recommended and multidimensional assessment tools should be developed.

Leadership and commitment of all members of the multi-professional team is needed to establish the integration of multidimensional symptom management and interdisciplinary collaboration as preconditions for integrated multidimensional hospice care.
Compassion is a Two-way Street: The Development of a Healthcare Provider Model of Compassion

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Background: Patients increasingly want and expect their healthcare providers to provide care that they consider compassionate, especially at the end of life. Healthcare providers are provided little guidance on the essential qualities, skills, behaviours, facilitators and barriers that are associated with compassionate care.

Aims: The objective of this study was to develop a theoretical model of compassionate care directly derived from palliative care providers understandings and experiences of providing compassionate care.

Methods: This study utilized grounded theory, a qualitative research method that allows researchers to construct a theoretical model of a construct, including the key facets, that is grounded in participant data. Focus groups with frontline palliative care providers and individual interviews with peer nominated compassionate care providers within palliative care were used. Additionally, focus groups with study participants and key stakeholders were conducted after the model was developed for the purposes of member checking and to inform uptake into practice. Analysis of transcribed data occurred concurrently through the 3 stages of Straussian grounded theory.

Results: 58 healthcare providers participated in this study, with the majority participating in focus groups and 15 individual interviews. Four categories, each containing numerous themes, emerged from the data, which served as the core content of a healthcare provider model of compassionate care.

Conclusion: Healthcare providers felt that compassion was motivated by virtues, embodied through healthcare providers presence and intention to actively know and understand a person and ameliorate their suffering. The model of compassionate care distilled from this study, including the various qualities, skills and behaviours associated with compassion will be presented.
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# Understanding the Reasons for Emergency Department Presentations for Patients with Cancer

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**Background:** As the population ages and cancer incidence increases, the frequency of people with cancer presenting to the Emergency Department (ED) during the course of their illness is increasing. Whilst the ED can be critical for the management of unexpected urgent medical problems, it can also be less than ideal for many other aspects of cancer care.

**Aim:** This study sought to understand the reasons for presentation to ED for patients with cancer.

**Methods:** A retrospective cohort study of consecutive patients with an already established diagnosis of cancer presenting to a tertiary, university hospital ED during a 3 month period. Patient demographic information, clinical characteristics, hours of presentation, reasons for presentation and outcomes were gathered.

**Results:** Eighty five ED presentations by 82 patients were included in the study (mean age 64, 52% male). The proportion of patients with solid organ, haematological, and both malignancies was 72% (n=59), 25% (n=21) and 3% (n=2) respectively. Lung was the most common malignancy (n=16, 27%), followed by breast cancer (n=8, 13.5%), and 62% of those with solid organ malignancy had metastatic disease. Of the 85 ED presentations, 48 (56%) were outside business hours. The most common reason for ED presentation was for symptom management, including pain (n=26, 35.6%), dyspnoea (n=14, 19.2%) and non-neutropenic sepsis (n=13, 17.8%). One third of patients with haematological malignancy presented to the ED with febrile neutropenia. The majority of patients (n=66, 78%) patients were admitted, and one died in the ED.

**Conclusion:** The majority of cancer patients presented to the ED for clinical symptom management, and for many, these visits occurred outside business hours. Creating processes to anticipate and address outpatient-based symptom and sepsis management may reduce ED utilisation by cancer patients, but must be responsive both during and outside business hours.
“Can we Keep our Patients at Home?”
A Retrospective Study to Identify Determinants of Unplanned Hospital Admission in Home Care Patients

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Hospital admissions are burdensome, costly & decrease patients’ quality of life. Past studies examined factors associated with readmissions to hospital but a comprehensive study has yet to be done for patients supported by homecare service (HC) in an integrated palliative care model. To identify factors associated with unplanned hospital admissions (UHA) of HC patients for future service prioritization. Cancer patients who had at least one unplanned admission & initially declined readmission to the hospital were identified. Their demographics, Advance Care Plans (ACP), details of UHA, Edmonton Symptom Assessment Scale (ESAS), Palliative Performance Scale (PPS) scores & number of HC contacts 2 weeks before the UHA were collected retrospectively by chart review. Data was analyzed using descriptive statistics. Frequencies/percentages & mean/median were reported for categorical & continuous variables respectively. 35 patients (mean age: 72.6±10.9 years) had at least 1 UHA. 89% (n=31) were Chinese with the majority in the lowest socio economic group (51%). 57% (n=20) lived with family caregivers (CG), cared for by spouses (40%). The most common cancer was gastrointestinal (GI) (29%) & lung (14%). There were 65 UHAs in total. A formal ACP was documented 28% (n=18) of the time. Median number of HC contacts was 5 (IQR 2.5–7) while median summation ESAS score was 6 (IQR 3–15). Most patients (57%) had a PPS < 60%. Most of the UHAs (63%) occurred after office hours due to physical symptoms (56%), i.e. dyspnea (17%) & pain (16%). Elderly Chinese with low socioeconomic status, Lung & GI cancer and cared for by their spouses appear to be at high risk of UHA. The high number of HC contacts 2 weeks preceding the UHA indicated their heightened needs. Formal ACP to establish goals of care early, emphasis on the 24/7 nature of HC support, simplified CG training & attending to the emotional needs of family members may help these patients manage better at home, potentially reducing UHA.
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Evaluating a Complex Palliative Care Intervention for Patients with Advanced Lung Cancer in Fife, Scotland: Demonstrating Impact through a Comprehensive, Mixed Methods Evaluation

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Background: In 2014 Fife Specialist Palliative Care secured funding to develop an innovative model of care for people with lung cancer who were for ‘best supportive care’. The proposal was informed by local expertise and evidence, and was supported by national and international evidence of unmet needs in people with lung cancer and of the wide-ranging benefits of proactive palliative care intervention. The overall aim of the project was to develop and pilot the new model of care in lung cancer, with a view to extending positively evaluated aspects to other patient groups with advanced malignant and non-malignant disease. Thus, the evaluation of the impact of the new model of care was critical.

Methods: A mixed-methods evaluation was undertaken, reflecting the complexity of the intervention and the spectrum of intended outcomes. The evaluation aimed to explore the meanings made by patients and families as they moved through the healthcare system and to make some analysis of the impact of the new model of care which encompassed:

- Quality of care and experience for patients, their families and carers
- Healthcare resource use

Results: 356 people with lung cancer, their families and carers have been supported by the new model of care to date. Identifying a historical group of patients for comparison of clinical pathways and outcomes was key to demonstrating impact through the evaluation. Qualitative interviews with service users and professionals prior to and following the new model being introduced provided meaningful insight into people’s experiences. Health economic analysis demonstrated clear cost savings as a result of more appropriate resource use, including a significant reduction in acute bed days. Key lessons learned from planning, conducting and reporting the evaluation will be discussed. Finally, plans for promoting the model nationally and internationally and extending the framework to other patient groups will be presented.
Understanding the Experiences of Caring for Advanced Cancer Patients who Require Emergency Department Care: Views of Health Care Professionals

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Background: The care of advanced cancer patients is complex and frequently involves multiple healthcare providers, with an Emergency Department (ED) presentation highlighting this complexity. The concerns of health care professionals providing care requires understanding.

Aims: To explore the views of healthcare professionals who care for patients with advanced cancer presenting to EDs.

Methods: Qualitative study exploring views of caring for advanced cancer patients in ED using
(1) focus groups with health professionals across disciplines/settings;
(2) semi-structured telephone interviews with ED providers across Australia.

The data were audio-recorded, transcribed, subjected to thematic analysis by 3 independent researchers, then discussed and consensus reached.

Results: In total, 8 focus groups (21 ED physicians, 22 ED nurses, 6 oncologists, 6 hospital and 28 community palliative care clinicians) and 11 telephone interviews (8 ED physicians, 3 ED nurses) were conducted (total 94 participants).

Three major themes emerged:
(1) healthcare professionals held contradictory understandings of palliative care, which was frequently seen as confined to the last hours of life;
(2) conflict between service providers delivering care, such as oncologists not confident to document limitations of treatment plans in case ED professionals misinterpreted them; and
(3) that ED professionals providing care highlighted tension between ideal care and realities of practice, such as the physical environment (privacy, noise, lack of information and delay and lack of defined pathways), and limited resources (access block and overcrowding, competition with other emergencies) were in tension with the desire to provide excellent, compassionate care.

Conclusion: The daily stressors of ED practice and entrenched perceptions of palliative care mean that ideal care for cancer patients is often not achieved. The need for improved communication between professionals is evident.
**Occupational Burnout Prevalence and Associated Factors among Kaunas Nursing Hospital Staff**

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Increasingly more reports in Lithuania are received about exhaustion of health care personnel, especially nursing specialist, emotional extenuation, unprofessionalism, conflicts in the working environment and indifference for the cared patients. Such phenomena indicate the prevalence of the burnout syndrome among health care personnel. The effects of the burnout gradually changes the medical staff as personalities, they become less flexible, react adversely to their surrounding society members and the environment. A research with participation of the Kaunas nursing hospital staff (doctors, nurses, assistant nurses) was performed for this purpose.

Aim of the study: to identify occupational burnout prevalence and associated factors among Kaunas nursing hospital staff.

The study attempted to identify problems affecting medical workers in their working and personal environment, the circumstances and work factors having a strong emotional and spiritual impact on them. The burden experienced by the medical personnel working with palliative patients, potential risk factors of the burnout, changes of behaviour and professional activities, and health disorders were identified.

The research method – quantitative research, anonymous questionnaire (validated Ch.Maslach burnout inventory), also it was used HAS scale and modified Dr. Steven Zarit questionnaire. The analysis of statistical data has been done by using SPSS 17.0 program and Microsoft Excel program. Statistical data analysis methods: chi square (χ²), exact Fisher, Mann-Withney U, Kronbach Alfa, Z - criterions, logistic regression analysis.

Statistically significant coherence (p<0.05) has been identified in occupational burnout and in individual and professional factors, such as age, workload, job satisfaction and relationship at work, involvement into making important decisions, stress frequency and disability to relax.
Nurses’ Attitudes towards Death on Institute Oncology of Ljubljana

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**Aim:** There are evidences that nurses’ attitudes toward death can have a significant impact on the way they care for their patients. As we didn’t have this data for our nurses, we decided to get them using a questionnaire.

**Method:** The multidimensional instrument Death Attitude Profile – Revised (DAP-R) was used. The questionnaire is composed of 32 statements grouped into five dimensions – Approach Acceptance (AA), Escape Acceptance (EA), Neutral Acceptance (NA), Fear of Death (FD) and Death Avoidance (DA). All the statements have a 7 point Likert scale from strongly disagree (1) to strongly agree (7).

**Results:** 123 (71.9%) questionnaires were returned. 91% of all the respondents were female, with an average age of 33.9 years and average work experience of 12.9 years. 44% had a higher education. 62% said they had a religious belief system. 27% come in contact with dying patients and death monthly, 24% daily, 23% weekly, 13% annually and 12% never. 54% have never had a previous education in palliative care (EiPC) and of those 72% said they would like to. NA had a mean score of 5.71 (±1.16), AA 4.13 (±1.85), FD 3.91 (±1.69), EA 3.89 (±1.90) and DA 2.97 (±1.71). A total of 46 significant correlations were found between the statements and demographic data. AA had a majority of these (27), as the statements have been found to be correlated with religious belief (10), EiPC (8), frequency of coming into contact with dying patients and death (4), age (3) and work experience (2). EA had 9 statement correlated with religious belief (4), age (2), work experience (2) and degree of education (1). EiPC also correlated with DA (5), FD (2) and NA (1). NA had 1 other correlation with age.

**Conclusion:** The majority of our nurses see death as a natural aspect of life. They believe it is a natural, undeniable, and unavoidable event. They don’t think that death is something to be avoided. Education about end-of-life care has a major role on the attitudes nurses have about death and dying.
From Evidence to Action: Scope for Improving Prognostic Communication and Management of Elderly Patients at the End of Life


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Background: Shared decision-making for elderly with poor prognosis is complex and has emotional, physical and financial implications. Delays in transition to end-of-life care pathways for the unrecognized dying elderly leads to suffering and misuse of hospitals.

Aims: Determine the timeliness of recognition of dying, communication of prognosis and appropriateness of care for hospitalized elderly with palliative care needs.

Methods: Four systematic reviews, two online surveys, a multicenter prospective cohort, a multicenter retrospective data analysis.

Results: Prognostic uncertainty and family pressure are two top reasons for doctors delivering unnecessary end-of-life interventions. A third of dying elderly receive non-beneficial treatments in the last six months of life. Unnecessary hospitalizations and long hospital stays are common among nursing home residents. Frailty is an independent predictor of death. Early discussions on the need for transition from active management to palliative care enable good deaths. Most older health service consumers want prognostic disclosure and participation in decision-making but clinicians perceive them as uninformed to make sound treatment decisions. Advance care documentation may lead to improved patient-doctor communication but high-level evidence is lacking. Early recognition of dying trajectories using evidence-based checklists is feasible in routine care. Decision aids at the end of life fail short of prognostic information and patient values. Futile care on elderly dying patients prolongs suffering, generates false hope for families, staff dissatisfaction and perpetuates unsustainable healthcare costs.

Conclusion and discussion: Public education on the science, ethics and cost-effectiveness of futile treatments and clinician’s uptake of prognostic tools in routine care to support open discussions can reduce the extent of suffering for elderly patients whose palliative care needs have not been identified early.

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Why Are People with Hematologic Malignancies Less Likely to Be Referred to Palliative Care and to Die at Home? A Qualitative Study on the Views of Italian Hematology Health Care Professionals

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People with hematologic malignancies (HM) are more likely to die in hospital when compared to people with solid tumors. Moreover, they are less likely to be referred to palliative care (PC) than solid tumor patients. Current study aimed to explore the views of Italian hematology health care professionals on the reasons why this happens.

A single-centre qualitative study based on grounded-theory principles enrolled 10 health care professionals working in a hematology ward in Italy. By the means of semi-structured interviews they were asked to talk about their experience in caring for hematologic patients, their views on the meaning of living with and dying from a hematologic illness, and on PC role in care pathway. Data were analysed to underline crosslinking issues and to draw a theoretical framework.

Complex interactions occur between communication processes, professionals’ and patients-families’ attitudes towards disease and care, illness and care pathway characteristics, organizational issues and how PC is perceived. Illness complexity and care pathway uncertainty, acute events occurrence, difficulties in predicting disease trajectory, high chances of therapy response may drive professionals to enhance hope and sustain positive communications. Sudden death is frequent and dying is lived as an acute event even when predictable. Lack of information-giving on end-of-life (EoL) and stigma on PC may preclude further planning. PC services may not provide adequate supportive care; patients are managed by Haematology specialists throughout whole care pathway.

Further research is needed in defining PC effectiveness, preferred place of care and death, illness and EoL trajectories, caregiver role. PC services should take into account illness complexity and unpredictability and develop flexible structures and effective communications. An effort should be done to break down stigma on PC, by the means of educational programs and close collaboration with hematology specialists.
Georgia National Palliative Care (PC) Strategic Plan – Progress Evaluation

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The main topics of this paper is presenting the current situation, achievements, challenges and barriers in the way of incorporation PC in healthcare (HC) system in Georgia. Giving the update of implementation Georgian National Program for PC, which was announced and presented during the 18th International Conference on PC in Montreal, 2010. For the research the qualitative method was used.

In 2010, the HC and social issues committee of the Parliament of Georgia approved the National Program for PC (for 2011 to 2015).

Since 2010 significant changes were made to increase the service network in the country: home-based PC service was implemented in capital and other districts of the country; three PC units for inpatient service were developed; more than 120 persons working in field of PC annually receive permanent salaries, handbooks, guidelines, and instructions of the first necessity are provided in Georgian language, educational courses on PC have been established in medical schools; Georgian National Academy of PC – Educational Research Resource Centre (GNAPC) started to provide international PC educational trainings for HC professionals.

The challenges in implementation of PC National Plan were meet since the 2013 and part of the activities were failed, which was effected the further implementation of quality PC in the country.

In peculiar, the inquiry-based study conducted at the initial step of PC launching, showed that the irrelevant comprehension of the state significance of PC by representatives of governmental structures, decision-makers and stakeholders are meaningfully impeding the decisions for approval of respective political strategy and financial assignments, necessary for preparation of appropriate human resources, drug availability and the practical implementation of PC. The years lasting tradition of tabooing the cancer diagnoses as well as widespread non-argument opioidophobia also have prevented the right understanding of this issue.
Inter-rater Reliability of the Physician Orders for Life-sustaining Treatment (POLST) form in Brazil

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Background: The Physician Orders for Life-Sustaining Treatment (POLST) Paradigm was developed in the USA and is considered one of the most successful strategies to translate the values of patients with limited life expectancy into a set of medical orders concerning cardiopulmonary resuscitation, a variety of medical interventions and artificial nutrition. We have recently performed the cross-cultural adaptation of the POLST form to Brazil. During that process we found that the inter-rater reliability of the POLST form has never been studied neither within nor outside the USA.

Aims: To assess the inter-rater reliability of the POLST form adapted to Brazil.

Methods: Eligibility criteria included age ≥ 21 years, being admitted at the Hospital where the study was conducted, an estimated length of hospitalization of at least 3 days at the invitation for the first interview and a negative answer from one of the patients’ physicians to the question: “Would you be surprised if this patient died within one year?” Two independent researchers interviewed patients using the same protocol within 7 days. Inter-rater reliability was assessed by Cohen’s Kappa and weighted Kappa statistics.

Results: Sixty-four patients were included in the study. Mean age was 64.2 years (SD: 13.7) and 35 (54.7%) patients were women. Median number of years of schooling was 5 years (IQR 4–16). Median score at the Palliative Performance Scale was 80% (IQR 60–90%). The raw proportion of agreement for cardiopulmonary resuscitation, medical interventions and artificial nutrition were 96.9%, 96.9% and 93.8%, respectively. The kappa statistics for inter-rater reliability concerning those domains were 0.91, 0.87 and 0.92, respectively.

Conclusion and discussion: Our study presents evidence of high inter-rater reliability of the POLST form adapted to Brazil. This finding will support the future implantation of the POLST paradigm in Brazil as a means to improve care at the end of life in the country.
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Improving Access to, and Advocacy for, Palliative Care through Developing Nurse Leaders in Uganda

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**Background:** Nurses have a pivotal role in the provision of palliative care (PC) & often spearhead development, shaping & guiding PC provision. They often work on their own & need to be equipped to lead and have roles as change agents and advocates, however, many have not had the opportunity to develop their own leadership skills.

**Aim:** To support the ongoing leadership of PC in Uganda through the development of nurse leaders & increase access to, & advocacy for, PC.

**Method:** In August 2015, 20 Uganda nurses were admitted to an 18-month nurse leadership fellowship (NLF). Three 1-week taught modules are interspersed with mentorship & supervision. 22 mentors were recruited in the UK to provide remote mentorship, with discreet periods of face-to-face mentorship in-country. Action plans were implemented after the first module, with nurses working on individual leadership skills as well as work-based projects. Following the second module, the nurses have been working on 4 national level projects, supported by faculty members & mentors.

**Results:** The NLF is having an impact, both on the nurses themselves and in increasing access to PC. Alongside individual leadership skills, nurses have implemented activities such as Link-nurse training, supervision & mentorship. 154 link-nurses have been trained, providing PC to more than 1,600 patients. Fellows presented 6 papers at an International Conference & have advocated for PC at the local & national level. 4 national projects are being implemented: a review of existing curriculum, nurse prescribing, a rapid appraisal of health systems & an evaluation of the link nurse program. Fellows have been recognised as leaders & invited to participate in national & international meetings.

**Conclusion:** The NLF has not only developed the nurses as leaders, but has led to increased access to PC, advocacy & other leadership activities. An evaluation of the program will be undertaken to review impact, challenges & replicability.
Integrating Palliative Care into National Health Systems in Africa: A Multi-country Intervention Study

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Background: Comprehensive and consistent palliative care is missing from the majority of essential health packages and health system plans in low and middle income countries (LMIC). Few models exist on how to achieve sustained integration in LMICs.

Aim: To develop a comprehensive public and primary health approach to facilitate integration of palliative care (PC) into national health systems in Africa.

Methods: A 3.5 year programme was implemented in 12 government hospitals, three each in Kenya, Rwanda, Uganda and Zambia. A four-pillared approach was utilised including advocacy, staff training, service delivery strengthening and international partnerships. A baseline assessment was undertaken and 27 indicators were agreed in order to guide and evaluate the intervention.

Results: Over 218 advocacy activities were undertaken and 4,153 community members attended awareness training. A critical mass of 781 staff were trained with the skills and resources to cascade PC through their organisations and into the community. All 12 hospitals had morphine available after 3 years (previously 6), supply chains had improved and prescribing had increased. 22 UK mentors contributed 750 volunteer days to support colleagues in all hospitals transfer knowledge and skills delivered through south-south training. 11 hospitals saw more than a 20% increase in identification of patients with more than 6,500 patients benefiting from PC services.

Conclusion: Integration requires investment in a set of core concurrent strategies. Integration requires simultaneously investing in: advocacy at all levels from Government to community; intensive and wide-ranging training across all cadres and disciplines to develop a critical mass; a set of core services supported by essential medicines; and investment in partnerships between hospital, district and community, and between international and national mentors and local staff.
New French 2016 Act for End of Life: “Except to Dye my Hands with your Blood, I Will Do All you Ask to Me” as Said Hyllos, to His Famous Dying Father HERACLES in the First Known Euthanasia Demand

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Aim and approach: Many countries adopted End Of Life (EOL) Acts. They concern 3 main axes: Medical Assistance for Dying (MAD), Medical Assisted Suicide (MAS), and Unreasonable Obstinacy (UO). In 2016 France adopted a quite different approach than others countries (French Act, FA). We compare FA and others countries’ acts regarding specifically these 3 axes.

Results:
MAD: Considering benevolence, it’s important to release suffering in EOL. For this aim, some countries allow doctors (Drs) to practice lethal injections (LI) on demand (so-called euthanasia in Belgium and MAD in Quebec). On the contrary FA imposes as a duty for Drs to use analgesics and sedatives at doses enough to relieve suffering, even at the risk to shorten life.

MAS: Considering autonomy, it’s important to respect EOL patients’ wills. Some countries assimilate wills to die as rights to die. Then, Drs must help patients to die quickly at the time they choose, either using LI (Belgium, Canada after federal Carter’s decision) or giving lethal preparation, taken by the patient himself (Swiss, Oregon). On the contrary FA forced Drs to respect patients’ wills (including expressed through advances directives). For example, patients with life sustaining treatment can legally obtain withdrawal and deep & continuous sedation until death occur.

UO: MAD or MAS demands can be only ways for patients to refuse UO. Paradoxically, countries which legalized LI or others MAS have indeed poor or even no law obligations for prohibiting UO. On the contrary, it’s one of the main point of FA, and Drs can be prosecuted if practice UO.

Conclusion: FA gave 3 new rights for patients: right not to be submitted to UO, right to be peaceful when dying even in complex situations needing sedative practice, and right to have their wills respected in any cases (excepting LI demands). This approach is closer to one of fundamental principles of Palliative Care: “Not to prolong and Not to shorten life”.

*Women of Trachis, Sophocles
What Do We Know about Palliative Care Development in Africa as a Continent? A Scoping Review of Comparative Studies

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Background: The first comprehensive cross-country comparison (CCC) on palliative care (PC) development in Africa is Wright & Clark’s (2006) “Hospice and PC in Africa: A Review of Developments and Challenges”. Since then, there has been no recent global comparative analysis of PC development across the whole continent.

Aims: To summarize relevant information on PC development in Africa from CCC studies.

Methods: A scoping review of peer-reviewed, published articles was conducted using PubMed, CINAHL, and Embase. 2 investigators independently rated each article by abstract and full text for inclusion according the dimension of the WHO PC Public Health Strategy (services, education, policies, opioid availability) and vitality.

Results: The search resulted in 465 articles, of which 27 articles met criteria for the final analysis. The most comprehensive CCC on service availability was Lynch et al’s (2013) “Mapping PC levels of development: a global update” on hospice-PC/population service ratios for 28 countries. For education, Rawlinson et al’s (2014) “The current situation in education and training of health-care professionals across Africa to optimise the delivery of PC for cancer patients” spoke of the progress in Uganda and South Africa in integrating PC in undergraduate and postgraduate training. For policies, Weaver et al’s (2015) “The prioritisation of pediatrics and PC in cancer control plans in Africa” compared 18 national cancer plans for inclusion of PC, though it focused on pediatrics. For opioid availability, Cleary et al’s (2013) report from the Global Opioid Policy Initiative compared 25 countries on opioid availability and consumption. There were individual but no comparative articles for vitality (national associations, research activities, conferences, advocacy).

Conclusion: There is a lack of up-to-date comparative analyses of PC development in Africa. The African Atlas of PC (under development) could fill that gap in the literature.
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Abstract type: Poster Exhibition

The Growth of Palliative Care in Nicaragua

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Background: Palliative Care is an essential component of care for patients with serious illness, particularly in the developing world where the vast majority of patients are diagnosed in advanced stages of disease. Unfortunately its introduction into these communities has been slow and fraught with barriers. Recently palliative care has grown in Nicaragua and has achieved some success. How Nicaragua has approached identifying and fulfilling palliative care needs may offer significant lessons to other developing nations.

Aim: Our aim was to conduct a palliative care needs assessment of the Nicaraguan health system and describe the perceptions of Nicaraguan palliative care experts regarding current areas of need and growth, and brief description of initiatives that have been put in place to help meet these needs.

Methods: Individual and focus group interviews with eighteen health care professionals working in palliative care in seven Managua hospitals. Results are developed by qualitative data analysis of interview transcripts for themes.

Results: Three areas were highlighted for improvement: education, medication availability, and palliative care awareness. A palliative care network was then established with the goal of developing and implementing interventions to overcome these barriers. Initiative they developed were improving access to palliative care education for community and health care personnel, and collaborating with the ministry of health to improve availability and access of opioids.

Conclusion: Understanding the barriers to providing palliative care in Nicaragua may help other countries with similar health care resource limitations and economies by permitting sharing solutions to overcome these barriers in providing optimal palliative care to patients within developing nations.
How Brazil Regulated Advance Directives and Why it Could Help Other Countries in Designing their Policies for End-of-Life Care

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Aim: To describe how advance directives have been regulated in Brazil and to explain how those regulations represent an innovation for the care at the end of life.

Design: Descriptive study

Results: In Brazil, unlike other countries, the regulation concerning advance directives (AD) was issued neither in State nor Federal law but as a resolution of the Federal Medical Council (FMC) in 2012. That resolution defined AD as the set of preferences of care that a patient has manifested explicitly concerning treatments he/she would want or not to receive if unable to communicate his/her will. It determines that physicians shall register the AD in the medical records and it states that physicians shall take into account those AD, including information provided by representatives appointed by the patient. One advantage of that regulation is that it was built within the heart of the medical profession, where decisions concerning withholding or withdrawing of life-prolonging treatments are made. It is also much easier to discuss, reach consensus and update such regulations within the FMC than it would be in any legislative parliament. Additionally, that regulation does not require notarization of AD, which decreases many barriers for advance care planning, and places emphasis in the domain of patient-physician relationship, where physicians can instruct, advice and support patients. Finally, AD are not treated as inflexibly binding documents but as an important piece of information that physicians must consider together with other pieces of information (e.g., from patients’ representatives and the clinical situation) to reach the best possible decisions to protect patients when they are unable to communicate their choices.

Conclusion: Although Brazil still faces multiple challenges to improve the provision of care at the end of life; we believe that the way advance directives were regulated in Brazil could offer some interesting insights for other countries about those matters.
### Background
Information on the state of palliative care (PC) in EMRO region is scant. This study is the first attempt at a systematic descriptive analysis of PC development in the region.

### Aims
To describe the current status of PC in EMRO countries according to the WHO PC Public Health Strategy, policies, opioid accessibility, services availability, educational programs, and national initiatives.

### Methods
Surveys were sent by email to up to two leaders of PC in each country. A follow-up telephone interview was conducted with one leader from each country. A scoping review of the state of PC in EMRO countries using the WHO PC Public Health Strategy was conducted using PubMed, CINAHL, and Embase.

### Results
Completed surveys were received from 15 of the 23 countries; telephone interviews were conducted with leaders from 14 of those countries. Among the countries that responded, only Kuwait has PC legislation, and PC is recognized as a specialty only in Saudi Arabia, Lebanon, Iran and Oman. Although Morocco, Qatar, Tunisia and Oman are the only countries with national PC programs, several other countries have programs under development. About half of the countries represented have national PC associations. Most countries have limited access to opioids, and there is limited access to basic PC services. Saudi Arabia (n=42) and Egypt (n=13) have the highest number of active PC services in the region, but these services are not covered by government or reimbursed by private insurance. PC education has been integrated in medical and nursing school curricula in Lebanon, Jordan, Oman and Pakistan. In the scoping review, 498 total articles were found; 425 after excluding duplicates. 113 titles and 96 abstracts met inclusion criteria. Lebanon had the greatest (n=27) followed by Jordan (n=11).

### Conclusion
PC remains underdeveloped in most EMRO countries. Efforts and resources should be mobilized to address the gaps identified to ensure that PC becomes accessible across the region.
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How to Promote Brilliant Palliative Care: An Interstate Study Using Video Reflexive Ethnography

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Background: Evidence-based practice is critical to quality palliative care (PC); yet clinicians inconsistently draw on evidence. Given the growing need for PC, it is important to better understand how clinicians coalesce generic guidelines with organisational protocols, government policies, and patient care and preferences. It is also important to understand how clinicians manage longstanding organisational challenges, like resource-scarcity, and deliver brilliant care – that is, PC that exceeds expectation and brings delight.

Aim: To promote brilliant evidence-based PC by clarifying the factors that enable it to flourish.

Methods: This study fused positive organisational scholarship (POS) and video reflexive ethnography (VRE). POS awards primacy to that which is life-giving, while VRE encourages individuals to learn from practices. To broaden the scope of the study, it was conducted in two community health services across two Australian states. Video footage of PC was captured for one year, and interpreted collaboratively by the researchers and clinicians. Analysis involved the identification of recurring, as well as idiosyncratic themes that helped to clarify the factors that contribute to brilliant evidence-based PC.

Results: Three key findings were apparent. First, brilliant evidence-based PC appears to require an interdisciplinary team of clinicians who genuinely work alongside patients and their families. Second, it involves a genuine respect for unconventional forms of evidence, like patient knowledge, transferred largely through Gabbay and le May’s mindlines. Third, it is enabled by positive deviance to workaround organisational challenges.

Conclusion: Brilliant evidence-based PC can be promoted by supporting clinicians to: work across disciplines; meaningfully engage with patients and their families; recognise and adapt different forms of evidence transferred via mindlines; and perceive challenges as opportunities to exercise creativity and innovativeness.
Tea Time: An Ethnographic Study of Tea Practices and Care in a British Hospice

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Tea is served in abundance in a British hospice yet there is little, if any, research into why it is that practices of tea have been inculcated into practices of hospice care in Britain. This paper explores different tea practices that have become embedded in the philosophy and practices of ‘hospice care’, as both a ‘tasks of care’ and an ‘emotional care’ such as compassion.

The research followed a modified Grounded-Theory approach. Ethnographic data was collected during a six week period by means of participant observation and semi-structured interviews of staff and volunteers in a British hospice.

Tea practices were very much intertwined and linked to care practices in the hospice. ‘Care’ is a multi-vocal word and can refer to both routine tasks of care or as an emotion, such as compassion. The two aspects of care, whilst separate are related, often conflated and yet remain inextricably linked. The complexity became apparent when participants were describing tea practices. Tea provided care as a form of hospitality to patients and their families but also used symbolically by healthcare professionals to ‘break down barriers’ as a demonstration of emotional care in bereavement. Offering tea provided a liminal space in which dialogue and compassionate care could be enacted. It was, however, also demonstrated that tea drinking is a culturally specific practice and that not everyone shares the same meanings associated with the beverage.

Tea practices align well with hospice philosophy providing holistic, family focused care and an opportunity for social interaction as opposed to medical intervention. Such practices, however, may also become problematic if seen to become routinised and also must be remembered that they form part of a culturally specific practice of care that may not resonate with all.

This paper demonstrates the value of ethnographic qualitative research in a holistic speciality such as palliative medicine, providing a platform for further research.
How to Approach End-of-Life Decision-Making in Chronic Progressive Disease: A Patient’s Story

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Background: The time-period in which incurable cancer patients do well by undergoing anti-cancer treatment is rising. Immunotherapy and targeted therapies have significantly prolonged survival. Such developments go along with less predictable disease trajectories and more prognostic uncertainty.

Aim: To longitudinally explore the experiences of patients with chronic progressive disease.

Methods: This ethnographic study (observational, interviews; such as day-care unit and doctor-patient consultations) in a cancer hospital describes medical practice focusing on the chronicity of cancer as of April 2015. We here present data of one lung cancer patient.

Results: A 72-year old woman was diagnosed with lung cancer 7 years ago; 2 years later she developed metastases. Genetic tests showed a mutation in the epidermal growth factor receptor (EGFR) and she started with gefitinib. She visited the hospital every three months. Given the side effects of gefitinib (like fatigue and nausea), it was decided to halve the dose. She highly appreciated the extensive discussions about quality-of-life and her uncertain prognosis. She was nevertheless scared to die, and conversations with a psychologist appeared to be very helpful. She started writing again. With this new life goal, her energy increased and she finished her autobiography approximately 6 months later. She felt she continued life like the period before being diagnosed with cancer. After the book release she started feeling more nauseous and tired. She realizes that she became afraid again, focusing on the next CT-scan only.

Conclusions/Implications: Partly due to new forms of ‘palliative’ systemic treatment, the previously well-defined borders between ‘curative’ and ‘palliative’ care seem to fade away. The prognosis of NSCLC, stage IV- EGFR+ differs from other types of lung cancer with some living more than 5 years. New ways to approach life and end-of-life decision-making need to be further explored.
Abstract number: P02-318  
Abstract type: Poster Exhibition

Health Care Utilisation in the Last Six Months of Life in Patients with End-stage Liver Disease: An Analysis Using the National Health Insurance Research Database (NHIRD) of Taiwan

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Background: End-stage liver disease (ESLD) is a major cause of morbidity and mortality in Taiwan. However, little is known about the health care utilisation during the end of life of these patients.

Aims: This study aimed to describe the patterns of health care utilisation by patients with ESLD in their last six months of life.

Methods: Population-based descriptive study using the NHIRD of Taiwan. All non-accidental adult decedents with ESLD who died in 2013 were included. Those who had malignant neoplasm of liver or intrahepatic bile ducts were excluded. Their health care utilisation were routinely recorded and described by using mean (standard deviation) or median (interquartile range, IQR and range, min-max) as appropriate for continuous data and proportion for categorical data.

Results: In 2013, 2944 adult patients died with ESLD in Taiwan. Most of the decedents were 40–64 years (55%) and predominantly male (69%). Nearly half of them (48%) died in hospital, and an additional 31% were discharged only when death was imminent. During the last six months of life, the median outpatient clinic visit was 18 (IQR=15, range 0–115), and the median emergency department attendance was 2 (IQR=3, range 0–60). The median number of hospitalisation was 3 (IQR=2, range 0–17), and the median length of hospital stay was 32 days (IQR=40, range 0–180). Only 21% of these patient received palliative care, including palliative shared care during hospitalisation (16.0%), palliative care unit admission (5.0%), palliative home care (3.4%), and formal family conference for advance care planning during hospitalisation (1.9%).

Conclusion: Our study revealed high level of health care utilisation in patients with ESLD in their last six months of life in Taiwan. However, their utilisation of palliative care services were low. Further studies focusing on the gap between their need and utilisation as well as the factors associated with their utilisation patterns can be of value.
Advanced Organ Disease Nurse Specialist Community Posts – A Pioneering Approach to Increase Access to Palliative Care for those with Advanced Liver and Renal Disease

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Background: It is well recognised that the palliative care needs of patients with advanced organ failure are similar to those with advanced cancer, yet the numbers of patients with non malignant disease referred to palliative care services (including our own unit) remains low (< 10% of all referrals). Our hospice looked for an innovative solution to increase access to palliative care for patients with organ failure.

Aim: To increase the numbers of patients with advanced liver and renal disease having their supportive needs assessed.

To increase access to palliative care services for people with advanced liver and renal disease.

To provide opportunities for advance care planning for these patients.

Method: We created innovative clinical nurse specialist posts in Advanced Liver Disease and Advanced Renal Disease, to work in the community setting (but able to review patients in the hospital and hospice settings). These nurses created new patient pathways, working with the hospital liver and renal teams, resulting in joint clinics, MDMs and new routes for referral in to palliative care.

Results: Within the first 3 months of the project, referrals to palliative care for patients with advanced liver disease have matched the previous 12 months already (projecting a four fold increase in referrals over the first year) and numbers of referrals into the renal service demonstrates a 19 fold increase (15 referrals in 3 months vs 3 in the previous 12 months). Further data will be available at conference. Patients are benefiting from various palliative care services, including day hospice and counselling as well as carer support and advance care planning clinics.

Conclusion: These innovative posts, through the process of joint working and changing patient pathways have the ability to significantly increase the numbers of patients with organ failure having their supportive care needs assessed and accessing appropriate palliative care services.
Abstract number: P02-320
Abstract type: Poster Exhibition

Is Palliative Care Appropriate for People after a Major Stroke?

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Background: The prognosis of people with total anterior circulation strokes (TACS) is as poor as many cancers, yet they are rarely identified for a palliative care approach.

Aims: To describe the experiences, identify unmet multidimensional needs, and determine whether a palliative care approach may be appropriate.

Methods: We conducted serial qualitative interviews with patients from 3 Scottish regions, and their informal and professional carers at 6 weeks, 6 months and 12 months after the stroke. Patients when able also completed the Patient Outcome Scale and the Euroqol5D-5L, and carers the Carer Strain Index. We also conducted a data linkage study of TACS patients admitted to the three regions during the study period.

Results: We conducted 99 interviews with 29 patients and their carers. 19 patients died. Patients and carers faced life and death decisions from the onset; patients experienced anxiety, pain and difficulty adapting to hospital life. Many died in hospital within 6 months. Uncertainty about the future and the sudden onset made good communication between professionals, patients and family vital. Transition home or to care home often brought a feeling of abandonment. Patients and families wished on-going support, with aphasia causing particular challenges. Adapting to new roles and identities and access to various resources took time. Participants found it difficult to discuss and plan for the future with different understandings and expectations. Data linkage showed that 60% of patients died within 12 months, of whom 92% died in hospital.

Conclusions: A rich understanding of participants’ experiences, needs and wishes was obtained. Improving communication, assessment, and planning were key themes. Given that all faced death, uncertainty, and difficult decisions from the outset, and wished for a more holistic approach to care, a palliative care approach could be helpful, both in hospital and in the community, although it may need a different name.
Adjuvant Criteria to Assist the Understanding of the Evolution Curve of Heart Failure and the Decision-Making Process

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Background: Patients (Pts) with Chronic Heart Failure (CHF) often many experience episodes of worsening of symptoms needing hospitalizations. It’s hard to know when these Pts are in final stage of life and make decisions.

Aims: Investigate hospitalization characteristics to identify high risk factors for inhospital mortality, in order that a palliative care (PC) team could be consulted briefly, to favour in decision-making and care.

Method: This was an observational, retrospective and unicentric study with 103 Pts with worsening of CHF needing inotropic drugs, from June 2014 to November 2015. We compared baseline and hospitalization characteristics of Pts that died in hospital and the ones discharged. Transplanted or listed Pts were excluded. Statistics were made using Qui-square, Student’s T-test and by ROC curve calculating the area under the curve (AUC). Confidence interval used was 95%.

Results: 68% were male, mean age of 61.8 (SD13.2) years, ejection fraction of 29.7% (SD11.5). 68% had previous NYHA functional class (FC) III/IV. Mean stay in hospital was 29.1 (SD26.8) days and in intensive care unit (ICU) 11.6 (SD19.3) days. 54 (52.4%) Pts died during hospitalization. Were statistically significant to predict inhospital mortality: FC III/IV (81.5% of pts who die had x 53.1% of discharged, p=0.002) and length of stay in ICU, mean of 16.2±22.1 x 6.6±14.3 days (p=0.011).

The AUC identified 15.5 days as the cut off for better sensibility (83.7%, p=0.011). Analysed together, this 2 criteria have a synergism, with a sensibility of 91.8% (p=0.003) and a negative predictive value of 81.0%.

Discussion: The combination of FC and length of stay in ICU are good predictors of inhospital mortality in pts presented with worsening CHF needing inotropic drugs, and can be used to help decision-making.

Conclusion: Identification of high risk pts for inhospital death and an early consultation to a PC team may lead to a better end-of-life care and improved use of health resources.

<table>
<thead>
<tr>
<th></th>
<th>Death N=54</th>
<th>Not Death N= 49</th>
<th>p</th>
<th>Sensibility</th>
<th>Specificity</th>
<th>Positive Predictive Value</th>
<th>Negative Predictive Value</th>
<th>Accuracy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Class III or IV</td>
<td>81.0%</td>
<td>53%</td>
<td>0.002</td>
<td>46.9%</td>
<td>81.5%</td>
<td>69.7%</td>
<td>62.9%</td>
<td>65%</td>
</tr>
<tr>
<td>ICU length of stay &gt;15.5 days</td>
<td>38.9%</td>
<td>16.3%</td>
<td>0.011</td>
<td>83.7%</td>
<td>38.9%</td>
<td>55.4%</td>
<td>72.4%</td>
<td>60.2%</td>
</tr>
<tr>
<td>Both Criteria</td>
<td>31.5%</td>
<td>8.2%</td>
<td>0.003</td>
<td>91.8%</td>
<td>31.5%</td>
<td>54.9%</td>
<td>81.0%</td>
<td>60.2%</td>
</tr>
</tbody>
</table>

[Statistical analysis for FC and ICU length of stay]
The Role of Community Pharmacists in Providing Palliative Care to People with Advanced Dementia Approaching the End of Life: A Qualitative Study

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Background: People with advanced dementia approaching the end of life (EOL) have been reported to be at an increased risk of polypharmacy (multiple medication use) and potentially inappropriate prescribing. However, little is known about the role of community pharmacists (CPs) in providing palliative care to this vulnerable patient group.

Aims: To explore the role of CPs in providing palliative care to people with advanced dementia approaching the EOL.

Methods: Twelve (six face-to-face and six telephone) semi-structured interviews were conducted with purposively sampled CPs recruited from a network of community pharmacies providing palliative care services in a region of the UK. Interviews were recorded, transcribed verbatim and analysed using thematic analysis. Two researchers confirmed final themes. Ethical approval was granted from the University ethics committee.

Results: An overarching theme of ‘the pharmacist as an intermediary between healthcare professionals (HCPs) and patients’ representatives’ was identified. Three subthemes emerged from this: unique role, relationships and communications, and a desire to become more involved. CPs’ knowledge and skills appeared to be under-utilised in the provision of palliative care to people with advanced dementia approaching the EOL. Communication between HCPs and patients’ representatives was not always optimal. CPs expressed that they had little involvement in providing palliative care to patients with advanced dementia approaching the EOL, but they identified a need and expressed their willingness to become more involved.

Conclusion: This study highlights that CPs are often a forgotten resource in the provision of palliative care for people with advanced dementia. With the appropriate training and resources, CPs’ role in decision-making regarding medication use for patients with advanced dementia may be enhanced.

Funding: This work was supported by the Department for Employment and Learning Northern Ireland.
Management of Dyspnea in Hospitalized Patients. Time for a Paradigm Shift

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Background: Dyspnea is frequent and disabling in patients with heart failure (HF) and respiratory diseases (RD). In spite of the availability of effective treatments that improve of this symptom, such as opioids, these drugs are probably underused in non-cancer related dyspnea management.

Aims: We aimed to describe and quantify the use of non-pharmacological and pharmacological measures for dyspnea relief in HF and RD patients.

Methods: Prospective longitudinal registry performed in the hospital setting. The electronic notes and prescriptions were reviewed. Patients were also asked to mark in a questionnaire the methods they used for dyspnea relief.

Results: Between April and September 2016, 259 patients were included (190 HF and 68 RD). Mean age was 74.0±1.2 years, and 157 (60.6%) were male. A total of 71 (27.6%) required admission in an intensive care unit, (62 [32.6%] HF vs. 9 [13.4%] RD, p=0.001); and 48 (18.7%) required non-invasive ventilation, (31 [16.3%] HF vs. 17 [25.4%] RD, p=0.10). Benzodiazepines were prescribed in 138 [53.7%], (112 [58.9%] HF vs. 26 [38.8%] RD, p=0.04). Opioids were used in 41 [15.9%] (34 [17.9%] HF vs. 7 [10.3%] RD, p=0.1). Mean dose by Morphine Equivalent Daily Dose was 8.7±0.8 mg (8.0±0.6 in HF vs. 12.3±3.3 mg in RD, p=0.03). Continued treatment for refractory dyspnea was only used in 15 patients (36.6%), (10 [29.4%] in HF vs. 5 [71.4%] in RD, p=0.04). The methods used by patients for dyspnea relief previous to hospitalization are described in Table 1.

In 59 patients with severe dyspnea at discharge (≥5 points in a 0–10 numerical scale) opioids were used only in 16 (27.1%).

Conclusion: Effective treatments for dyspnea are underused in patients with HF and RD, especially opioids. Few patients received a continued treatment for chronic refractory dyspnea. Our data suggest a great room for improvement and the need to a paradigm shift regarding dyspnea assessment and management in these patients.

### Methods used by patients for dyspnea relief

<table>
<thead>
<tr>
<th>Method</th>
<th>Total N=258</th>
<th>Heart Failure N=190</th>
<th>Respiratory Medicine N=68</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleeping with high headboard</td>
<td>140 (54.3)</td>
<td>115 (60.5)</td>
<td>25 (36.8)</td>
<td>0.001</td>
</tr>
<tr>
<td>Fan</td>
<td>16 (6.2)</td>
<td>15 (7.9)</td>
<td>1 (1.5)</td>
<td>0.03</td>
</tr>
<tr>
<td>Oxygen</td>
<td>46 (17.8)</td>
<td>15 (7.8)</td>
<td>31 (45.6)</td>
<td>0.0001</td>
</tr>
<tr>
<td>Continuous Positive Airway Pressure</td>
<td>24 (9.3)</td>
<td>11 (5.8)</td>
<td>13 (19.1)</td>
<td>0.003</td>
</tr>
<tr>
<td>Inhalers</td>
<td>91 (35.3)</td>
<td>37 (19.5)</td>
<td>54 (79.4)</td>
<td>0.0001</td>
</tr>
<tr>
<td>Communication with GP regarding dyspnea</td>
<td>153 (59.5)</td>
<td>98 (51.6)</td>
<td>54 (82.1)</td>
<td>0.0001</td>
</tr>
<tr>
<td>Seeking for medical attention during admission due to acute dyspnea</td>
<td>96 (37.5)</td>
<td>73 (38.6)</td>
<td>23 (34.3)</td>
<td>0.53</td>
</tr>
</tbody>
</table>

(Methods used by patients for dyspnea relief)
Palliative Care Consultation for Hospitalized Cardiologic Patients: Increasing Recognition of Needs But Still Too Late Evaluations


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Background: Heart failure (HF) is a major cause of hospitalization worldwide, demanding expressive health resources and expenses. Advanced HF is becoming more common, requiring palliative care (PC) approach in order to promote a better care, health resources allocation and quality of life.

Aims: To understand the context, reasons and time of PC consultation asked for cardiologic hospitalized patients (Pts) in order to highlight opportunities to improve quality of care and more rational and cost-effective use of health resources.

Methods: We reviewed forms of evaluation and follow-up of a tertiary cardiology school hospital Pts from January 2010 to July 2016 provided by the PC specialized team.

Results: 391 forms were reviewed. There was a continuous increase on demand for PC consultation from 2010 to 2015 (28 to 116 consultations asked, resulting in a 314% increase in 5 years). 53% were men, mean age of 68.6 (SD 19.2) years. More than 85% have a Palliative Performance Scale less than 50%. About 95% already were in terminal phase of HF or in actively dying process. Pts stayed in hospital in a median of 33.2 (SD 40.9) days, being under simultaneous evaluation with PC team for just a quarter of this period, on average. Only 14% of the Pts received more than 5 medical visits, and for 11.5% there wasn’t enough time for a single evaluation, majorly (87%) because they died before.

Discussion: We observed a progressive and marked increase in the number of PC consultation requests, also seen in partial numbers of 2016, reflecting a greater recognition of the need for PC among HF patients. Most of the requests were for critically ill patients or in late stage of HF. Pts stayed few days accompanied by PC specialists, not allowing enough time to complete palliative interventions and advanced care planning.

Conclusion: HF hospitalized Pts have a great need for PC and they should be recognized early enabling a more efficient approach by PC team to allow a better end-of-life care.
Ethnographic Study of Agitation in Frail Older People with Advanced Dementia

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Background: Agitation is common in advanced and terminal dementia and is distressing for individuals, families and staff. It may arise from unmet need e.g. pain, thirst or boredom.

Aims: To enhance understanding of agitation in people with dementia at the end of life, how it is perceived and responded to by paid and family carers in care homes and acute hospitals, developing theory in an unexplored and sensitive area.

Methods: Non-participant ethnographic study in 2 acute hospitals and 2 care homes, of people with advanced dementia or with moderate dementia and acute illness, focussing on behaviours and care received (structured observations of type and frequency of agitation, staff response, environment and field notes), and in-depth qualitative interviews with staff and families. Observations were coded in NVivo, and themes developed iteratively, analysed in the context of preceding events and used to ground analysis and theory development from the interviews.

Results: 12 hospital patients and 5 care home residents were observed (median 2 observations each, lasting on average 2 hours 25 minutes). Common types of agitation were verbal aggression, hitting & resistance to care. Staff response varied by context. Care home staff had better knowledge of residents, responding in a personalised way. Hospital patients were left for periods without intervention and response varied among sites, reflecting structures such as institutional attitude to dementia and staffing levels. 19 staff (mixed roles) and 8 family carers were interviewed. They could attribute causes of agitation but were less confident how to respond. Key themes were feeling overwhelmed and anxious leading to a fear of approach and engagement. These were ameliorated by knowing the person well, training and confidence.

Conclusion: Organisational context and culture were key drivers of how staff in hospitals and care homes understand, respond to and manage agitation in advanced dementia.

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Abstract number: P02-327  
Abstract type: Poster Exhibition

Examining Anxiety, Depression, Self-care and Quality of Life in Advanced Heart Failure Patients

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Background: Evidence indicates that the long term prognosis of heart failure (HF) is worse than many cancers. The unpredictable disease trajectory and high symptom burden makes clinical management complex. Therefore, it is important to examine symptom burden and quality of life (QoL) for people living with advanced HF.

Aim: To evaluate levels of depression and anxiety, self-care and QoL in a cohort of patients with advanced HF in Ireland.

Methods: A postal survey using validated instruments measuring depression, anxiety, QoL, illness beliefs and self-care was undertaken. Patients with advanced HF were recruited from three regional health care trusts in both Northern Ireland and Republic of Ireland. Data analysis was undertaken using SPSS.

Results: Some 112 patients completed the questionnaires. A similar number of patients had depression 19 (20%) and anxiety 19 (19%) scores warranting further evaluation. Patients < 75 years had higher levels of depression (P=0.024) and anxiety (P=0.005) and poorer QoL (P=0.005) compared to those aged ≥ 75 years. More than half the patients (n=59) had inaccurate acknowledge of their condition and those with inaccurate knowledge had significantly lower self-care maintenance (P=0.109) and management scores (P=0.034). The number of self-reported appointments with healthcare professionals (HCP) in the previous 6 months ranged from 1–51. There was a significant relationship between the number of visits patients had with HCPs and self-care management (r=0.275 P=0.035). However, there was also a significant relationship between the number of appointments and overall QoL (r=0.294 P=0.017) and physical QoL (r=0.317 P=0.003), suggesting patients’ QoL declined, the more frequently they attended appointments.

Conclusion: Younger age was associated with poorer outcomes in relation to depression, anxiety and QoL. Improving patients’ knowledge could lead to better self-care abilities.
The current Evidence Base for the Feasibility of 48-hour Continuous Subcutaneous Infusions (CSCIs): A Systematically-structured Review

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Background: A continuous subcutaneous infusion (CSCI) is an effective method of multiple drug administration commonly encountered in end-of-life care when the oral route is compromised. At present, current practice is to limit syringe driver infusion time to a maximum of 24 hours as dictated by available chemical and microbiological stability data. However, the ability to deliver prescribed medication by a CSCI over 48 hours may have numerous benefits in both patient care and health service resource utilisation.

Aim: To present the current evidence base for the stability of 48 hour multiple-drug CSCIs in current clinical practice.

Design: A systematically-structured review following PRISMA guidelines.

Method: Three electronic databases (CINAHL, EMBASE, and MEDLINE) and the grey literature were searched with no time limits. Empirical studies published in English reporting data on the physicochemical or microbiological stability of continuous subcutaneous infusions or solutions stored in polypropylene syringes were included. Full-text articles were assessed against a modified version of a data extraction template suggested by Hawker et al.

Results: Ten studies were included in this review reporting the chemical compatibility and stability of 51 different combinations of 12 drugs. Of the 51 combinations, 25 used drugs and concentrations relevant to UK clinical practice. All 51 combinations reported were assessed as being chemically compatible 48 hours at ambient temperatures (20–26°C). The greatest risk of clinically significant chemical degradation was observed with midazolam. Only one study reported the microbiological stability of the solution examined.

Conclusion: There is currently limited evidence for the physical, chemical and microbiological stability of solutions for continuous subcutaneous infusion over a period of 48 hours. More stability data is required before the use of 48-hour CSCIs can be evaluated for use within clinical practice.
What Do Healthcare Workers Think about Palliative Care in Parkinson’s Disease? A National Survey and In-depth Interviews

**Background:** A palliative care approach is recommended in all life-limiting diseases, including Parkinson’s disease (PD). However, research shows that people with PD have unmet palliative care needs.

**Aims:** The aim of this study was to investigate the knowledge, attitudes, and training of Irish health care workers (HCWs) in palliative care in Parkinson’s disease (PD).

**Methods:** This was a multi-method study. A survey was distributed nationally to HCWs (final n=306), and in-depth interviews were conducted with 30 HCWs. Results were analysed with SPSS (surveys), and Thematic Analysis (interviews).

**Results:** The survey showed that most HCWs (90%) believed that people with PD have palliative care needs; however, 76% of HCWs said that these needs are met “sometimes” or “never”. Few people with PD are referred to Specialist Palliative Care; 48% of hospital consultants had referred no patients in the previous 6 months, and 7% had referred >10. These results were explored in-depth in the interviews. A number of perceived barriers to palliative care in PD were evident. A lack of education on PD and palliative care meant that HCWs were unsure of the appropriateness of referral, and patients and carers weren’t equipped with information to seek palliative care. A lack of communication between PD and palliative care specialists impedes collaboration. Uncertainty about the timing of palliative care meant that it was often not introduced until a crisis point, despite the need for early planning due to the prevalence of dementia.

**Conclusion:** Most HCWs recognised a need for palliative care for people with PD; however, several barriers need to be addressed to deliver this care. Implications for clinical practice and policy include the need for an integrated model of care, and education for HCWs, patients, carers, and the public on the nature of advanced PD, and the potential of palliative care in support of patients and their families.
**Background:** COPD is the fourth leading cause of death in the world. Advanced COPD can produce similar distressing symptoms as advanced cancer. Despite this, access to palliative care is lower, probably because of a lack of knowledge about the natural history of COPD and experience in follow-up in palliative care settings.

**Main objective:** Describe the natural history and end of life of advanced COPD patients followed by a palliative homecare team.

**Methods:** Prospective observational cohort of patients with COPD stage IV referred to our palliative homecare team to be followed up from pulmonologist, family care physicians and palliative care units.

All data were analyzed by SPSS vs 18. Survival mean was calculated by Kaplan Meier method.

**Results:** 50 patients were included from December 2012 to October 2016. At the endpoint 37 had died. Age mean 73 years (sd 13), 76% males. At the beginning of the follow-up mean VEMS1 was 26 (sd 4.39), BODE index 8.4 (sd 1.5) and PPS 52 (sd 10.69). Dyspnea grade IV was the main symptom at the first visit in 45 patients (90%) with 5 points mean (sd 2.38) in ESAS scale. Opioids were needed to control dyspnea in 35 patients (77%), mainly morphine (90%) at a mean dose of 17 mg (sd 16). Survival mean of the cohort was 8.5 months (IC 2.4–20). 18 patients (48%) died at home and 12 (32%) died at hospice. The main cause of death was respiratory failure (90% of patients). Sedation was needed in 24 patients (65%) mainly because of dyspnea in 20 cases. Advanced directive was worked with 18 patients (48%).

**Conclusions:** Describe natural history of COPD can help to identify inclusion criteria for palliative care programs. The profile of our patients is males with severe grade of airway obstruction, functional impairment and an important dyspnea that needs opioids for control and has a relatively short survival time. The inclusion in a palliative care program of these patients seems to facilitate die at home or hospice and develop advanced directives.
Abstract number: P02-331
Abstract type: Poster Exhibition

Demonstrating the Potential Benefit of Palliative Care Input for People Living with Dementia, Using Case Studies

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Background: Although dementia is a life-limiting illness, it is often not recognised in this way. People with dementia, and their carers, have been shown to have palliative care needs equal to those of cancer patients. Although palliative care is recognized as quality care at end-of-life, palliative care for people with dementia is still evolving.

Aim: To demonstrate the benefit of a palliative care approach for people with dementia, through case studies.

Methods: We conducted 6 case studies with people with dementia and their families. We used quantitative (questionnaires) and qualitative (interviews) data to explore their palliative care needs, and potential benefit of Specialist Palliative Care input.

Results: Caring for a loved with dementia is very difficult, carers experienced high levels of anxiety, depression, and caregiving-burden. Carers wanted more emotional support, and felt that sometimes they were not included in the unit of care. Carers found it difficult coping with transitions of care, especially when a decision was made to move the person with dementia into long term care. Many carers experienced anticipatory grief. In cases of young onset dementia (< 65 years) their children can greatly benefit from emotional support.

Conclusion: People with dementia and their families could be greatly supported through a palliative care approach. Carers value formal psychological and emotional support, assistance with decision-making about their loved one’s care needs, and advice on advance care planning.
Use of Opioids and Characteristics of Non-cancer Patients Admitted in a Hospital Palliative Care Unit (PCU)

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Background: There are very few studies about the needs and doses of opioids, for pain and dyspnea, requiring at the end of life in no cancer patients. That could be hold because of the low percentage of these that are referred to a PCU, and low evidence in their use, lack of education by no palliative doctors.

Aim: Identify indications of opioid use and profile of palliative no cancer patients referred to our PCU.

Methods: Retrospective study of the last two years inpatients. Collecting data by reviewing clinical records of demographics data, reasons and indications of opioid treatment, type of opioid, dose, route, opioid switching during admission, average daily opioid dose. An statistical analysis of the data with SPSS 12 was used.

Results: A total of 1203 patients were reviewed, obtaining 12% of non-cancer patients (N: 143) patients with disease mixed disease (advanced cancer associated with advanced organ) were rejected. A 67% of patients are referred from other hospitals being 54% women with a median age 82 years (39–107) and staying in our UCP an average of 25 days. Only 14% were discharged home. The most common diseases was neurological 40%, and cardio-respiratory 18%–14%. The use of opioids in our sample is 76% (N: 118), and only 25% (N: 30) previously took admission. It was necessary to perform an opioid rotation in 25% of hospitalized patients, being 90% rotation oral to subcutaneous (N. 27). The most frequent indication for prescription opioid was dyspnea, 87% (N. 103) and only in 15 patients it was for pain. The most frequent opioid used was subcutaneous morphine 91% (N:107 ) and the total daily dose was 8mg.

Conclusion: A high percentage of non-cancer elderly patients are treated with low doses of subcutaneous morphine for dyspnea at the end of life in our UCP. While there is evidence on the effectiveness of opioids in relieving dyspnea, more studies are need to contribute to reduce the concerns about using them by no palliative physicians.
Systematic Review on Symptom Clusters in Dialysis Patients

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Background: Symptom cluster (SC) refers to a stable group of co-occurring symptoms. Previous studies in oncology identified synergic effect of SCs on quality of life, functional status and mortality. End-stage renal disease patients undergoing dialysis have similar symptom burden, and often experience multiple symptoms. Understanding interactions of symptoms and their impact provides valuable information for improving symptom management in renal setting.

Aims: This systematic review aims to
1) identify common SCs of dialysis patients,
2) explore their correlation to health outcomes, and
3) examine approaches of cluster identification.

Methods: Literature search was conducted in eight electronic databases with manual search to identify SC studies on dialysis population. Keywords used include ‘peritoneal dialysis or haemodialysis’ AND ‘symptom cluster or multiple symptom or concurrent symptom or symptom constellation or symptom co-occurrence’. Two reviewers critically appraised the methodological quality of studies. Findings were summarised narratively.

Results: Eight studies were reviewed. No consistent cluster has been identified across studies, but five groups were emerged: cardiac/gastrointestinal, comfort/energy, electrolyte imbalance, emotional and sexual. SCs were found correlated to impaired quality of life, depressive mood, declined functional status and increased mortality. Other correlates of SCs include age, gender, dialysis indicators and biochemical markers. Studies used various symptom measures and identified SCs mainly by factor analysis.

Discussion: Evidence suggests that SCs exist in dialysis patients. However, results are inconsistent due to methodological variations. Significant correlations between SCs and health outcomes have been observed. It implies the importance to optimise symptom assessment and management for dialysis population. Future research may examine the pattern of SCs over time to advance the understanding of renal symptomatology.
Abstract number: P02-334
Abstract type: Poster Exhibition

**Early Palliative Care for Non-malignant Patients in a Transplant Program: Data Collected from a Transplant Palliative Care Clinic**

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**Background:** Although patients within a transplant program are awaiting disease modifying or curative treatment, they are also facing advanced non-malignant illness and the possibility of death. Patients awaiting organ transplantation have difficulty accessing palliative care resources and often do so only sporadically in the inpatient setting at end of life. Currently, there is little access to ambulatory palliative care for patients awaiting organ transplantation and there have been no descriptions of programs delivering such care in the medical literature.

**Aim:** The purpose of this study is to describe the population, and TPCC interventions for patients referred to the clinic, in addition, to examine the impact of an outpatient palliative care clinic model on symptoms for patients awaiting transplantation.

**Methods:** A retrospective review of 200 patients referred to the Transplant Palliative Care Clinic (TPCC) was conducted. Patient demographics, diagnoses, reason(s) for referral to the PC team, palliative performance score (PPS) at time of consultation, interventions performed, and symptom scores pre and post intervention were evaluated. Time to opioid discontinuation post-operatively was also assessed for pre-lung transplant patients.

**Results:** Data analysis is ongoing but will be available at time of presentation. The majority of patients are awaiting lung transplantation (~75%), followed by heart transplantation (~20%). Approximately 50% of the heart transplant patients had a ventricular assist device. Pre-lung and pre-heart transplant patients have a significant symptom burden. Interventions used within the clinic will be outlined. Baseline and followup symptom assessment scores will be presented.

**Conclusion:** Patients awaiting heart and lung transplantation have a significant symptom burden. The involvement of specialized palliative care services for these patients may improve symptom management and facilitate advance care planning.
Abstract number: P02-335
Abstract type: Poster Exhibition

Low Diagnosis of Terminal Heart Failure and Palliative Care Intervention in a Tertiary Cardiologic School Hospital

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Background: Patients (Pts) with advanced heart failure (HF) have a high mortality and morbidity, progressive loss of health status and quality of life, often needing hospitalizations. Identify high risk Pts is critical for appropriate care, including an approach by a specialized palliative care (PC) team.

Aims: Evaluate the characteristics of hospitalizations, as well as the identification of end stage HF and the need for PC in a tertiary cardiology school hospital.

Methods: A unicentric, observational, retrospective study with 113 Pts admitted at the emergency room from June 2014 to November 2015, with worsening HF, with diagnosed congestion and hypoperfusion, needing inotropic drugs.

Results: About 66% were male, median age of 62 (SD 13.5) years. 69% had previous NYHA functional class III or IV and median ejection fraction was 25% (SD 11.2). The median hospitalization period was 25.0 (SD 42.2) days. Pts stayed in Intensive Care Unit a median of 24.5 (SD 35.7) days. 9 Pts (7.9%) were transplanted and 56 (49.6%) died during hospitalization. Just 5 Pts (4.4%) received discussions of end of life and advanced care planning, and only 2 pts (1.7%) were evaluated by a specialized PC team. 57 Pts (50.4%) were discharged (none received PC evaluation), and 24 (42.1%) of them had at least 1 rehospitalization among the next 6 months after discharge. 6 Pts (25% of readmitted Pts) died during rehospitalization.

Discussion: Pts with worsening HF profile C have a high inhospital mortality. Even in a tertiary cardiology school hospital, in the vast majority of Pts the terminal stage is not recognized. The PC specialists is rarely requested, discussion of end of life are not made and the best treatment and care possible is not offered.

Conclusion: Terminal HF diagnosis is a challenge and improved education, early recognition of end stage HF and widespread of PC knowledge is not only desirable but needed, what may lead to a better care and optimized use of health care resources.
Challenges of the Integration of Palliative Home Care for Amyotrophic Lateral Sclerosis (ALS) in Greece

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Background and aim: Integration of palliative care in the management of ALS is essential. A unique collaboration of a Tertiary Academic Neurology Center, with hospital-based multidisciplinary care, and a community-based palliative care unit in a sub-urban area of Athens, Greece was initiated. The purpose of this report is the analysis of the challenges of this collaboration: causes of palliative care denial or acceptance.

Methods: Clinical data and qualitative interviews were obtained by the hospital’s social worker and the palliative care nurse. The Revised-Functional ALS Rating Scale (R-FALSRS) and the problems and needs were assessed.

Results: 8 patients were eligible to receive palliative home care (6 males, mean age 62 years, mean time from diagnosis 44 months, mean score R-FALSRS=19). An average of 4 visits (range 3-8) from the key persons took place introducing palliative care. Three patients died during their hospitalization. 2 patients completely denied. Barriers included “retaining control and normality within their home”, good functionality, low levels of unmet problems and needs, no symptom burden and/or well treated symptoms. Thus, three patients finally agreed. A high problems and needs burden, was reported; numerous physical symptoms, social and spiritual needs, as well as a need for psychological support.

Conclusions: Involvement of palliative care home services in patients with ALS in a sub-urban region of Athens, Greece, seems to be more feasible when their unmet problems and needs are high. Increased awareness should focus on the involvement of palliative care even without increased disability or at the end-of-life.
Modified Medical Research Council Dyspnea Scale (MMRC) as an Indicator of Impaired Quality of Life for Patients with Idiopathic Pulmonary Fibrosis

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Background: Idiopathic pulmonary fibrosis (IPF) is a severe progressive disease with median survival from two to seven years. Patients suffer from multiple symptoms, but the existing data on IPF patient’s quality of life (QOL) and detailed symptom burden is limited.

Aims: To study patients QOL and symptoms in a real-life cross-sectional questionnaire study.

Methods: We sent the modified Edmonton Symptom Assessment Scale (ESAS), the Modified Medical Research Council Dyspnea Scale (MMRC), and the RAND 36-Item Health Survey (Rand-36) to 300 patients whose data is registered in the prospective FinnishIPF registry study in April 2015.

Results: 253/300 (84%) of patients returned the questionnaire. The severity of dyspnoea in MMRC (cut point 2 in scale 0–4) correlated to QOL measured by RAND36 (general health, vitality, physical, role-physical, bodily pain, social, role-emotional and mental health, p< 0.001), co-morbidities (COPD p< 0.001, heart insufficiency p< 0.001, diabetes mellitus p=0.002) and symptom burden.

The three most common symptoms by ESAS were tiredness (96%, mean intensity 4.7/10), shortness of breath (89%, 5.0/10) and cough (86 %, 4.2/10). The incidence of chest pain correlated positively to the increased MMRC score (p< 0.001).

Conclusions: The use of MMRC in screening for QOL has not been reported in IPF before. Our results indicate that MMRC is a useful and fast screening tool for identification patients with impaired QOL and increased needs for palliative care.
The Perceptions of People with Parkinson’s Disease and their Carers’ of Palliative Care

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Background: Palliative care is recommended for non-cancer illnesses, including Parkinson’s disease. However, past research with healthcare workers highlights unmet palliative needs in this population and referral rates to Specialist Palliative Care are low. Some healthcare workers perceive a ‘fear’ in their patients about introducing palliative care. However, less is known about the views of people with Parkinson’s disease and their carers about palliative care.

Aims:
(1) To explore the palliative care and related issues most affecting people with Parkinson’s disease and their families, and
(2) to examine perceptions about/understanding of palliative care.

Methods: This was a qualitative study; semi-structured interviews were conducted, transcribed and analysed using thematic analysis. A total of 31 people participated, both people with Parkinson’s disease (n = 19) and carers (n = 12), across three Movement Disorder Clinics in the Republic of Ireland.

Results: People with Parkinson’s disease and their carers were unfamiliar with the term palliative care. When informed of the role of palliative care, most felt that they would benefit from this input. People with Parkinson’s disease and carers experienced a high illness burden and wanted extra support. Crises requiring Specialist Palliative Care involvement may occur at diagnosis and later, with advancing illness. Participants wanted more information about palliative care and especially further supports to address their psychosocial needs.

Conclusion: A holistic palliative care approach could address the complex physical and psychosocial symptoms experienced by people with Parkinson’s disease and their carers, and people with Parkinson’s disease and their carers are open to palliative care. Further research needs to explore how palliative care can be introduced into the routine care for people with Parkinson’s disease.
Palliative Care in Chronic Kidney Disease: An Integrative Review

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Chronic Kidney Disease (CKD) includes anatomical, functional and temporal changes that make it a progressive and incurable disease, included in the scope of palliative care (PC). The aim was to review the scientific literature regarding palliative care in DRC, identifying trends and dimensions of studies on the subject. This is an integrative literature review, whose guiding question, according to the PICO strategy, was “which published evidence on palliative care in the DRC?”. We referred to the databases LILACS, Scielo, PubMed, Scopus and Web of Science, and employed different search strategies with controlled and uncontrolled descriptors. The sample was 46 abstracts that addressed the chosen theme and met the inclusion criteria: be available online and in English, Portuguese or Spanish, published in the last 10 years. From the summaries, reading all articles, regardless of carried out study design was started. Predominated the literature review articles, mainly from 2015. The topics included conceptual and pathophysiology, symptoms burden and its impact on quality of life, and the work of the multidisciplinary team in palliative care. Studies on the epidemiology of CKD, covering its most recent definition, were not found. Among the main findings are that patients in the 5th stage of CKD and not yet undergoing dialysis has the same symptom burden compared to oncologic patients, thus emphasizing the proper management of these symptoms on quality of life and the importance of palliative care; and that health teams are not yet prepared for the management of symptoms in the DRC. There is growing interest in the DRC and palliative care in the last years, probably due to their influence on survival and quality of life of patients, but there is still a gap in the implementation of palliative care and training of professionals who assist kidney patients in late stage disease.
**Evaluation of a Namaste Service for Patients with Dementia**

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**Background:** Namaste care is a programme designed to improve the quality of life for people with advanced dementia, based on the Hindu term meaning ‘to honour the spirit within’. Volunteers provide meaningful activities and sensory stimulation, especially through touch, in the patient’s home.

**Aim:** To evaluate the impact of a hospice-led Namaste care programme for patients living with advanced dementia.

**Methods:** Monthly case work sharing sessions were held as part of supervision of the Namaste volunteers between October 2014 and November 2015. We conducted conventional qualitative content analysis of the anonymised notes from the sessions.

**Results:** Over the 14 month period, 55 case sharing reflections involving 19 volunteers and 24 patients took place. Of 24 patients’ experiences, 18 were reported by the volunteers as positive (median 2 sessions per patient, range 1–4). Common themes emerging were that the individual enjoyed the massage and manicure sessions, appeared relaxed and displayed positive emotion. The volunteers noted increasing trust, rapport and connection developing over time. Often more sessions were requested at the end of the care period. One patient had a negative experience, as he appeared calmer when left alone and one patient displayed mixed emotional responses. Volunteers’ experiences of delivering Namaste were overall positive. Challenges reported included unpredictability and difficulty bringing the sessions to an end.

**Discussion:** Our findings support the view that Namaste has a positive impact on patients with advanced dementia and is an overall positive experience for the volunteers. Whilst the data captures the perceptions of the volunteers, it was considered a valid approach, given the inability of those with advanced dementia to give direct feedback. Future work could include structured interviews with volunteers and family members of patients receiving Namaste care.
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Nursing Diagnoses on Heart Failure Patients in Palliative Care

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**Background:** Heart failure (HF) is characterized by a short survival around 50% in 5 years and 10% in 10 years, besides a bad quality life. In this scenario, it is believed the introduction of palliative care as a strategy for nursing care, understanding comfort as required outcome.

**Aims:** Identify nursing diagnoses that have association with the comfort measured by End of life questionnaire comfort – patient on HF patients in palliative care.

**Method:** Cross-sectional study that followed a sample of 20 patients with HF in palliative care. Monthly nursing consultations were held from November 2012 to May 2013 at a federal hospital in the city of Rio de Janeiro (Brazil). In order to verify the association of nursing diagnoses of NANDA – I found with the comfort measured by questionnaire (validated in Brazil) was used the Fisher’s exact test and Mann-Whitney test . The study was approved by the ethics committee of the research site.

**Results:** The following diagnoses were associated with the lowest comfort (p < 0.05): Impaired resilience; Death anxiety; Fatigue; Activity intolerance; Powerlessness; Excess fluid volume. However, the diagnoses associated with comfort (p < 0.05) were the following: Readiness for enhanced health management; Readiness for enhanced decision-making; Readiness for enhanced.

**Discussion / conclusion:** When nurses show diagnoses they are strengthened to achieve greater resolution in the comfort of action for these patients. It was noticed that patients with self-acceptance issues related to their diseases to their ending had less comfort, while willing to discuss the matter and having therapeutic regimen adherence had better comfort values. This study was funded by own resources.
Discharge Planning between Cancer and Non-cancer Patient at an In-patient Unit in Taiwan

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Background: Early palliative intervention in life-threatening illness become more common in recent years, rate of in-patient unit discharges increasing rapidly. Nowadays, family caregiving responsibility is changing; foreign caretakers are mostly substitutes for family members in Taiwan.

Aims: Analysis the discharge planning process and compare the difference between cancer and non-cancer patients.

Methods: A retrospective study design. The medical records of 241 patients accepted discharge planning were reviewed during February 2015 to September 2016. Descriptive and t-test statistics were calculated.

Results: The participants’ mean age was 72.8±15.1 years and 85.1% of the sample was cancer patients. The majority of patients (75.4%) started discharge planning within 14 days, the mean was 11.7±8.7 days (prepare time). 81.9% patients were discharge, the mean was 8.6±8.1 (actual time). Time spent on discharge planning (t(53.7)=-2.01, p=.97) and actual time (t(58.7)=-1.36, p=.17) in two group was non-significant. The highest symptom priority ranking in cancer patients were pain (41%), constipation (34.6%), dyspnea (25.5%); in non-cancer patients were dyspnea (37%), cough (37%), others (33.3%): infection. Family (74.3%) was mainly medical decision maker. The caregivers were mainly the foreign caretakers (44%), and then spouse (16.6%). Result of discharge planning were return to home (53.1%), refer to nursing home (28.6%), dead (9.1%). 37.3% patients need assistive device service and 50.2% caregiver need extra information.

Conclusion: Cancer and non-cancer patients have the different symptom after the discharge; individualization caring strategy is indeed. Health care provider could more empower the patients and reach a consensus with family to obtain the best interest in patients. 9.1% patients died during the discharge planning, that’s show the prognostic variability in this population. There is a continuing need for an adequate theoretical basis for the practical application of discharge planning in end-of-life patients.
**The Use of Low Dose Oral Morphine in Children with Cancer**

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**Background:** In 2013 the MHRA issued a safety alert against the use of codeine in children under 12 years. Guidance changed to low dose (LD) morphine (0.1mg/kg) for children with cancer with moderate pain, if paracetamol is not effective. It is unknown whether LD morphine has the same side effect profile and efficacy as the recommended standard start dose (SD).

**Aims:** The aim of this study was to establish whether LD morphine is being prescribed and if it is effective at reducing moderate cancer-related pain in children. Reported side effects and parental perceptions of morphine were reviewed.

**Method:** A prospective study of opioid naïve children up to 12 years prescribed oral morphine in a tertiary oncology centre between 2015 and 2016. A survey was conducted of children and parents at 24 hours and 7 days (if continued) after starting morphine.

**Results:** 22 children were included; mean age 6.6 yrs and mean weight 24.3kg. 8 were prescribed LD morphine (mean 0.12mg/kg) and all discontinued within 7 days. 14 had SD morphine (mean 0.19mg/kg) with 3 continuing at day 7. In those given LD morphine pain scores were significantly higher before morphine was taken than after on the first occasion it was given only $z=2.37, p=0.02$. In those given SD morphine there was a significant reduction in pain score at all time points on day 1. By day 7 the reduction in pain score was not significant in those on SD. Despite this there was no dose titration, or a long acting opioid commenced. There was no difference in side effects experienced between LD and SD morphine. Parental concerns included side effects, addiction and withdrawal.

**Conclusions:** Our study suggests that children with cancer should be given the standard 0.2mg/kg dose of morphine if paracetamol is ineffective to manage pain. Efficacy and dose should be reviewed regularly to ensure continued effective pain relief. Parents need education to alleviate their fears over giving their child morphine.
Nicotine Addiction in Advanced Cancer Patients is Linked to Worse Pain Outcomes

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**Aim of investigation:** Cancer pain can be successfully treated following the WHO analgesic ladder but still exists an important group of patients with suboptimal outcomes. Patients with difficult pain will need higher doses of morphine (MEDD: Morphine Equivalent Daily Dose), Opioid rotation and more coanalgesic drugs. The main objective is to know if nicotine addiction in a sample of advanced cancer patients present similar outcomes as those with difficult pain.

**Methods:** Patients were recruited at the outpatient clinic of the supportive palliative care team at the University Hospital Arnau de Vilanova (Lleida, Catalonia). Patients were divided in two samples according to their smoking habitude: never or < 5 years (N=50) and current or > 5 years (N=211). Sociodemographic and clinical variables (Fagestrom test, CAGE questionnaire, DN4 screening for neuropathic pain, BPI for pain related interference with quality of life, need for opioid rotation-ROP-, number of coanalgesics used and the Morphine Equivalent Daily Dose – MEDD) were recorded. The SPSS v 20 statistical package was used. Significance threshold was set at p<0.05. Univariate and multivariate analysis with an OR (IC 95%) was used.

**Results:** The smokers sample were younger (p<0.001), with more men (p<0.001), a higher level of psychological distress (p=0.016), higher scores for the CAGE questionnaire (p<0.001), a higher final MEDD (p=0.002) and more need for opioid rotations (p=0.028) to achieve a better pain control respect the non-smokers sample.

The multivariate analysis showed that a Fagestrom test ≥ 7 (high nicotine addiction) [p=0.016 OR 2.01(1.15–3.56)] correlate with higher pain scores.

**Conclusion:** Advanced cancer patients with a smoking history and a Fagestrom test ≥ 7 are at risk of needing higher MEDD and more opioid rotation to achieve a good pain control.
Systematic Literature Review: Assessment of Pain

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Background: Pain control is a priority in palliative care. Intensity is one of the major elements in pain assessment, and should be evaluated through scales, which enhance its objectivity. The knowledge and adequate use of the existing instruments for pain evaluation is essential.

Aim: Identification of valid and reliable pain assessment instruments.

Methods: A systematic literature review was undertaken, on Pubmed® database. Papers published on the period between 2000 and 2015, written in English, French, Spanish and Portuguese were included.

Results: 3217 articles were identified, after exclusion and inclusion criteria and abstract review, 103 papers were selected for full text analysis. 16 different pain assessment instruments were identified and characterized. Heterogeneity in pain assessment scales was found, and these could be broadly divided in: one-dimensional instruments, multi-dimensional and quality of life scales.

Discussion: An absence of consensus regarding pain evaluation scales was identified. The lack of standardization of assessment tools renders the comparison of efficacy and effectiveness of pain controlling interventions particularly difficult. However, it was possible to make an extensive survey of pain assessment scales, identifying the psychometric characteristics of each of the identified scales, country, and type of study, context, target population and number of citations.

This study confirms the need for standardization of pain assessment scales, by the health services, in compliance with the World Health Organization recommendations for Palliative Care.
Response to Oral Opioids for Breakthrough Pain (BTP) in Advanced Cancer Patients with Adequately Controlled Background Pain

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Background: Patients with sub-optimally treated BTP report more functional impairment, worse mood and more anxiety. In clinical practice, oral immediate release (IR) opioids are most commonly used to manage BTP. However, evidence regarding the efficacy of oral IR opioids for BTP control is limited. This lack of empirical data has partly contributed to the increased use of rapid onset fentanyl products for BTP, despite their cost, need for titration and lack of long term safety data.

Aim: To determine the proportion of cancer patients, who stated that their IR opioids were “effective” or “very effective” for BTP control.

Methods: In this prospective study, patients with advanced cancer seen at our outpatient Supportive Care Center who had cancer pain being treated with opioids were asked to complete a self-administered survey. Information collected for baseline demographics, pain characteristics, alcoholism (CAGE-AID questionnaire), tobacco use and symptom burden (using Edmonton Symptom Assessment System [ESAS]). We assessed effectiveness of BTP medication using a 7 point Likert scale ranging from “very ineffective” to “very effective”. “Effective” or “very effective” were defined a priori as a response to IR opioids for BTP.

Results: 592 cancer patients were enrolled and 192 (32%) had background pain ≤3. Among them, 152 (79%) reported BTP and 143 (75%) were taking IR opioids. 127/143 (89%) were responders. Morphine (n=53, 37%) and hydromorphone (n=36, 25%) were the most commonly used BTP opioids, with a median BTP morphine equivalent daily dose of 30 (15–45) mg. In logistic regression, non-responders were more likely to be younger (OR 1.06/year, p=0.02), and had higher ESAS pain (odds ratio [OR] 0.76, p=0.01), anxiety (OR 0.81, P=0.02) and dyspnea (OR=0.76, P=0.007).

Conclusion: A vast majority of patients reported BTP response to oral IR opioids, supporting their use in clinical practice. Our data suggest that few patients would require rapid onset opioids for BTP.
A Randomized, Double-blind, Non-inferiority Study of Hydromorphone Hydrochloride Immediate Release Tablets versus Oxycodone Hydrochloride Immediate Release Powder for Cancer Pain: Efficacy and Safety in Japanese Cancer Patients (PROHEAL Study: A Phase 3 Randomized Study Of Hydromorphone Immediate Release vs Oxycodone for Cancer Pain)

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Background: Hydromorphone is a standard opioid analgesic for cancer pain that is not yet approved in Japan, where options for opioid switching are limited.

Aims: To confirm the efficacy and safety of hydromorphone immediate-release tablets in opioid-naïve cancer patients with moderate to severe cancer pain.

Methods: This was a multicenter, joint, active-controlled, randomized, double-blind, parallel-group, non-inferiority study where hydromorphone tablets or oxycodone hydrochloride powder was orally administered four times daily for 5 days. The initial dose of hydromorphone and oxycodone hydrochloride was 4 mg/day and 10 mg/day, respectively, and the dose adjusted as necessary. Efficacy was evaluated as the intergroup difference (95% confidence interval [CI]) of the least squares mean by analysis of covariance, using the baseline visual analog scale (VAS) as a covariate for change in VAS score at treatment completion/discontinuation in the full analysis set.

Results: Non-inferiority of hydromorphone versus oxycodone was confirmed, with an intergroup difference (95% CI) in the least squares mean of −4.1 mm (−10.4 to 2.2 mm) for change in VAS scores, which was below the upper limit of the 95% CI at 10 mm, the non-inferiority limit determined at the time of planning. Adverse events occurred in 83.7% (77/92) patients in the hydromorphone group and 78.2% (68/87) in the oxycodone group. The most frequently observed adverse events were somnolence, constipation, vomiting and nausea.

Conclusion: The efficacy and safety of hydromorphone tablets are equivalent to those of oxycodone immediate-release formulation.
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A Successful Interprofessional Cooperation between Palliative Care and Neurosurgery in the Treatment of Intractable Oncological Pain

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Background: There is a great importance to deliver good pain management to cancer patients suffering from advanced metastatic disease. There are selected patients for whom pharmacotherapy does not achieve acceptable pain relief or is limited by marked side effects. These patients, may benefit from neurosurgical procedures that selectively intervene along the pain processing pathways. Patients with localized pain can benefit from selective percutaneous cordotomy, while patients who suffer from diffuse pain due to widespread disease are candidates for stereotactic radiofrequency cingulotomy. Careful patient selection is critical for the success of these procedures. In the last year we have established a specialized service consisting of palliative care specialists, pain specialists and a neurosurgeon specifically for this task.

Aim: To present our experience in interdisciplinary evaluation of cancer patients undergoing neurosurgical interventions for intractable pain.

Methods: Retrospective review of all patients who were evaluated and operated for intractable oncological pain.

Results: Nineteen cancer patients suffering from intractable pain due to metastatic disease were selected for neurosurgical intervention. 10 patients with localized pain underwent percutaneous selective cordotomy and 9 patients with diffuse pain underwent bilateral stereotactic cingulotomy. 14 of 19 operated patients achieved good sustained pain relief (73.5%). We had no procedural related mortality. There was 1 operative complication of mild hemiparesis after cordotomy. 2 patients who developed transient apathy after cingulotomy. There was a high degree of satisfaction among patients and families from the procedures.

Conclusion: In carefully selected patients, evaluated by a interdisciplinary palliative care team, neurosurgical procedures can produce significant pain relief.
Retrospective Study of Opioid Switching to Methadone for Cancer Pain Control: Comparison between Unsuccessful and Successful Cases

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Background: In Japan, oral administration of methadone was approved for patients with cancer pain in March 2013. As methadone exhibits complex pharmacokinetics with inter-individual differences and rare but serious adverse effects, methadone is only prescribed as a fourth-line drug by cancer pain specialists. Not all patients are successful to be switched to methadone.

Aims: To evaluate what were the differences in the clinical aspects between unsuccessful cases (UC) and the successful cases (SC) of pain control.

Methods: The clinical aspects of 71 patients who were prescribed oral methadone in our hospital between April 2013 and September 2016 were analyzed. Methadone was initiated after the use of other opioids due to refractory pain in the stop-and-go switching method. According to the Japanese definition, the success of dose titration is determined on the day after methadone has been administered for more than 6 days at the same dose with acceptable adverse effects. The efficacy parameters are as follows: the rescue administration has been less than twice a day, and the numerical pain rating score (NRS) has decreased from baseline. Based on this definition, 61 cases were successfully switched to methadone, and the 10 cases were failed.

Results: A comparison of the UC with the SC revealed that the number of patients who died within 20 days from the start of methadone administration were significantly greater in the UC than that in the SC (UC: 8/10, SC: 6/51, P< 0.01). No significant differences were observed for the mean age (UC: 65, SC: 68), NRS (UC: 6.8, SC: 6.9), for the average oral morphine equivalent daily doses before methadone administration (UC: 153, SC: 159), and for other parameters.

Conclusion: The reason for the failure of the switch to methadone was the rapid disease progression and poor prognosis of the patients. Oral methadone may not be appropriate for the cases with a poor prognosis, though an accurate estimation of the prognosis is difficult.
Rotation from Methadone to Another Strong Opioid for the Management of Cancer-related Pain is Safe and Effective

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As cancer survival rates improve, and the use of methadone (Me) for cancer pain increases, the clinical challenge of rotating from Me as part of multiple sequential opioid trials is becoming more common. Aims To evaluate the outcomes of patients (pts) who were rotated from Me to other strong opioids. Methods Pts rotated off Me to another strong opioid, who had outcome data pre-rotation (pre-R) and post-rotation (post-R), were included. Data were: Brief Pain Inventory (BPI); Condensed Memorial Symptom Assessment Score (CMSAS); EQ-5D. All opioid doses were converted to daily morphine equivalent dose (MEQ). Results Of 175 Me pts identified at the time of data analysis, 18 pts fulfilled inclusion criteria. 10 pts were male; mean age: 52.16 years. Cancer sites: breast (5 patients); head and neck (2); other (12). Reasons for rotation: sedation (3); uncontrolled pain (4); other (11). Rotation to: oxycodone (9); fentanyl (3); morphine sulphate (4); and hydromorphone (2). Across all encounters, mean Me dose (MEQ): 270.27mgs/day (SD 225.22). Mean MEQ of other opioids: 150.88mgs/day (SD 96.81). Post-R, pain severity improved: least pain/24 hrs: 4.12 (SD 2.23) pre-R vs 3.24 (SD 1.79) post-R (p = 0.007); average pain/24 hrs: 5.94 (SD 1.97) vs 5.37 (SD 1.71) (p = 0.046); current pain: 5.67 (SD 2.26) vs 4.98 (SD 2.11) (p = 0.044); interference with general activity: 6.27 (SD 2.3) vs 5.36 (SD 2.8) (p = 0.024); and interference with work: 6.35 (SD 2.6) vs 5.29 (SD 3.1) (p = 0.020). Post-R, severity of constipation increased: 1.79 (SD 0.93) vs 2.25 (SD 1.06) (p = 0.026). Health-related quality of life was stable post-R (p = 0.856). One pt required Me to be restarted due to pain. Mean Me pre-R MEQ was 209.67mgs/day (SD 201.2). Mean MEQ of other opioids pre-R and post-R was 150.88mgs / day vs 175.06mgs / day (p = 0.431). Total daily MEQ fell post-R: 275.54mgs / day vs 179.62mgs / day (p = 0.026). Conclusions Rotation off Me is a safe and effective intervention to improve cancer-related pain.
Radiofrequency Thermocoagulation of the Gasserian Ganglion to Control Facial Pain due to Medication-related Osteonecrosis of the Jaw

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**Background:** Medication-related osteonecrosis of the jaw (MRONJ) is an important complication in patients treated with antiresorptive agents such as bisphosphonates and denosumab. Treatment of MRONJ is extremely difficult, which makes it a distressing long-term complication.

**Case report:** The case of a 68-year-old woman with intractable facial pain due to MRONJ is reported. Bone scintigraphy detected bone metastasis, and then bisphosphonate was started to prevent skeletal-related events. One year later, she began to complain of swelling and pain in the left jaw. The patient was then diagnosed as having MRONJ. The pain due to MRONJ was especially severe when eating and at the time of local irrigation by the dentist. This led to reduced oral intake, and infections of the jaw became uncontrollable. She was very distressed, and her quality of life (QOL) was severely decreased. Alleviation of the MRONJ could not be expected within the patient’s life expectancy, because the MRONJ was treatment-resistant, and she was in the terminal stage of her disease. Since the pain was located within the trigeminal nerve distribution and was resistant to analgesics, it was decided to investigate the usefulness of radiofrequency thermocoagulation of the gasserian ganglion to control the pain. After the procedure, the pain completely disappeared. Since adequate local irrigation could be performed, management of the MRONJ was improved. The patient was very satisfied. Up to the time of death, there was no recurrence of the pain or worsening of the MRONJ.

**Discussion:** This case suggests that the procedure was useful for improving the patient’s QOL. This procedure is the commonest technique for treating trigeminal neuralgia. It is quick and affords immediate benefit with infrequent complications, and it is therefore ideally suited for the palliative care setting. This is the first case report of radiofrequency thermocoagulation of the gasserian ganglion to control the pain due to MRONJ.
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Abstract type: Poster Exhibition

**A Randomized, Double-blind Comparative Study to Investigate the Conversion Ratio of Hydromorphone to Morphine in Japanese Cancer Patients**

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**Background:** Various conversion ratios have been reported for hydromorphone to morphine.

**Aims:** To confirm the conversion ratio of hydromorphone immediate release tablets from morphine in cancer patients who had achieved pain control with oral morphine.

**Methods:** This was a multicenter, joint, active-controlled, randomized, double-blind, parallel-group, comparative study in which 71 patients who achieved pain control with morphine 60 mg/day and 90 mg/day were switched to hydromorphone tablets at a dose converted at a hydromorphone:morphine ratio of 1:5 or 1:8, respectively, and treated for up to 5 days. The efficacy was evaluated as the pain control ratio.

**Results:** The pain control ratio in the full analysis set was 83.3% (25/30) in the conversion ratio 1:5 group and 95.0% (38/40) in the conversion ratio 1:8 group, and both groups demonstrated highly successful pain control. The incidence of adverse events was 46.7% (14/30) in the conversion ratio 1:5 group and 58.5% (24/41) in the 1:8 group; the difference was not clinically relevant. Frequently observed adverse events (incidence >5%) were nausea, vomiting, diarrhea, somnolence, and dyspnea.

**Conclusion:** A highly pain control ratio was achieved by a switch at either conversion ratio, and no notable difference was observed in the incidence of adverse events. A switch from morphine to hydromorphone is effective at a dose converted at a ratio of 1:5 and 1:8.
Abstract number: P02-355
Abstract type: Poster Exhibition

The Impact of Opioid Analgesics Treatment on Quality of Life of Cancer Patients with Severe Pain

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Aim of the study: To compare analgesia, adverse effects and the quality of life (QoL) during treatment with slow release morphine and oxycodone and transdermal fentanyl and buprenorphine in cancer patients treated at home and in palliative medicine outpatient clinics.

Patients and methods: Patients diagnosed with cancer and severe pain (NRS 6–10) failing to non-opioids and/or weak opioids treatment. Patients were randomized to morphine, oxycodone, fentanyl or buprenorphine (all groups subdivided to predominant neuropathic and nociceptive pain) and followed for 28 days. Immediate-release oral morphine was rescue analgesic. All patients received lactulose 10 ml twice daily; no antiemetics were used as prophylaxis.

Results: A total of 62 patients participated, 53 patients completed the study. Good analgesic effects were obtained for all the four opioids, for both nociceptive and neuropathic pain. The average use of co-analgesics was greater in patients from neuropathic pain group. Morphine treatment was associated with less negative impact of pain on ability to walk and work (BPI-SF), better physical functioning (EORTC QLQ C-15-PAL), better mood (HADS) and less consumption of rescue morphine. All 4 opioids improved global QoL, especially during the first 14 days of the treatment.

Among adverse effects nausea and drowsiness increased at the beginning of the treatment and later gradually decreased. Appetite, well-being, anxiety, depression, and fatigue improved. No changes were seen for constipation, vomiting and dyspnea. Physical and emotional functioning and global QoL (EORTC QLQ-C15-PAL) and activity (Karnofsky) improved.

Conclusions: All the opioids have a similar analgesic effect, best evident in the first 14 days of the treatment. Morphine is the most effective in the improvement QoL. When initiating opioid therapy requires prophylaxis of constipation is effective and required, for the first few days antiemetics to reduce nausea may be considered.
The Use of Bisphosphonates and Denosumab in the Management of Malignant Bone Pain

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Background: Metastatic bone disease is a common site of disease in advanced cancer; affecting 75% of breast and prostate cancer patients with advanced disease. Metastatic bone disease causes significant morbidity and is associated with skeletal related events (SRE) including bone pain; resulting in a significant impact on quality of life.

Aims: To identify the evidence base in order to recommend best practice in the use of bisphosphonates and denosumab in the management of malignant bone pain.

Methods: The clinical questions were selected using the Patient, Intervention, Control, Outcome format to guide the systematic literature review. Electronic searches of Medline, Embase, Cinahl and Cochrane databases were carried out in January 2015. Of 102 articles, 14 were included following a process of step-wise critical appraisal.

Results: Bisphosphonates, and where clinically appropriate denosumab, should be considered as an option for the management of bone pain due to metastatic disease. Bisphosphonates are effective in treating pain from metastatic bone disease in patients with breast cancer, prostate cancer and multiple myeloma, as well as other solid tumours. It is not possible to recommend the superiority of one bisphosphonates over another, although the best quality evidence for effectiveness in reducing bone pain is for zoledronic acid versus control. Intravenous administration is recommended, as oral bisphosphonates are poorly tolerated, and less clinically effective. Denosumab is also recommended as a treatment option for patients with painful bone metastases and for patients with solid tumours and multiple myeloma. Denosumab use has been shown to lead to an equivalent significant reduction in pain scores as zoledronic acid.

Conclusions: These findings have led to an update of our regional palliative care guidelines. Future focus should be on disseminating this evidence and standardising best evidence-based practice among palliative medicine professionals.
Factors Influencing the Analgesic Effect of Acetaminophen Injected Intravenously in Japanese Patients with Cancer

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Background: An acetaminophen intravenous injection (IV APAP) was released in November 2013 in Japan. No studies have been conducted on the factors influencing the effects of IV APAP in Japanese patients with cancer.

Purpose: To assess the factors influencing the analgesic effect of IV APAP in Japanese patients with cancer.

Methods: We retrospectively evaluated 50 patients with cancer who received IV APAP for cancer pain at a municipal hospital in Japan between January 2014 and July 2016. The degree of pain was evaluated using a 4-point verbal rating scale (none: 0, weak: 1, strong: 2, severe: 3). We divided the patients into two groups according to their response to IV APAP (good response and poor response group) and compared their characteristics by reviewing their medical charts.

Results: In the good response group, there were significantly more women, fewer patients received opioid medication, the opioid doses were lower, and the nitrogen levels in blood urea were higher than in the poor response group (Table 1). Moreover, sex, opioid dose, and dose of opioid medication of < 45 mg/day (as oral morphine) were contributing factors for a good response to IV APAP in a univariate logistic regression analysis. Sex was also found to be associated with a good response to IV APAP in a multivariate logistic regression analysis (odds ratio, 6.1; p = 0.03). In addition, the mean body weight of the women was lower than that of the men (54.4 kg vs. 47.4 kg, p = 0.06).

Discussion: Most IV APAP is glucuronic-conjugated. Glucuronidation is more active in men or in patients with high body weights. Hence, the analgesic effect of IV APAP was observed to be higher in women than men because of the increase in blood concentration of APAP in women.

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### Patients' background characteristics

<table>
<thead>
<tr>
<th>Group</th>
<th>Age (years), Mean ± SD</th>
<th>Female, n (%)</th>
<th>Weight (kg), Mean ± SD</th>
<th>Degree of pain before IV APAP administration, Median ± 95%CI</th>
<th>Patients receiving opioid medication, n (%)</th>
<th>Opioid doses, Median ± 95%CI</th>
<th>AST (U/L), Median ± 95%CI</th>
<th>Scr (mg/dL), Mean ± SD</th>
<th>BUN (mg/dL), Mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good response</td>
<td>67.3 ± 15.9 (n=38)</td>
<td>24 (63.2)</td>
<td>51.2 ± 12.9 (n=32)</td>
<td>2.0 ± 0.2 (n=38)</td>
<td>22 (57.9)</td>
<td>10.0 ± 19.9 (n=38)</td>
<td>29.5 ± 17.8 (n=28)</td>
<td>0.8 ± 0.3 (n=28)</td>
<td>25.7 ± 13.4 (n=28)</td>
</tr>
<tr>
<td>Poor response</td>
<td>71.2 ± 7.8 (n=12)</td>
<td>3 (25.0)</td>
<td>48.4 ± 10.5 (n=10)</td>
<td>2.0 ± 0.3 (n=12)</td>
<td>11 (91.7)</td>
<td>82.5 ± 57.3 (n=12)</td>
<td>22.5 ± 16.2 (n=10)</td>
<td>0.6 ± 0.2 (n=10)</td>
<td>17.6 ± 6.4 (n=10)</td>
</tr>
<tr>
<td>p</td>
<td>0.27</td>
<td>0.02</td>
<td>0.53</td>
<td>0.47</td>
<td>0.03</td>
<td>&lt; 0.01</td>
<td>0.07</td>
<td>0.26</td>
<td>0.02</td>
</tr>
</tbody>
</table>

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[Patients' background characteristics]
Use of Analgesic and Psychotropic Medication in UK Care Home Residents Living with Dementia

La Frenais F.1,2, Livingston G.1, Cooper C.1, Marston L.3, Barber J.4, Vickerstaff V.2, Stone P.2, Sampson E.L.2

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Use of Analgesic and Psychotropic Medication in UK Care Home Residents Living with Dementia

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Use of Analgesic and Psychotropic Medication in UK Care Home Residents Living with Dementia

La Frenais F.1,2, Livingston G.1, Cooper C.1, Marston L.3, Barber J.4, Vickerstaff V.2, Stone P.2, Sampson E.L.2

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Background: Prescribing to the heterogeneous care home population is challenging. This study focuses on analgesics, as historically pain is undertreated in care home residents with dementia, and psychotropics, which can have serious side effects and may be used inappropriately. Symptoms of agitation may be a response to untreated pain and there is guidance against antipsychotic overuse.

Aims: To
(i) describe prescribing patterns and PRN administration by care staff of analgesics and psychotropics;
(ii) compare use of analgesics across dementia severity
(iii) test associations between agitation and medication use.

Methods: We collected data from the largest prospective clustered cohort study of residents living with dementia or probable dementia in English care homes. Dementia severity (Clinical Dementia Rating) and agitation (Cohen-Mansfield Agitation Inventory [CMAI]) data were collected during structured interviews. Medication data and PRN administration in the prior 2 weeks were extracted from care records: opioids (strong and weak), non-opioids, NSAIDs, antipsychotics, anxiolytics, hypnotics, antidepressants. Prevalence (95% CIs) of medication prescribing were calculated. We used regression models to identify factors associated with analgesic and psychotropic use.

Results: 86 care homes and 1489 residents were recruited (52.7%). 40% of residents had clinically significant agitation (CMAI>45). Of the 65% (62–67%) residents prescribed analgesics, 37% residents were prescribed PRN only. More residents were prescribed strong opioids (11%) than weak opioids (6%). 56% (53–58%) residents were prescribed psychotropics, and 17% prescribed antipsychotics. Results will be presented in full at conference.

Conclusion: Many care home residents only receive analgesics PRN. It is vital to understand how PRN medication is used, and whether residents, especially those with more severe dementia, are at risk of not asking for, or being given, analgesia for pain.

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**Characteristics of Breakthrough Cancer Pain at a Comprehensive Cancer Center in Japan**

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**Background:** Breakthrough cancer pain (BTcP) has negative impact for pain management and daily activities. Personalized pain goal (PPG) can quantify the achievement of pain management by patient’s own. However, the characteristics of BTcP in Japanese patients and influence on PPG have not been presented.

**Aims:** The aim of this study is to clarify the characteristics of BTcP and its impact for daily activities and PPG in Japanese patients.

**Methods:** Outpatient cancer patients were consecutively enrolled who visited the National Cancer Center Hospital East from March 2015 to September 2015 and had received opioid medication over two weeks. We selected patients with BTcP using a definition of BTcP; 1) adequate baseline pain therapy, 2) controlled baseline pain, and 3) episodes of severe pain flares, and questioned their characteristics of BTcP.

The achievement of PPG was defined as lower average pain intensity over the previous 24 hours than PPG. We analyzed the difference of pain interference with daily activities (NRS; 0 to 10) and achievement of PPG between patients with or without BTcP by using t-test and z-test.

**Results:** Of the 348 patients, 119 patients reported BTcP (female, 37 %; mean age, 60.1 years), and 81 patients completed all questionnaires. Most frequent episodes of BTcP were two to three times a day (49.4 %). Most reported time to peak intensity was within ten minutes (75.3 %). All patients received short-acting opioids as rescue doses, with 44.4 % patients reporting “effective all time” and 9 % patients reporting “ineffective all time”. Compared with patients without BTcP, patients with BTcP had significantly higher pain interference with daily activities (BTcP, 2.8±2.2; without BTcP, 1.3±2.0; p < 0.01) and lower achievement of PPG (BTcP, 36.1 %; without BTcP, 67.6 %; p < 0.01).

**Conclusion:** The time to peak intensity of BTcP in Japanese patients was earlier than previous studies. BTcP had significantly inference on daily activities and achievement of PPG.
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Abstract type: Poster Exhibition

Characteristics of Breakthrough Cancer Pain Based on Breakthrough Pain Assessment Tool in Korea

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Background: Breakthrough pain (BTP) is one of the most prevalent and formidable symptoms in cancer patients. However, understanding about BTP is still limited.

Aims: This study is to validate Korean version of Breakthrough Assessment Tool (BAT) and to assess BTP and efficacy of rescue medication in Korean adult cancer patients.

Methods: Among the cancer patients who had visited at pain clinic in outpatient setting, or admitted as an inpatient for cancer treatment and supportive care in general ward or hospice care unit, 120 participants with BTP were administered by the Korean BAT from September, 2015 to August, 2016. Information about cancer and rescue medication was obtained by reviewing medical record. Cronbach’s α coefficient, Pearson’s correlation coefficient, and intra-class correlations were used.

Results: Korean version of the FCRI would demonstrate good validity (coefficients of Cronbach’s α: 0.86, internal reliability: 0.27–0.80, test-retest: 0.30–0.62, Ps< 0.01). Of the 120 patients, 67.5% had cancer related pain, 15% treatment related pain, and 15.8% from both of them. BTP was represented up to 37.8% predictably, 12.6% unpredictably, or 30.3% spontaneously. The median number of episodes was three times a day. Although having a meaningful effect of rescue medication required 20–30 minute, pain killer was the most effective relieving factor (69.7%). The usefulness of pain killer reported six point (0: not at all, 10: perfectly). The mean level of bothering from side effect of rescue medication was very low; 1 (0: not at all, 10: very much).

Conclusion: We confirmed the Korean version of BAT is a reliable and valid measurement of BTP. Improving physician awareness about the characteristics of BTP by BAT may help to establish appropriate BTP management plans.
Experience with Ketamine in Treating Paediatric Oncology Patients with Neuropathic Pain

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Background: A few reported case studies recognize the role of ketamine in paediatric oncology patients with neuropathic pain but without the details on the methods of delivery, side effect and user experience.

Aim: This study reviews the use, side effects and user reports of ketamine in neuropathic pain in a paediatric oncology population.

Method: Retrospective data collection on all paediatric oncology patients given ketamine for clinically documented neuropathic pain from 1st January 2011 to 30th September 2016 at a single Tertiary Paediatric Oncology centre from an Electronic Patient Record.

Results: Fifteen patients were given ketamine as adjuvant alongside other neuropathic agents and opiates. Mean age was 16yrs (range 9–20yrs), 67% were female and 87% had a solid tumor. 80% started with oral or buccal route (initial 50–100 mcg/kg/dose; titrated to max 1–3mg/kg/day) and 20% with subcutaneous/intravenous infusion (initial 40–80 mcg/kg/hr; titrated to max 100–400mcg/kg/hr). Length of use ranged from 1 day-17months. 40% of patients were given ketamine during palliative care and 34% at end of life. There was concurrent use of other neuropathic agents: amitriptyline(60%), gabapentin (40%) and pregabalin (7%). Side effects reported were transient drowsiness in two patients; one oral and the other intravenously with concurrent escalation of opiates. There were no cases of serious adverse events, which warranted the termination of ketamine. 73% of patients reported benefit in pain reduction.

Conclusion: The use of ketamine as an adjuvant in paediatric neuropathic cancer pain management appears to be safe with minimal side effects and reported analgesic benefit to the patient. Our findings reinforce non-concurrently escalation of opiates at the initiation or titration of ketamine. A prospective study to determine objective clinical benefit is warranted.
Protocol for Ketamine Use in a Palliative Care Unit

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Introduction: Ketamine, at sub-anesthetic doses, is a potent analgesic. Several protocols are available on the use of ketamine for pain. However, they vary in the selection of patients, starting dose, titration, duration of use, adjustment of co-analgesia and recommendations in the control of psychotomimetic side effects.

Aim: To study the impact on cancer pain with the use of a standardized ketamine protocol in a Palliative Care Unit (PCU).

Design: This is a prospective study where patients from the PCU in a tertiary hospital were recruited. Baseline pain was characterized using the Edmonton classification system for cancer pain. A 7-day algorithm was designed to standardize the titration of ketamine. The starting dose of ketamine was 75mg/day with increments of 100mg daily, until analgesia was optimized. Pain was rated with the Numerical Rating Score (NRS) or the Visual Analogue Scale. The protocol made recommendations for the titration of baseline opioids, use of adjuvants and psychotropics. Systemic and local side effects were monitored and addressed.

Result: 6 cancer patients with a mean Palliative Performance Score (PPS) of 38.8% (SD13.3) were started on ketamine using the protocol. The pain was predominantly neuropathic. Pain was rated at NRS 7.5 before decreasing to 1.0 after ketamine was introduced. The mean morphine equivalent daily dose (MEDD) decreased from 125.5mg (SD 54.6) to 85.2mg (SD 30.7) with ketamine. The final mean daily ketamine dose to achieve stable pain control was 108.33mg/day. Time to reach stable pain control was 3 days and the most common side effect was sedation.

Conclusion: The protocol standardized the use of ketamine in mainly neuropathic cancer pain, with reduction in pain score and the MEDD. Time to reach stable pain control was 3 days with minimal side effects.
Exploring Additional Complexity to Breakthrough Cancer Pain (BTcP) Using the Edmonton Classification Symptom for Cancer Pain (ECS-CP). Does the Politopic BTcP Has to Be Considered?

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**Aim of Investigation:** Studies of BTcP focuses on only one type of incident pain per patient with multiple episodes. The ECS-CP is a useful tool that helps to classify cancer pain according to five main features: Type of pain, incident pain, Psychological distress, addictive behaviour and cognitive failure. The main objectives of our study are: 1. to investigate correlations between incident pain and the other four features of the ECS-CP. 2. To determine if in a single patient more than one type of BTcP (polytopic) can be detected.

**Methods:** Retrospective review of patient seen at the outpatient clinic between 2014–2015. Sociodemographic data, related to cancer diagnosis (type and existence of metastases) were recorded. The Algorithm of Davies was used to diagnose BTcP. The ECS-CP was used to individualize each type of BTcP. Descriptive statistics were used.

**Results:** 277 of 705 patients screened (39, 34%) fulfilled BTcP criteria. Men (63, 9%). Mean of age (68, 2 years). Lung cancer (31, 6%). Metastatic disease (83%). More than one type of BTcP can be present in the same patient. In the sample of 277 patients, 486 different types of different (origin, localization, intensity, duration) were individualized (mean of 1, 75 BTcP per patient). 138 patients presented 1 type of BTcP (49, 8%); 85 patients (30, 7%) with 2; 42 patients (15, 2%) with 3; 8 patients (2, 9%) with 4. 4 patients (1, 4%) with 5 types of BTcP.

Altogether with the incidental component of cancer pain, 244 types of BTcP (50%) presented a component of neuropathic pain. The addictive behavior (alcohol) was present in 130 types of BTcP (26, 64%) and the psychological distress was present in 222 types on BTcP (45, 49%).

**Conclusions:** Polytopic BTcP is highly prevalent in our sample (50, 02%). The use of the ECS-CP allows adding clinical and relevant complexity to the existing incident component of cancer pain (neuropathic, psychological distress and addictive behaviour).
Self Reported Experience & Barriers to the Use of Intrathecal Drug Delivery Systems: Results of a State-wide Survey of Hospice Clinicians

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Methods: An electronic, 18-question survey was sent to 180 hospice clinicians (physicians, nurse practitioners & nurses) in the state of Minnesota, USA, identified though mailing lists from the Minnesota Network of Hospice and Palliative Care (MNHPC) organization. The survey was administered by the Mayo Clinic Survey Research Center with IRB approval.

Results: Response rate was 66% (120/180). Slightly more than 50% of respondents had ever cared for a patient with IDDS with low contact frequency. If a patients had an IDDS, only 28% of respondents expressed confidence in managing their pain and the vast majority (over 80%) of respondents preferred the use of systemic therapies overall for primary pain management. Access to IDDS support from clinicians and vendors able to perform in-home device adjustments was listed as another barrier to utilization of this therapy.

Discussion: There are a number of self-reported barriers to the use of IDDS in a hospice setting.

Background: Pain is one of the most commonly experienced and feared symptoms faced by patients with a serious illness. While effective use of systemic analgesic therapies can control pain in most settings, a substantial minority of patients will have inadequate analgesia and/or intolerable side effects with systemic therapies. For these patients, intrathecal drug delivery systems (IDDS) deliver pain medications with greater potency and/or few systemic side effects and are associated with significant patient benefit. However, despite these benefits, the integration and management of IDDS for patients receiving hospice care has not been previous studied.

Aims:
1. To identify the familiarity and experience of hospice clinicians in the management of pain in patients with IDDS in a hospice setting.
2. To identify hospice clinician-reported barriers to the management of pain in patients with pain and IDDS in a hospice setting.
Quality of Life and Adherence to Opioid Therapy for Pain in Cancer Patients

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Background: Pain is a feared symptom in cancer patients. It affects their performance status and quality of life. If pain is not adequately controlled, it has a deteriorative effect in several aspects of patient’s life. It produces anxiety and emotional distress, interferes with functional capacity, and affects the familial and social roles and job’s performance. Adequate pain management could increase the well-being of these patients.

Aim: To study the correlation between adherence and quality of life, and adherence and performance status.

Methods: A descriptive multicentre study in three different hospitals in the same city was developed. Main inclusion criteria were: outpatients with cancer (solid tumours), opioids prescribed by oral route (around-the-clock or as-needed) and responsible for taking their medication. The study was performed along two years. Morisky-Green test was the tool used to assess the adherence evaluated with, FACT-G scale for quality of life and Karnofsky index (KPS) for performance status. Data were obtained through personal interviews after his visit to the oncology department.

Results: 60% of patients have a normal level of performance status according to KPS. The average score of quality of life was 67 (maximum score 108). Rated subscale was social and family well-being. Only 45.8 % have a good degree of adherence. Statistical change in quality of life and functional capacity according to the degree of adherence was not found. There is a positive correlation between functional capacity and quality of life (Spearman’s rho: 0.324).

Conclusion / discussion: Further research is recommended in order to clarify the relationship between pain management and quality of life. To improve quality of life and to reduce the influence of pain in performance in cancer patients, individualized care and a multidisciplinary approach are required.

This is an academic study with no funding from pharmaceutical companies.
**Revival of an Old and Forgotten Opioid to Successfully Treat Intractable Cancer Related Neuropathic Pain**

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**Background:** Levorphanol is an underutilized and forgotten synthetic mu-opioid agonist originally developed in the 1940s.

**Aim:** We describe 2 cases where Levorphanol was successfully used to treat intractable cancer associated neuropathic pain.

**Case 1:** A female in her 30s with osteosarcoma of the humerus underwent forequarter amputation of the left upper extremity. She developed intense phantom pain described as shooting pain and tingling in the left arm area and a strange unexplainable sensation that was extremely distressing. Hydromorphone extended and immediate release preparations along with gabapentin did not provide any relief prompting an opioid rotation to levorphanol 2 milligrams taken every 8 hours. A week later the patient reported almost complete resolution of the phantom pain. She only had a mild sensation of occasional tingling in the left upper extremity.

**Discussion:** Levorphanol is a more potent NMDA receptor antagonist than methadone and blocks the uptake of both serotonin and norepinephrine like methadone. Unlike methadone, levorphanol does not utilize the cytochrome P-450 system and thereby not subjected to numerous drug interactions and has no associated risk of QTc prolongation. More research on the use of levorphanol (due to NMDA antagonism) for intractable pain syndromes is required. It is time to revive this old opioid.
Efficacy of the Cryoablation to Control Cancer Pain. A Systematic Review

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Background: Achieving proper cancer pain control only with opioids can be problematic due to side effects or complications. In the recent years, new interventional techniques such as a cryoablation have appeared to substitute them.

Aim: To summarize the current scientific evidence to control cancer pain with cryoablation.

Materials and methods: A systematic review was conducted in Scopus, PubMed and Cochrane databases. All articles published before 31st December 2015 whose title or abstract specifies cancer pain control as a primary or secondary endpoint were selected. Articles without abstract and non-systematic reviews were excluded.

Results: 30 articles were included: 1 randomized clinical trial, 3 non-randomized clinical trial, 1 ambispective study, 10 retrospective studies, 8 case series and 7 case reports. 517 patients were selected and 601 lesions were treated. Lung cancer was the most frequent primary tumour. 82.16% of the total of metastases treated involved bone, with or without soft tissue associated. Decreases of 62.5% in the mean score pain 24h after cryoablation, 70% at 3 months and 80.85% at 6 months were described. These were related to an improvement of 44.2% after 4 weeks and 59.6% at 8 weeks on quality of life measured as a decrease in interference of pain on daily living activities. In addition, reductions of 75% at 24 hours and 61.7% at 3 months in opioid necessity were reported. In comparison with radiofrequency or bisphosphonates, cryoablation was more advantageous. In addition, cryoablation combined with radiotherapy, vertebroplasty or bisphosphonates seems to be better than cryoablation alone. Finally, a great variability of complications as bone fracture or transient neural injury were found among studies, but no mortal complications were reported.

Conclusions: Cryoablation could be a useful and safety strategy to control cancer pain. More studies are needed to confirm these results.

Fundings: There is no funding source to declare.
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**Effentora® Fentanyl Buccal Tablet (FBT) in clinical practice Non-interventional study ErkentNIS**

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**Background:** A high percentage of patients with advanced cancer disease suffer from breakthrough cancer pain (BTCP). BTCP is defined as transitory pain exacerbation despite opioid baseline therapy. Fentanyl buccal tablet (FBT) as a rapid acting opioid (RAO) is indicated for the treatment of BTCP in adult cancer patients.

**Aim:** The aim of this non-interventional study (NIS) was the documentation of the feasibility and tolerability of FBT in patients with BTCP.

**Methods:** This NIS was performed in 64 centers in Germany and Austria. Data were collected from May 2011 until November 2012. Data of 263 patients were available for analysis. Average time of observation was 32.5 days. Prior initiation of baseline opioid therapy patients rated a basic pain score of 8 (out of 10) points on a numeric rating scale (NRS). At the beginning of the study patients described an average of 2 to 5 BTCP episodes per day.

**Results:** FBT treatment was started with a dose of 100 µg in 69.2% and with 200 µg in 24.7% of the patients. After titration of FBT, adequate analgesic BTCP control was achieved within 5 minutes in 36.1%, within 10 minutes in 67.8% and within 15 minutes in 95.4% of the patients. BTCP control was rated as excellent or good by 92.4% of the patients, onset of action was assessed as excellent or good by 89.3% of the patients, potency of FBT was rated as excellent or good by 90.9% of the patients. Tolerability of FBT was assessed as excellent or good by 96.6% of the patients and safety of FBT was considered as excellent or good by 98.5% of the patients. Adverse drug reactions were registered in (2.7%) of all patients.

**Conclusion:** The study showed that treatment with FBT lead to a rapid pain relief and reduction of the number of BTCP episodes. The general patient satisfaction was rated as excellent or good, in conjunction with a very good tolerability.
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Non-Interventional Study with Effentora® Fentanyl Buccal Tablets (FTB)

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Background: Cancer patients with chronic pain often experience Breakthrough Cancer Pain (BTcP) which is a transitory exacerbation occurring in the presence of controlled background pain. BTcP. It coincides with a loss of physical function, emotional distress and a reduced quality of life. Fentanyl Buccal Tablets (FTB) are a rapid-onset opioid analgesic indicated for the management of BTcP in adult cancer patients.

Patients and methods: This non-interventional study, conducted from 03/2009 to 08/2010, recruited 497 patients, in 98 centers. Statistical analysis included 440 patients. Efficacy, tolerability, FTB use and patient satisfaction were analyzed. This study was part of the risk management plan for Effentora® and 3 major risks were identified and recorded.

Results: Mean maximum BTcP intensity was significantly reduced from a baseline of 7.7 (± 1.9) to 2.1 (±1.8) at the final visit. The number of BTcP episodes declined in 55.7% of patients. 87.0% of the study population rated their pain relief as “very good” or “good”. 18.4% of patients achieved adequate BTcP relief within the first 5 min after use of FTB. 47.0% within 5–10 min and 84.7% within 15 minutes. Adverse drug reactions were documented in 0.9%. 97.9% of patients expressed a preference for FTB over their previous on-demand medication. 4 cases (0.9%) were flagged for possible misuse and there was enough evidence in 3 cases to raise suspicion of misuse by the patient or a third party. 1 patient used the medication incorrectly.

Conclusion: FTB rapidly reduces maximum BTcP intensity and frequency in cancer patients receiving baseline opioids for chronic cancer pain. The incidence of adverse events was low (0.9%) and possible misuse was rare (0.9%).
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Abstract type: Poster Exhibition

**Adherence to Oral Opioids in Cancer: A Multicenter Study**


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**Background:** Over one third of patients with cancer pain rate this pain as moderate or severe. Opioids are the first choice of treatment in these cases. In chronic situations, medication adherence rates are lower than expected. To measure adherence to treatment is necessary if we want to optimize the therapeutic management of pain. Few studies about adherence to oral opioid therapy can be found in literature.

**Aim:** To describe adherence to oral opioid therapy in cancer pain.

**Method:** A descriptive multicentre study in three different hospitals in the same city was developed. Main inclusion criteria were: outpatients with cancer (solid tumours), opioids prescribed by oral route (around-the-clock or as-needed) and responsible for taking their medication. The study was performed along two years. Adherence was evaluated with Morisky-Green test, through personal interviews after his visit to the oncology department.

**Results:** 131 patients were included, 53 male and 78 female. Median age was 59.69 years (SD=12.11).

Only 45.8% have a good degree of adherence according to Morisky-Green test. No significant differences were found in adherence depending on age, sex or type of opioid. Most frequently used opioids were morphine and tramadol, but results were not different with other opioids like codeine, oxycodone or tapentadol.

**Conclusion and discussion:** Patients do not show a good degree of adherence to the treatment prescribed by the physician, obtaining results even worse than in other chronic diseases. More research is needed to determine factors depending on professionals or drugs that contribute to less-than-optimal adherence, as well as to design effective professional interventions to improve this adherence. This is an academic study with no funding from pharmaceutical companies.
Use of Morphine in Patients Admitted to the Institute of Oncology and Radiobiology of Cuba

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Objectives: To analyze the behavior of prescription morphine in hospitalized patients at the Institute of Oncology and Radiobiology (INOR). Describe sociodemographic, clinical and check risk / benefit of using continuous therapy with morphine in the period 2010–2015.

Materials and methods: Observational, descriptive, retrospective study of drug use on the practical consequences and prescribing habits of morphine in patients with indication through consumer records in the INOR, period January 2010 to December 2015. The universe consisted of 368 Medical records (MR) corresponding to 415 inpatient records in the INOR. The cause of non-correspondences between the MR and records is given by prescription through records to the same patient at different times. Summary measures, absolute and relative frequencies, Wilcoxon and Chi square for non-parametric data and Student t test for parametric data were used, with a confidence level of 95% (a = 0.05).

Results: Predominant age group 25–59 years (70.8%) more often female (54.1%). Oncological locations in order of frequency: sarcomas, gynecological and head and neck tumors prescribing morphine was assessed favorable. The risk / benefit ratio was 78.9%.

Conclusions: The pain caused by cancer very significantly compromises the quality of life of patients, so treatment should be effective and clearly defined goals. Treatment with opioid medications is the basis for the management of pain in these patients.

Keywords: Morphine; oncologic patients
Capsaicin for the Treatment of Chemotherapy-induced Peripheral Neuropathy

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Introduction: Chemotherapy-induced peripheral neuropathy (CIPN) is a common complication of chemotherapy. Certain chemotherapy drugs are more often linked to neuropathic pain syndrom. It is difficult to recommend effective treatment as the underlying etiology is not clear. The optimum approaches in the prevention and management of CIPNs is a treatment challenge. If the pain location is well limited, transdermal medications can be applied. Qutenza (Capsaicin) 8% is the pungent component of chili peppers. The substance is a selective antagonist of vanilloid receptor (TRPV1).

Goal: The effectiveness of 8% capsaicin patch in CIPN treatment.

Materials and methods:
11 patients hospitalized due to CIPN

8 females, 3 males

Type of cancer: 4 breast, 3 ovarian, 2 rectum, 2 prostate.
Chemotherapeutic agents: taxoids 6, taxoids and cisplatin 2, bevacizumab 2, bevacizumab and cisplatin 1.

All patient didn’t respond to pharmacological treatment of CIPN

3 patients had the patch applied twice, in the space of 3 months,

2 patients had repeated Qutenza apply three times every 3 months, 8 only one treatment

Location of patch application: feets

Premedication EMLA cream, paracetamol intravenously.

The efficacy evaluations: Melzack, Q1Q C30 forms, NRS scale before, after application and day after

Results: The patch was applied according to the protocol
Average NRS before application was 7, after capsaicin patch application 3.

8 patients reported reduction in pain score by 5 points and functional improvement.

The effect lasted 6 to 8 months.

In 3 patients was no improvement.

2 patients reacted with strong erythema, the application time was shortened.

2 patients required rescue medication

Conclusion: Qutenza 8% can be considered as CIPN treatment when pain is well limited.

Capsaicine is a therapeutic option for patients not responding to oral pharmacotherapy

The main question is how to determine who will and will not respond to capsaicine.
Music Therapy for Reducing Pain in Palliative Care

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Pain is the most prevalent symptom in palliative care. For its control, as recommended by the WHO, the use of analgesics and other therapeutic adjuvants are important. In this context, music therapy has been an important to relief of pain and promoting comfort. We aimed to evaluate the effectiveness of the use of music in the treatment of pain in patients in palliative care. This is an integrative literature review, whose guiding question, according to the PICO strategy, was “which published evidence on music therapy in relief of pain in palliative care?”. We referred to the databases LILACS, Scielo, PubMed and Cochrane Library, and employed different search strategies with controlled and no-controlled descriptors. The sample was 10 abstracts that addressed the chosen theme and met the inclusion criteria: be available online and in English, Portuguese or Spanish, published in the last 10 years. From the summaries, reading all articles, regardless of carried out study design was started. The findings showed that music therapy showed positive effects in reducing the intensity of pain and anxiety in 100% of the patients and stabilization of vital signs in 90%, and promote comfort, relaxation and improvement in interpersonal relationships. Its importance is reiterated when it sees the humanization of care. New research using robust methodologies, expansion and randomization of the sample, using validated scales for pain assessment and deep clinical evaluation of the patient may confirmed the use of music as adjunctive therapy in the management of pain.
Simple Screening for Impairment of Skilled Hand Function in Chemotherapy-induced Peripheral Neuropathy

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Background: Chemotherapy-induced peripheral neuropathy (CIPN) usually affects both the sensory and motor function of hands and feet, resulting in impaired skilled hand function. CIPN can interfere with an individual’s ability to work and even force unwilling discontinuation of chemotherapy.

Aim: Quantitative and objective evaluations for this condition have not been established. We investigated relationships among skilled hand function and the clinical sensory and motor features of CIPN.

Methods: Twelve CIPN patients and 12 age-matched controls were enrolled. We recorded their reach-and-grasp movements using a three-dimensional measurement system, and calculated the normalized jerk of these movements as quantitative indexes of skilled motor function. Clinically, we evaluated sensory function by measuring the touch detection threshold with von Frey filaments. Numbness was rated on an 11-point numerical rating scale. We used the number of sequential hand grip-release cycles in 10 seconds as an evaluation of clinical motor function.

Results: Our kinematic analyses revealed that while grasp movements were impaired in CIPN patients, reach movements were comparable to normal, indicating that the distal part of the forearm is particularly affected in CIPN. Disturbed hand function was directly correlated with poor scores on the hand grip-release test and the sensory tests.

Conclusion: Our findings indicate that the hand grip-release test has potential as a simple screening test to objectively and quantitatively evaluate skilled hand function in CIPN patients, in clinical settings. Future studies should confirm the clinical efficacy of this technique for decision-making regarding chemotherapy, quality of life (QOL), and cancer survivorship in cancer patients.
30 Days-survival Prognostication in a Sample of Advanced Cancer Patients Evaluating the Barthel Index, the Palliative Performance Scale Version 2 and the Karnosfsky Performance Scale Using the Classification and Regression Tree (CART) Analysis

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**Aim of Investigation:** Survival prognostication at the end of life of cancer remains a major challenge. Several tests have been developed in order to help professionals to determine survival intervals. The EAPC recommends combining subjective prognostic judgements and objective validated tools. The aim of this study is to develop and to validate a SP tool in a sample of advanced cancer patients based only on the functional tests Barthel Index (IB), the Palliative Performance Scale version 2 (PPSv2) and the Karnosfsky Performance Scale (KPS) using the CART analysis.

**Methods:** We developed the BKPs3 (Barthel-Karnofsky-PPSv2 survival Tree) in order to help to prognosticate 30-days survival in a sample of advanced cancer patients. The multivariate analysis suggested that the 3 functional tools held statistical significance. Further we designed a validation study including 335 advanced cancer patients recruited in the sanitary region of Lleida using the Classification And Regression Tree (CART) analysis. Sensibility and specificity, positive predictive value (PPV) and negative predictive value (NPV) of the BKPs3 were calculated with the AUC with a confidence interval of 95%.

**Results:** 30-days survival in the sample was 42, 1% (N=141). Mean of age was 68.99 (SD 13.8). The CART analysis designed a decision tree based only on the KPS and the IB. Cut-off points were 55 for the KPs and 48 and 88 for the IB. 4 survival groups can be defined with a 30-days survival of 10, 8%, 39, 1%, 56, 1% and 74, 3%, respectively. Sensibility was set up at 78, 35 %( 71,76 - 83,79) while specificity was 65,96% (57,44 - 73,59). The PPN was 76% (69, 36 - 81, 62) and the NPV was 68, 69% (60, 26 - 76, 42).

**Conclusions:** The BKPs3 prognostic tool shows good sensibility, positive predictive value and negative predictive value with medium specificity values in the sample of advanced cancer studied and can be easily used among advanced cancer patients to determine 30-days survival prognostic.
Safe Use of Opioids for Chronic Cancer Pain Management – An Experience from a Tertiary Cancer Care Center in India

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Background: WHO considers annual morphine consumption as a benchmark of a country’s ability to effectively treat moderate to severe cancer pain, as well as an index to evaluate improvements in the provision of adequate pain management services. Recently received data from developed countries alarm that there are enough chances of inappropriate use of these medication which has led to increased mortality and morbidity. This information may further increase the nonavailability of pain medication globally. In this situation it is important to find out a strategy to keep the balance of opioid use v/s misuse. In this study, the pattern of oral morphine consumption and steps taken towards its safe use since last 10 years at a tertiary cancer care center of India are discussed.

Methods: Data of Morphine procurement, consumption and distribution from 2006 to 2015 was retrieved from the available record. Morphine consumption per patient and other factors were calculated and analyzed. The steps taken for safe use of opioids are assessed.

Results: The consumption of oral morphine has increased from 3.67 kgm to 14.05kgm from 2006 to 2015. The number of patient seen per year have also increased proportionately from 4245 to 11584. Trends of morphine dispensed per patient visit indicative of fluctuations. Probably other factors govern its uses are
1) addressing total pain,
2) improving knowledge of safe opioid practice
3) close follow up and
4) selection of right patient.

Conclusions: This study suggests that there is a need to improve knowledge of safe use of opioids among physicians and nursing staff, which has lacked in the academic curriculum. Besides improving knowledge we have to change the attitude towards its use. It is definitely the mainstay of cancer pain management but neither a sole agent responsible to manage pain nor it will be misused if we follow and practice the principles of safe use of opioids.
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Keeping Alive the Ketamine Dialogue: Subanesthetic Subcutaneous Ketamine Infusion as an Opioid Adjuvant

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Introduction: Although a body of clinical literature exists detailing Ketamine as treatment for Opioid Induced Hyperalgesia (OIH), few clinical studies examine subanesthetic Ketamine as an opioid adjuvant to enhance treatment of escalating pain in cancer patients. This case study highlights one experience.

Case description: LN was a 64-year-old female, hospice enrolled, with a diagnosis of advanced Non-Hodgkin’s Lymphoma. On 06/14/2016 the patient was transferred from home to an inpatient hospice house to treat rapidly escalating back pain not responsive to daily increases in her oral opioids. On admission, a Fentanyl intravenous (IV) patient controlled analgesia (PCA) infusion was started, her oral opioids stopped, and oral Dexamethasone maximized. Throughout that first night her pain scale never dropped below 10/10, despite increasing her PCA dosing.

On the morning of 06/15/2016, with LN screaming in pain, her IV PCA dosing was increased again. By early afternoon, with her pain scale only minimally reduced, the Fentanyl basal dose was increased by 50%, her demand dose was doubled, and a Ketamine subcutaneous (SC) infusion was begun, starting at 1mg/hr (0.016mg/kg/hr). The morning of 06/16/2016 found the patient comfortable for the first time, with a pain scale down to 6/10. From 06/17/2016 through 06/20/2016, LN’s pain scale occasionally rose, necessitating small increases in her Fentanyl IV PCA dosing, and/or her Ketamine SC infusion. Her pain scale never rose back to the level she exhibited prior to Ketamine initiation. From 06/20/2016 to her death on 06/26/2016 she was comfortable, with a registered pain scale 5–6/10 on stable Fentanyl PCA and Ketamine infusion doses.

No psychotomimetic side effects were observed with the low Ketamine dose utilized.

Conclusion: Ketamine, as an NMDA receptor antagonist, can be a useful adjunct to traditional opioid analgesics in treating rapidly escalating pain in a hospice population.
Pain Control in Patients with Addictive Behaviour

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Pain is a multidimensional and complex phenomenon, an unpleasant sensory and emotional experience associated with tissue damage, but also encompasses patient driven psychosocial and spiritual elements. Intensity should be evaluated through scales. Pain treatment should include both pharmacological and non pharmacological therapies. In resistant pain all aspects of the “total pain” conceptual approach need to be considered.

A 64 year old Caucasian female doctor, divorced with depression and ethanol and benzodiazepine addiction, requiring previous hospital admissions. Due to a traffic accident the patient suffered an L1 fracture with spinal cord compression. She was transferred to a rehabilitation hospital, with the therapeutic goal of rehabilitation and pain management. On admission the pain was graded as severe (8–9/10 on a Likert scale), and the patient requested intravenous opioid treatment, although nonverbal evidence of intense pain was absent. She was started on Pregabalin 75 mg BD and Paracetamol 1g TDS, and psychiatric evaluation and treatment was undertaken. Due to continuing pain, with identical, and in discussion with the attending psychiatrist, long acting opioids were started: Buprenorphine 35 µg / h, in combination with both paracetamol and metamizol, along with adjuvant pharmacological therapy and physiotherapy treatment. The patients’ global symptoms and functional status slowly and gradually improved without further need to increase opioid analgesia, although the patient stated intensity kept constant for some weeks, before gradually subsiding.

This case illustrates the difficulty of pain control in patients with a prior history of substance abuse. Given their perceived pain thresholds and vulnerability, extra vigilance is required by Healthcare professionals when managing such patients, minimising unnecessary titration therapy. Self-medication is an evolving problem requiring greater awareness in healthcare professionals.
Interventional Pain Treatment to Relief Refractory Pain in Advanced Cancer Disease – Intrathecal Administration of Analgesic Medication via Implantable Drug Delivery System (IDDS): A Case Report

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Cancer pain is prevalent and often multifactorial. In most patients cancer pain is effectively treated by conservative medical management regarding the WHO analgesic guidelines, including the use of co-analgesics. There are new estimates (2016), severe and chronic cancer pain occurs in approximately 46 % of patients with advanced disease.

To obtain acceptable pain or symptom relief for this patient group the inclusion of a fourth step to the WHO analgesic ladder was necessary, including advanced interventional methods (e.g. intrathecal or epidural as neuro-axial techniques).

Different medications can be infused (e.g. Morphine, Bupivacaine, Clonidine) into the cerebrospinal fluid in an attempt to relieve intractable cancer pain, reducing disabling adverse effects of systematic analgesics, in order to achieve a higher quality of life. Spinal delivery of drugs for the treatment of chronic malignant pain by means of an implantable drug delivery system (IDDS) began in the 1980s. There are still discussions and controversies like e.g. indications, complications and cost-effectiveness in this treatment option.

In some cases after careful consideration this interventional pain-relieving approach should be considered.

We report a successful use of an Medtronic internal Drug delivery pump system (SyncroMed II pump, 40 ml) in a patient with metastatic bowel cancer (huge soft tissue metastasis in the lumbosacral area) for optimizing refractory palliative pain control. In this case we assume a pronounced increase in the patient’s quality of life. The treatment was cost-effective compared to the external pain-pump.

Due to the nature of case report, we cannot make generalized statements regarding the overall indications, the rates of complications, the limits of the duration of use, or the cost/benefit of this treatment option.
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Abstract type: Poster Exhibition

**Effect of Splanchnic Nerve Block with Cone-beam CT, who Patients with Epigastric Malignancies**

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**Background:** Cone beam CT (CBCT) and biplane fluoroscopy may be helpful for block therapy with patient who have a difficulty for treatment in anatomically. In our department, splanchnic nerve block (SNB) is performed using Xtra Clarity (a fluoroscope; Philips, the Netherlands). This allows for the precise delineation of the spread of contrast medium in the retrocrural space (RCS) with the use of CBCT and helps achieve satisfactory postoperative analgesia. We assessed the use of CBCT as an aid to improve analgesic outcomes in patients undergoing SNB.

**Methods:** A total of 24 patients who underwent SNB for pain associated with epigastric malignancies between June 2015 and December 2015 were included. Numerical rating scale (NRSs) and changes in opioid dose (using morphine conversion) were assessed preoperatively and at one week after surgery. The associated complication frequencies were retrospectively assessed. SNB was mainly performed by the transdiscal approach at Th12/L1 or L1/2 level. A contrast medium was injected into the RCS by using the loss of resistance technique, and its spread was monitored using fluoroscopy and CBCT. A neurolytic agent (dehydrated ethanol) was administered in doses between 10–20 mL.

**Results:** The mean NRS declined from 5/10 (preoperative) to 0.86/10 at one week after surgery ($p < 0.05$). The opioid dose (after morphine conversion) also declined from 86.6 mg to 58 mg at the respective time-points ($p < 0.05$). Transient hypotension occurred in eight (33%), nausea in five (21%), and diarrhea in three (13%) patients. There were no serious adverse effects. The use of CBCT allowed the precise visualization of the spread of the drug even in the two patients in whom the distribution was difficult to confirm by fluoroscopy image, and a satisfactory analgesic effect was achieved.

**Conclusion:** SNB is an effective analgesic modality for pain associated with cancer in the epigastric region. We believe that the use of CBCT helps improve the analgesic effect.
Current State of Intrathecal Analgesia (IA) in Palliative Care Practices in France in 2016

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Background: Intrathecal analgesia is a specific interventional pain technique which is indicated for refractory pains. It is a different way of administrating drugs because it is in the spinal area. Analgesics go directly on to receptors so the efficiency could be higher and the side effects are less important compared to systemic administration.

Aim: Because one of the most important questions in palliative medicine is “have you done everything possible to alleviate pain?”, it seems interesting to determine if this kind of analgesia is well known by physicians who look after palliative patients, in which proportion it is done but also if there are any limitations.

Methods: Exploratory transversal study. Together with biostatisticians of the University Hospital we came up with a questionnaire in 6 parts (including some easy-to-answer questions) sent to the practitioners.

Setting/participants: 130 were emailed to the doctors of three types of structures: Palliative Care Units, Mobile Palliative Teams and Centers for Cancer Treatment. Eventually, 54 questionnaires were collected.

Results: 63 % answered that they use intrathecal analgesia but less than 5 times a year. A detailed analysis of the results proves that this technique is not easy to perform and there are many boundaries linked to the heavy process, the timing, the lack of knowledge and institutional procedures.

Conclusion: Intrathecal analgesia has to be performed more often and needs to be prescribed earlier in the disease when patients suffer from a refractory pain. Some patients don’t benefit enough from interventional pain techniques. We have to perform this sort of pain management to improve patients’ quality of life.
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Risk Factors Associated with Pathogenesis and Frequency of Respiratory Depression in Patients Administered Opioids

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Introduction: Respiratory depression is a major adverse effect associated with the use of opioid analgesic medications such as morphine, oxycodone, and fentanyl. Results of respiratory depression can often be critical. The pathogenesis and frequency of this adverse effect may depend on the opioids used, concomitant medications, and patient background. However, limited information about these risk factors is available. Therefore, we evaluated the effects of patient background and concomitant medications on the pathogenesis and frequency of respiratory depression using the Japanese Adverse Drug Event Report (JADER) database published by the Pharmaceuticals and Medical Devices Agency (PMDA), Japan.

Methods: From the JADER database, data tables in which patient backgrounds and information of drugs and adverse effects were included were constructed to assess the frequency of respiratory depression during concomitant drug administration as well as patient background during each opioid administration. Furthermore, multiple logistic regression analyses were performed to demonstrate the effects of risk factors.

Results and discussion: In patients administered morphine or fentanyl, higher age was a significant risk factor associated with respiratory depression. On the other hand, bupivacaine, amitriptyline, and gabapentin were potential risk factors in morphine, oxycodone, and fentanyl, respectively. These findings may be helpful for better selection of medications in patients administered opioids.
Retrospective Analysis of the Impact of Tapentadol for Cancer Pain Treatment

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Introduction: Tapentadol (TP) is a centrally analgesics acting with 2 mechanisms of action: mu-opioid receptor agonism and norepinephrine reuptake inhibition. TP has been developed for the management of chronic pain, therefore there is paucity of information regarding the efficacy and tolerability in cancer pain management. The present study was performed to clarify the clinical impact of TP therapy for cancer pain treatment.

Methods: After IRB approval, patients with cancer pain to whom TP was prescribed within 2 years were enrolled. TP was prescribed to treat either moderate nociceptive pain or neuropathic component based on imaging examination and/or a character of pain. The TP doses were calculated from the previous opioid consumption, with a conversion ratio with oxycodone of 5.0. Pain intensity was evaluated using numerical rating scale (NRS; 0–10) before and after administering TP.

Results: Ninety-five patients were enrolled and TP, initial dose was 50–400 mg/day, was prescribed. Eight patients were excluded from the analysis due to oral intake failure within a few days. Mixed pain mechanisms (nociceptive and neuropathic pain) were found in the 34 patients, pure neuropathic and nociceptive pain mechanisms were observed in 32 and 21 patients, respectively. The pain relief could be achieved within 1–13 days following TP administration in 81 patients. The median NRS scores were 7 and 2 before and after TP treatment, respectively. Thirty-three patients who were opioid naïve exhibited no nausea and vomiting. Nausea was improved by switching to TP in 8 out of 17 patients.

Discussion: TP was effective and well tolerated in the management of cancer pain. From baseline to the final assessment, individual reductions in pain intensity of at least 50%, were achieved by 93% of the patients. TP had a better gastrointestinal tolerability profile than other opioids, with a lower incidence of gastrointestinal adverse events such as nausea and vomiting.
An Easy, Different Types of Pain Treatment Choice, Self-questionnaire to Identify Opioids Prescription Patterns for Palliative Care Physicians

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Background: Pain is one of the most common symptoms in the patient at the end of life. The WHO considers that opioid consumption is a good indicator of how pain is treated.

Aim: To determine consumption patterns habits by a questionnaire about opioid prescription in Palliative Care (PC) physicians who work in the Community of Madrid (Spain).

Methods: Our aim was to know opioid prescription consumption patterns and perceptions. We designed a questionnaire with closed answers in Google Forms web. The pilot began on 26th February and it finished on 20th May 2016.

Results: We got response of 56 questionnaires out of a sample of 123 physicians associated in the regional association of PC (46% of the sample). The socio-demographic professionals profile was a woman, between 35 and 54 years old, with 2 to 10 years of experience in the job. 51% of the people who answered the questionnaire worked in hospitals and 49% of them in home-based support teams, 93% answered that they prescribe opioids for moderate to severe cancer pain and 95% for noncancer pain. The second step WHO ladder, opioid of choice was Tramadol (79%). 91% preferred Morphone in the third step opioid group. None of them answered Buprenorphine or Tapenadol.In noncancer pain were more different responses: 64% preferred Morphone and 20% Fentanyl. In the breakthrough pain opioid treatment:45% preferred “fast fentanyls”, 30% the same opioid baseline and 20% used fast-release Morphone. 88% preferred the oral route as the first choice for opioid route.In patients with severe renal impairment, 43% preferred Morphone and 25% Fentanyl. In the liver patient, 55% used to choose Morphone and 22% Fentanyl. Most of them described their ability to prescribed safely opioids between 8–10/10.86% of them said that they managed the latest opioid guidelines (EAPC guide the best known).

Conclusion: PC Physicians describe their level of knowledge and ability to manage opioids as accurate. However, it seems that could have been some lacks of knowledge.
Limitations in Chronic Pain Management and Efficacy of Alternative Modalities during Mega Disaster in an Underdeveloped Nation

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Background: Palliative care is a new concept in an underdeveloped nation in South Asia. Pain is the commonest symptom for chronic ill patients to seek medical care. WHO pain ladder is followed and morphine remains the drug of choice for outpatients. However the prescription of morphine is restricted to a very small quantity in only a few designated tertiary hospitals. During disasters the hospital management focuses trauma care over the palliative care forcing these chronic pain patients to resort to the counter analgesics which leads to inadequate pain relief, increased side effects and difficulty in dose adjustment later on.

Aim: This retrospective analysis is to evaluate limiting factors and alternative methods employed to combat pain and the adverse effects encountered.

Results: The number of chronic pain patients attending the pain clinic reduced drastically since outpatient departments remained closed. The patients were either deprived of analgesics or they had to result to NSAIDs causing inadequate pain relief, gastritis and increase in opioid dosage following their regular outpatients visit.

Conclusion: During disaster the focus shifts to care of acute trauma patients and palliative care takes backseat. Pain is one of the capacitating symptoms forcing people to seek hospital care. Lack of opioids leads to consumption of over the counter pain ailments with poor quality of pain relief and increase in adverse effects. Therefore disaster prone countries should consider inclusion of palliative care in their disaster management policies to provide optimal care to chronic pain patients.
You Must Be Able to Make my Pain Better? Oromucosal Cannabis for Pain Associated with Duchenne Muscular Dystrophy

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Introduction: A 30 year old gentleman with Duchenne muscular dystrophy (DMD) was admitted to a specialist palliative care inpatient unit for pain control.

Case report: The patient had a background of DMD, associated cardiomyopathy and previous spinal stabilisation. He had a PEG tube in situ and had non-invasive-ventilation for 8 hours per night. The patient presented with constant, throbbing lower back pain, radiating to the lower limbs bilaterally. Various analgesics were trialled with little effect i.e. Pregabalin, Diamorphine, Morphine, Ketamine, Lidocaine patches, Fentanyl and Benzodiazepines. A trial of cannabis oromucosal spray showed significant analgesic benefit. The patient found it particularly beneficial when used together with Morphine. The patient was discharged home after a five week inpatient stay and experienced ongoing benefit from the oromucosal cannabis spray.

Discussion: The patient’s pain was very complex and there were various factors, not only physical but a strong psychological component, contributing to his total pain. The cannabis oromucosal spray comprises controlled proportions of delta-9-tetrahydrocannabinol and cannabidiol. It has antinociceptive and antihyperalgesic effects at peripheral and central CB receptors.

There is currently no evidence for the use of cannabis-based analgesia in DMD. There is evidence for its use in multiple sclerosis, neuropathic pain and cancer pain. There is also evidence to suggest synergistic analgesic effect with opioids.

Summary points: This case report highlights that there may be a place for cannabis based oromucosal spray in the management of pain associated with DMD.

There is a need for further research on the use of cannabis-based analgesia.
Distress in Cancer Patients with Pain

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Pain and distress decreased the quality of life and adherence to treatment of cancer patients. This study analyzed the factors related to distress in cancer patients with pain. Cross-sectional, retrospective and quantitative study, with 167 patients. Patients were evaluated by the Distress Thermometer (practical, family, emotional, spiritual and physical domains) and by the Edmonton Symptom Assessment System (ESAS). Chi-square and t student tests were used. There was a higher prevalence of physical problems (82%), followed by practical (71.9%) and emotional problems (70.1%). Patients with mild pain reported a greater amount of problems (17) related to distress followed by moderate (15) and severe pain (4). The factors cited as causing distress were worry (61.7%), transport (50.3%) and nervousness (49.1%). Regardless of pain intensity, depression, nervousness, sadness and worry (p< 0.001) were related to distress. In mild pain, practical problems (p = 0.001), emotional (p < 0.001) and physical (p = 0.005) were associated to distress. In moderate pain, having a paid function (p = 0.043) and practical (p < 0.001), family (p = 0.042), emotional (p < 0.001) and physical (p < 0.001) problems were associated with distress. The distress was related to emotional (p = 0.005) and physical (p = 0.002) problems, especially depression (p = 0.001), nervousness (p < 0.001), sadness (p = 0.003) and worry (p = 0.008) in patients with intense pain. Despite the pain does not have related to distress, to know the influence of pain in the depacientes cancer distress help in understanding the psycho-emotional state and early diagnosis of distress.
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Prevalence and Characteristics of Breakthrough Cancer Pain (BTcP) in a Sample of Advanced Cancer Patients Attended at the Outpatient Clinic in a Teaching Hospital


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Aim of investigation: Breakthrough cancer pain (BTcP) is defined according to its main features: high intensity, short time interval between onset and peak intensity, short duration, potential recurrence over 24 hours and non-responsiveness to standard analgesic regimes. BTcP is detected in 50%-90% of hospitalized cancer patients, in 89% of patients admitted to terminal-patient care centers, and in 35% of ambulatory care cancer patients. The literature refers to BTcP as a single type of pain with multiple episodes. The purpose of this study is to determine the prevalence and main characteristics of BTcP in a sample of advanced cancer patients attended at the outpatient clinic of a teaching hospital.

Methods: Retrospective revision of advanced cancer patient’s files attended at the outpatient clinic over the period 2014–2015. Sociodemographic data, related to cancer diagnosis (type and existence of metastases), functional and cognitive tests and characteristics of BTcP (volitive, non-volatile or idiopathic) and etiology of BTcP (due to tumor, treatment or idiopathic) were recorded.

The Algorithm of Davies was used to diagnose BTcP. Descriptive statistics were used.

Results: 705 patients were found to have pain diagnoses from whom 277 (39.34%) fulfilled BTcP criteria. 63.9% were man. Mean of age was 68.2 years. Main diagnosis was lung cancer (31.6%). Metastases were diagnosed in the 83% of the sample. Volitive BTcP was assessed in 103 patients (37.8%); non-volatile BTcP in 232 patients (83.75%). BTcP due to the tumor was present in 270 patients (97.47%) and secondary to the treatments was present in 35 patients (12.63%). Mean lower pain (Visual Analogic Scale) was 1 [0–5]), and the mean maximum pain was 6 [4–10].

Conclusion: Similar prevalence to the related in the literature is detected in our sample. Non-volatile and related to the tumor are the main characteristics of BTcP. More than one type of BTcP can be assessed in a single patient.
“Schubert Dressing”: Musical Counter-stimulation to Accompany Painful Interventions

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Context: Benefits of music therapy to patients hospitalised in palliative phase have previously been reported (OPPERT, PAL 2012, 2014, 2016).

Objective: To observe potential sensory counter-stimulation effects in patients in a palliative care unit exposed to music during painful care interventions: bathing, dressings, intravenous or intra-abdominal catheter insertion. Study concerned: patients 80% oncological, 10% neurological; 20% dementia, 5% psychotic; 230 hospitalisations per year; 10 beds; average stay 12 days.

Method: Open, monocentric, prospective study by a music therapist/cellist intervening at patient’s bedside. Analysis of 200 “Schubert dressings” over 3 years in collaboration with Unit’s health personnel. All patients consented consecutively to receiving music therapy or not to accompany painful intervention. Following data compiled on a specific observation form: age, pathology, cognitive status, art tastes, intervention type, pre-medication, session length. Following data compiled before, during and after intervention: pulse rate/BP, respiratory rate, thoracic expansion, pain status (VRS, BRS), communication and anxiety (expressed directly and hetero-assessed indirectly), patients’ and carers’ sentiments.

Results: Earliest results (intermediary results of 100 dressings based on forms reporting comparatively with and without musical counter-stimulation) reveal:

- 10–50 % pain reduction with “Schubert dressing”, showing musical stimuli can relieve pain sensation
- muscle relaxation
- reduction in anxiety
- beneficial effect on carers

Conclusion: Despite methodological difficulties, discussed and analysed, associated with assessment – difficulty applying scales approved for long term assessment used over a short period, and issues of subjectivity – due to carers’ responses to music therapy session, “Schubert dressing” sessions had significant positive effects on feelings of pain and anxiety experienced by patients during painful interventions.
**Cone-beam CT-guided Splanchnic Nerve Block after Control of Refractory Malignant Ascites Using Concentrated Ascites Reinfusion Therapy (CART) in Advanced Cancer Patients**

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**Background:** We have recently reported that C-arm fluoroscopic cone-beam CT (CBCT)-guided splanchnic nerve block (SNB) is invaluable for refractory abdominal pain in advanced cancer patients. The CBCT-guided SNB has made it possible to perform fluoroscopic real-time observation and three-dimensional CT image acquisition. This technique requires patients to be in the prone posture, which is difficult for those with massive ascites. The recent advance of concentrated ascites reinfusion therapy (CART) has become capable of processing larger volumes of ascites safely.

**Aims:** To report the feasibility and usefulness of CBCT-guided SNB conjoined with CART.

**Methods:** The subjects were three patients with advanced malignancies (pancreatic cancer 2, hepatoma 1) in their 50s-70s, showing refractory abdominal pain and massive ascites. In the CART procedure, as much of ascites as possible was collected by gravity and was filtrated and concentrated about tenfold. The concentrated fluid was infused back into the patients. In the CBCT-guided SNB, a 22-gauge needle is advanced from the posterior approach into the retrocrural space under real-time continuous fluoroscopic observation. After the mixture of lidocaine and iopamidol was injected and its spread was assessed with fluoroscopic and 3D-CT images, the mixture of 99% ethanol and iopamidole was injected through the same needle.

**Results:** The ascites drawn off was 5230 g, 7064 g, and 5174 g, and that concentrated and infused volume was 585 g, 657 g, and 745 g in each patient, respectively. All patients became capable of keeping in the prone posture and underwent CBCT-guided SNB successfully 4, 1, and 4 days after the CART, respectively. Significant pain relief was obtained in the patients, causing a decrease in pain scores and/or the opioid consumptions.

**Conclusion:** The CBCT-guided SNB after ascites control with CART is a feasible option to improve the QOL in advanced cancer patients with massive ascites and refractory abdominal pain.
Opioids Consumption Evolution between 2004 and 2014 in Primary Care and Hospitals in a 6 Million Inhabitants European Region

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Background: Pain is one of the most common symptoms in the patient at the end of life.

Aims: To describe the available opioid evolution consumption in the Community of Madrid (CM) (Spain) between 2004 and 2014 in Primary Care and Hospitals (medical prescriptions).

Methods: The CM population in 2011 census (the latest one) was 6,421,874 inhabitants. Our research is an analytical, observational, cross-sectional, retrospective study of prescriptions made in the CM in Primary care and Hospitals of the Public Health Network Services between 2004 and 2014. The data were provided by the Pharmacy Regional Service from Farmadrid® data base. Data were expressed as DDDs per inhabitant per year to homogenize and compare data.

Results: In Primary Care, Tramadol was the most widely used opioid in this period. In the third step opioids: Fentanyl was the most widely used, followed by Buprenorphine and Oxydone. Morphine was the fourth one. In medical prescriptions made from Hospitals, tramadol was also the most used opioid. In the rest studied opioids, Fentanyl was the second one. Oxycodone was the third until 2012 but has been over by Morphine. In 2014, Tapentadol has reached the second place.

Conclusion: These data are similar to others published in Spain and in the rest of Europe. In our region, there are only few studies that were published by our research group. Morphine that is supposed to be the gold standard opioid is not the most prescribed one.
Complaining about Pain

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Research that connects phenomenology to clinical cases as part of a philosophy thesis defended in 2014 at the university Paris-Est.

COMPLAINING ABOUT PAIN
Elusive, indistinguishable, subjective and always suffering, pain is a singular human experimentation. It always is about “I”, “I am suffering”, “I am in pain”.

The human painful experience is influenced by his culture, personal history, consequences, circumstances, and every meaning assigned to it.

The human pain, hardly communicable to someone else, cannot be objectivized nor be measured. Pain is to be shown and told.

The painful man must be welcomed, observed and listened in order to be acknowledged as suffering which means to be rehumanized because pain dehumanizes.

Why is the painful man complaining about pain?
Because of the malaise of living; his relationships with his environment change, he tries to escape from unpleasant sensations he is alienated from, without forgetting the meaning that represents to him this suffering according to the stakes and circumstances.

How to complain about pain?
Using a universal language, which is never the same, and can be used by everyone. The complaint, always addressed to someone, exaggerated and insistent, somehow tied to the reason causing this suffering, reveals a malaise and is asking for help.

Complaining about pain constitutes a bold encounter challenging humanization; at the risk of creating resentment from the painful man if he thinks he is not acknowledged and pain relieved.
Neuropathic Pain after Heavy-particle Beam Therapy: A Report of Three Cases

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Background: Heavy-particle beam therapy (HPBT), it is possible to restrict the damage to the normal cells to a minimum, while causing continuous sufficient damage specifically to the cancer cells. However, in case of nerves running through the cancer lesion, neuropathic damage following irradiation with HPBT is likely.

Aim: We investigate peripheral neuropathy involving pain and paralysis resulting from HPBT.

Methods: Neuropathy after HPBT in our hospital were retrospectively studied.

Results: There were three cases of the patient developing neuropathic pain and paralysis following HPBT. All three cases using HPBT was effective in the suppression of local tumor growth.

Case 1: A woman in her 30s with an unknown primary intrapelvic tumor developed. Methadone and pregabalin were administered for pain. Methadone was reduced and stopped when the pain alleviated two months after HPBT irradiation with a total dose of 73.6 GyE in 16 fractions. However, 3 months after irradiation, she experienced severe gripping pain again, allodynia, paralysis.

Case 2: A man in his 50s had a recurrence of rectal cancer after surgery. HPBT with a total dose of 70.4 GyE in 16 fractions was administered. After 3 months, although the pain improved, the patient developed movement disorder of the left sciatic nerve. Six months following this, he developed paralysis.

Case 3: A woman in her 80s had a primary adenoid cystic carcinoma in the right maxillary sinus. HPBT with a total dose of 64 GyE in 16 fractions was administered. After 14 months of irradiation, right supratrochlear neuropathy and pain appeared.

Discussion: Neuropathy does not develop in every case of HPBT. The elements that make a patient prone to developing pain or paralysis after HPBT remain unknown, and the measures to prevent neuropathy remain unclear.

Conclusions: Further study of the factors mediating the neurological symptoms is required to devise measures to improve the quality of life for cancer survivors.
Evaluation of the Efficacy of Acupuncture Treatment in Cancer Patient

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Cancer patients often complain about neck stiffness, backache and lumbago. The cause of this symptom is thought to the muscle stiffness and blood flow disorder due to bedridden state. The previous study showed the efficacy of acupuncture treatment to cancer patients but there are a few reports of using objective evaluation. A Daeki Amylase Monitor® (NIPRO) is portable optical salivary analyzer that measures salivary amylase activity(sAA). In this study, we assessed sAA and Visual Analog Scale (VAS)value in cancer patients undergone acupuncture treatment.

With IRB approval and informed consented, seven patients were participate. After the stabilization period, treatment was done using the pyonex needle®(Seirin). We measured sAA and VAS value in four conditions:
(1) after lying on a bed for five minutes before the treatment (control),
(2) five minutes,
(3) fifteen minutes,
(4) one hour after the treatment.

Data are expressed as mean ± standard deviation. ANOVA followed by Fisher’s PLSD test was used to determine the significance of differences. The p-values of less than 0.05 were considered to be statistically significant.

Two male and five female patients were enrolled this study. Average age was 61.1±15.8 y.o., height 157.7±6.9cm and weight 49.8±6.7kg. The sAAs in each condition were
(1) 19.4±13.5IU/L
(2) 9.5±9.8IU/L,
(3) 12.5±13IU/L and
(4) 10.7±11.2IU/L.

The VAS values were
(1) 50.2±23.7mm,
(2) 29.3±20.2 mm,
(3) 20.3±24.6 mm and
(4) 16.3±21.9 mm.

There was a tendency in degradation but not the significant difference in sAAs before and after the treatment (P=0.07). But, VAS value was significantly decreased after the treatment. (Control vs 5minutes, 15minutes and one hour).

Salivary alpha amylase reacts rapidly with the psychological stress and therefore analyzing sAA is a useful objective assessment method for psychological stress. Our result indicates that the acupuncture treatment may not block sympathetic nerve nor have a relieving effect on patients’ stress.
Clinical Characteristics of Pain in the Elderly Patients Hospitalized under Palliative Care

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Introduction: The elderly patients under palliative care frequently suffer unnecessary pain from the use of a number of drugs. Despite the fact that this awareness is of a public order, investigation on pain, in the elderly, are inexpressive in the Brazilian context.

Objective: To study the clinical characteristics of pain in elderly hospitalized patients under palliative care (PC).

Methodology: A qualitative study performed with 22 elderly patients under PC in a public hospital of the city of Salvador-Bahia, Brazil, between March 1 and July 15, 2011. The research used a questionnaire about the complaint of pain, comprising: intensity, location, time and analgesics prescribed. Descriptive analyzes were performed through the distribution of univariate and bivariate frequencies and descriptive measures (average, standard and median deviation). The STATA software version 8.0 was used for data analysis.

Results: In the Palliative Performance scale, 72.7% presented scores lower or equal to 60%. Most referred to other complaints as well as pain, 72.7%. In relation to the location of pain, 54.5% reported pain only in one region, with emphasis to the chest (18.2%) and members (13.6%). 9.1% informed having diffuse pain. The intensity verified, using the Numeric Scale, was preponderantly intense (45.4%), and with reference to duration, 68.2% informed less than 6 months, characterized as acute pain. All the elderly patients were under pain-killing pharmacological therapeutics, most using 01 or 02 drugs (77.3%), with a greater proportion in the therapeutic scheme of the first step of the WHO (88.3%) and only 18.2% were using benzodiazepine sedatives.

Conclusion: The presence of pain in elderly patients under palliative care is a reality that should be investigated and alleviated, even in the face of the myths about pain during the ageing process. Thus, the adequate use of pharmacologic and non-pharmacologic therapeutics permitted the comfort of these patients.
Efficiency and Safety of Continuous Intrathecal Morphine Infusion for Pain in Cancer Patients

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**Background:** Intrathecal opioid administration is widely used in patients with severe cancer pain which is not manageable by conventional methods, therefore placing an indwelling intrathecal catheter is helpful.

**Aim:** Efficiency and side effects of intrathecal morphine administration through intrathecal catheters connected to a subcutaneous injection port in cancer patients.

**Methods:** Study included 9 cancer patients with 8–10 NRS pain level corrected by bolus intrathecal morphine. Intrathecal catheterization with the implantation of a subcutaneous injection port (POLYSITE®, Perouse, France) was performed in an operating room. We punctured the spinal canal with a Tuohy needle at the L2–L3/L3–L4 level. Using fluoroscopy we intrathecally inserted one end of the catheter through the needle to level Th10–11. Then we placed the other end of catheter in the left/right costal arch to frontal axillary line and connected it to the port. The port had been inserted in subcutaneous pocket.

A 2mg morphine bolus dose (Morphine hydrochloride 10mg/1ml, Ukraine) was administered to all patients. It was adjusted in the following days based on pain level.

**Results:** Day 1. 5 patients experienced a reduction of pain by 0–2 points with the intrathecal morphine administration. Day 3. 4/5 of patients did not need any further correction doses. 1 patient had two 5mg boluses. Day 7. 8/9 of patients did not need any analgesics. 1 patient received extra 30 mg of morphine systemically.

Side effects were nausea, vomiting (22.2%) and urinary retention (22.2%) managed by conservative methods of therapy. We did not observe symptoms like respiratory depression, bradycardia, hypotension, impaired consciousness, drowsiness. 8/9 of patients died due to disease progression. 1 patient had a “port-a-cath” system explantation due to a successful cancer treatment.

**Conclusion:** Morphine administration through intrathecal access ports is efficient and safe for chronic pain treatment in cancer patients.
Opioids Use at an Internal Medicine Department of an Acute Tertiary Hospital. Is there Conformity with Recommendations?

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Background: Use of strong opioids is a quality marker on pain and dysnea control in cancer patients (CP) and no cancer patients (NCP). In Portugal, at Internal Medicine Departments (IMD), end-of-life care is provided by internists rather than palliative care specialists. In recent years internists become familiar with strong opioids use and with comfort care in terminally ill patients (P), CP and NCP.

Main: Evaluation of the degree of conformity between Internists practice at an IMD and international recommendations for opioids prescription in Palliative Care (PC).

Methods: Retrospective study; data collection obtained by consulting medical records of hospitalized P at a IMD, deceased in the 2nd half of 2014; a descriptive statistical analysis was done.

Results: There were 160 deaths in the 2nd half of 2014 (average age 79 years, 58% women, average delay 8.5 days) corresponding to a mortality rate of 8.3%, highlighting that 42.6% of P died in the first 3 days. Palliative CP (PCP) 69; No Palliative CP (NPCP) 4; Palliative NCP (PNCP) 45; No Palliative NCP (NPNCP) 44. Pain present in 55P: PCP 39; PNCP 7; NPNCP 8. Dysnea present in 87P: PCP 33; PNCP 27; NPNCP 24. Prescribed Opioids (descending order): Morphine, Fentanyl, Tramadol, buprenorphine and hydromorphone. During hospital stay, excluded the last 3 days (L3D), 104 P (65.4%) were on opioids, of these 82P (78.9%) received round-the-clock dosing (RCD) of which only 26P (38%) received RCD with provision of a ‘breakthrough dose’ to manage transient exacerbations of pain. At L3D 46P were on opioid RCD with provision of a ‘breakthrough dose’. Prescription of laxatives for constipation in 26P on opioids received RCD, L3D excluded. At L3D a continuous morphine perfusion iv was performed in 51 P (29 PCP, 12 PNCP and 9 NPNCP).

Discussion and conclusion: Although opioids prescription have become part of the clinical practice of internists and opioids indications are being fulfilled, there are aspects that require optimization.
Downward Trend in a Destructive Nervous Block to Obstinacy Cancer Pain after Methadone Introduction

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Background: In March, 2013, Methadone was published in Japan and a prescription example is increasing gradually. Even in our hospital, we prescribe methadone for refractory cancer pain. After methadone introduction, an operation case in a destructive nervous block (DNB) is decreasing clearly in our hospital.

Aims: Investigate a change in the number of cases, which operated a DNB before and after methadone introduction, and it’s examined whether a methadone is the substitution means of the DNB.

Methods: An investigation considered the cancer pain patient cases which operated the DNB from January, 2007 to August, 2016, and the cases which were prescribed methadone from March, 2013 to August, 2016 retrospectively. It was in the methadone prescription example, the number of cases, which was DNB adaptation, was considered.

Results: The yearly average in 2007–2013 was 18 cases of DNB and 2014–2016 was only 2 cases. After 2014 we have begun to use a methadone in earnest, the yearly average methadone introduction number from 2014 to 2016 was 14.3 cases. There were 41 cases that adaptation for DNB before during 46 cases, for which a methadone was prescribed during a period.

Conclusion and discussion: D-methadone has a NMDA (N-methyl-D-aspartic acid) receptor antagonist action, and the workings that prevent opioid tolerance formation and the effect to neuropathic pain are expected. Obstinacy which requires DNB method of treatment when it’s before in our hospital, the case (lung cancer and malignant pleura mesothelioma etc.) from which we could get the good analgesic effect by using a methadone to cancer pain also existed much. The case which can’t carry out nervous block method of treatment by high inflammatory index and clotting dysfunction etc. are also increasing. Base on the above it’s made the thing that methadone introduce first, and if effect insufficiency, considers a DNB second in our hospital. We’ll also use a methadone aggressively from now on.
End-of-Life Care in Residential Care Homes – An Innovative Pilot Project

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Background: Care homes play an important role in the care of older people at the end of life. Approximately 22% of people die in a care home. With an aging population, it is likely that this number will increase in the future. It is therefore imperative that care home staff have the appropriate knowledge and skills to provide quality care for those residents at the end of life.

Aims: The Supportive Care Home Team successfully implemented an innovative model of care provision for improving End of Life Care (EoLC) in nursing homes. The local Clinical Commissioning Group commissioned a one year pilot to continue this work within the residential care home setting. The pilot aimed to support staff in developing awareness and confidence in caring for residents at the end of life.

Method: Staff in the care homes had end-of-life care educational sessions. This didactic learning was further developed by use of experiential learning, role modelling and reflections. The Clinical Nurse Specialist (CNS) discussed residents EoLC needs with the General Practitioner (GP) at their regular palliative care meeting.

Outcomes: Staff recognised the importance of holistic care and actively engaged with thinking ahead, including advance care planning discussions. There was an increase in number of Future Wishes discussions offered; from 1.9% to 80.4%, Those registered on an Electronic Patient Palliative Care Coordination System rose from 17.1% to 28% and of those registered, 67% achieved their Preferred Place of Death.

Lessons learned: Factors which helped to enable the pilot were a supportive manager/GP), engagement from members of the multi-disciplinary teams and an adaptive approach of the CNS facilitator. Challenges experienced included care homes having more than one GP, managers who were less engaged with the project and staffing shortages.
Prescription Patterns for Older People Approaching the End of Life in the Hospice and Hospital Palliative Care Setting: A Retrospective Cross-sectional Study

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Background: Older adults with cognitive impairment in hospice or hospital palliative care units have limited life expectancy. The use of medications of questionable benefit in this vulnerable patient group has been reported.

Aims: To investigate medication use during the last seven days of life, in deceased older patients cared for in selected hospices or hospital palliative care unit in a region of the UK, and to examine whether cognitive impairment influences the number of medications prescribed.

Methods: A retrospective cross-sectional study of medical and prescription records of patients aged 65 years and older, admitted to selected hospices and a hospital palliative care unit. Data collected included demographic characteristics, cognitive status and prescribed medications during the last seven days of life. Data were entered into SPSS and statistical analysis performed using descriptive statistics and Mann-Whitney U tests as appropriate. Ethical approval was obtained.

Results: Of 143 patients, 26.6% had documented cognitive impairment. Commonly prescribed medications included central nervous system drugs (n=1002, 44.5%), gastrointestinal system drugs (n=332, 14.8%), ear, nose and oropharynx preparations (n=190, 8.4%), antipsychotics (n=180, 8.0%), cardiovascular system drugs (n=124, 5.5%), respiratory system drugs (n=94, 4.2%) and endocrine system drugs (n=89, 4.0%). Patients with cognitive impairment were prescribed a greater number of medications (n=705) than those with no documented impairment (n=411); this was not statistically significant (p=0.13)

Conclusion: Older people in receipt of hospice care take a large number of medications. They continue to receive medication for chronic conditions rather than medications exclusively for symptom palliation. The total number of medications prescribed during the last seven days of life may vary according to cognitive status.

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**Dignity of Older Adults in the Final Stage of Life**

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**Background:** Dignity is a universal value stemming from the very essence of humanity. In order to protect the elderly from loss of dignity, we must investigate the factors which affect it. The interest in dignity of older adults in the final stage of life has been increasing recently. The Patient Dignity Inventory (PDI) can be used to assess dignity in old age, as it includes physical, psychosocial, spiritual and existential issues affecting personal dignity.

**Aims:** To ascertain how age, sex and type of disease affect the assessment of dignity amongst older adults in the final stage of life.

**Methods:** A cross-sectional study; Czech version of the PDI questionnaire. Mann-Whitney U-test and Spearman’s correlation were used for statistics. Reliability was verified using Cronbach alfa (0.916).

**Results:** The sample included 256 older people (average 73.1±11.2 years); 144 (56.3%) women; 136 (53.1%) oncology patients. Lack of autonomy (self-sufficiency, control over one’s life and illness) and lack of sense of one’s worth (respect, understanding, usefulness) threaten the dignity of the aged people (75+) significantly more than of the young-old (p< 0.05). Women showed significantly worse assessment than men in areas lack of independence in activities of daily living (p=0.003) and attend to bodily functions dependently (p=0.009). Oncology patients show more negative assessment in the psychological areas (depression, insecurity, fear of future; p=0.026) and existential (sense and meaning of life; spiritual life; privacy; I am not who I used to be; p< 0.0001).

**Conclusion and discussion:** Age affected the assessment of autonomy and self-esteem, female gender is linked to worse assessment in the area of independence and cancer is linked with worse assessment of psychological and existential areas. Nursing activities focused on these areas can help in protecting older people’s dignity in the final stage of life.

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Rules-of-Thumb for Dementia End-of-Life Care

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Background: The end of life for someone with dementia can present challenges for practitioners. Difficult decisions can be aided by rules-of-thumb; schematic patterns which are brief, easy to remember and applicable in complex situations. For example, FAST is used to identify symptoms of a stroke: Facial weakness, Arm weakness, Slurred speech, Time to call 999 (UK emergency services).

Aim: To develop a toolkit of rules-of-thumb for practitioners making decisions about care for someone with dementia at end of life.

Methods: This study had three phases:
1) Development of rules-of-thumb in focus groups with caregivers (n=10) and health/social care practitioners (n=24), and a co-design group;
2) Testing the rules-of-thumb in practice for 6 months in 5 different clinical settings;
3) Evaluation and refinement of rules-of-thumb at 3 and 6 months.

Results: Four categories of decisions were identified which could be represented by rules-of-thumb; eating/swallowing difficulties, agitation/restlessness, reviewing treatment, and routine care. The rules-of-thumb are arranged as flowcharts, prompting practitioners through a series of thought-evoking questions. Eating/swallowing difficulties have two rules; ensuring eating/swallowing difficulties do not come as a surprise and reflection about ‘comfort-feeding’ only. Agitation/restlessness encourages a holistic approach, considering the environment, physical causes, and caregivers’ health/wellbeing. Reviewing treatment/interventions guides practitioners through a process of considering the benefits to quality-of-life and maintaining comfort. Finally, routine care such as bathing, prompts practitioners to ensure care interventions have positive impacts on quality-of-life.

Conclusion: The toolkit was used in a variety of ways including to engage in conversations with caregivers and training. Teams liked the simplicity of the rules-of-thumbs, making their implicit knowledge explicit, enhancing their confidence in making decisions.
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Dementia Palliative Care Guidance Documents

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Background: There has been growing recognition of the complexities involved in providing palliative and end-of-life care for people with dementia. However there is a notable void of practice guidelines to support health and social care staff to do so.

Aim: To develop a suite of guidance documents for health and social care staff working in all care settings to assist them in the delivery of palliative and end-of-life care with people with dementia.

Method: A desk top review of Irish literature on dementia and palliative care was completed and compared against an Irish review of the educational needs of staff working with people with dementia. Following a process of consultation and feedback seven care domains were agreed upon as focus for the documents. An expert advisory group (EAG) was convened for the development of each document and a project advisory group was in place to oversee their overall development. Literature reviews were carried out and consensus within each EAG was achieved. Key themes from the literature informed key considerations and guidance.

Result: Seven guidance documents with accompanying factsheets, listed below, were developed.
1. Facilitating discussions on future and end-of-life care with a person with dementia
2. Advance care planning and advance healthcare directives with a person with dementia
3. Loss and grief in dementia
4. Management of hydration and nutrition
5. Pain assessment and management
6. Ethical decision-making in end-of-life care for the person with dementia
7. Medication and dementia: Palliative assessment and management.

Conclusion: The documents are available for use and require translation into practice so that people with dementia can be assured that their palliative care needs are appropriately addressed.
Recognising the Need for Innovation in Digitalising Urgent or Advance Care Planning in Adults Aged 70 Years and Over Following Emergency Admission

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Background: There is a need to share patient-held electronic care plans across multiple sites to improve end-of-life care and empower patients. In Scotland, approximately 1 in 3 hospital inpatients are in their last year of life. However, no data exists for England, including following emergency admission.

Aims: To review outcomes of a cohort of patients aged 70 years+ admitted as an emergency to a large London hospital Trust during 2015. The aims were to assess the 1-year mortality of a cohort of emergency admissions and pattern of admissions, to explore the need for innovation in urgent or advance care planning.

Methods: Admission data was obtained via Cerner, the electronic patient record, over 6 months from 1st May-31 October 2014. Patients were stratified according to emergency overnight admission and age. Follow-up data on mortality and repeat admissions were analysed.

Results: There were 6,701 admissions aged 70+years from May 2014–October 2014. Within the cohort, 49.4% were aged 70–79 years, 38.3% were 80–89 years and 12.3% were 90+ years. 1-year combined mortality was 22.4%, rising with age from 20% (70–79 years) to over 25% (90+ years). 12.7% patients died within 3 months, 4.8% died between 3–6 months, 3% died between 6–9 months and 1.9% died between 9–12 months.

Conclusions: The data from London and Scotland both indicate that a single admission over the age of 70 years old is a significant predictor of death within 1 year. An emergency admission over the age of 70 years could be used to aid recognition of the last years of life and initiate care planning. The data highlights the need to innovate by widely sharing electronic, patient-accessible care plans across multiple sites and out-of-hours care providers to improve end-of-life care. Widespread digitalisation could transform practice, putting patient choice at the centre and reducing unscheduled admissions.
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**Staff Reflections on Reducing Emergency Room Visits at End of Life and Hospital Deaths for Long Term Care Residents**

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**Study aims:** The goal of this study was to examine current rates of resident deaths, Emergency Department (ED) use within the last month and week of life, and hospital deaths for long term care (LTC) residents. In addition, we compared these rates across four LTC homes in Ontario, Canada and explored potential explanations about why these variations existed across homes.

**Methods:** This study used a mixed methods approach. First, chart audits were conducted in four LTC homes in southern Ontario, Canada, to capture trends in hospital use over a one-year period for the following indicators:

1. resident deaths at hospital versus LTC home;
2. ED visit in the last year, month, and week of life;
3. average number of ED visits/resident;
4. planned versus unplanned ED visits;
5. ED visits that became hospital admissions.

Next, these chart audit findings were presented to staff at each site to raise awareness and stimulate reflections on local factors affecting hospitalization trends at EOL. Staff were probed to reflect on potential reasons why their homespecific findings were either higher, lower, or similar to the average rates across all four homes.

**Results:** Chart audits revealed that 59% of residents across sites visited Emergency Departments (ED) during the last month of life and 26% of resident deaths occurred in hospital. Staff expressed surprise at the amount of hospital use during end of life (EOL). Reflections suggested that clinical expertise, comfort with EOL communication, clinical resources (i.e. equipment) and family availability for EOL decision-making could all impact non-desirable hospital transfers at EOL. Staff appeared motivated to address these areas of practice following this reflective process.

**Conclusions:** Localized chart data combined with group reflective opportunities can serve to raise awareness and engage staff in collective solutions to address preventable hospitalizations at EOL.
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Abstract type: Poster Exhibition  

**Dying in the Complex Frail Elderly: Role of Multidisciplinary Anticipatory Clinical Management Plans in Secondary Care**

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**Aim:** Significant numbers of elderly frail patients with multiple complex comorbidities are admitted to hospital. Increasing hospital admissions & readmissions are in those entering the dying phase of life, with only limited planning for end of life (EoLC). This study looked at the role of consultant geriatrician led anticipatory clinical management plans (ACMP) in association with community palliative care teams (CPCT) in reducing hospital readmissions, improving primary & secondary care communication & upholding patient & family EoLC wishes.

**Methods:** Frail elderly patients admitted to a specialist geriatrics ward were reviewed by a consultant geriatrician & those with complex comorbidities, felt to be approaching the last few months of life identified. ACMPs were developed for & with each patient in conjunction with family & multidisciplinary team & was communicated to primary, secondary & CPCT. Notes & outcomes of 43 patients with ACMP in place were analysed.

**Results:** Identified patients (mean age 84 years), were deemed to be elderly complex frail, with an average 6 significant comorbidities. 65% (n=28) suffered from dementia; 9% (n=4) suffered known malignancy. 97% that died, did so in patient’s/family’s preferred place of care – average 59 days from ACMP placement. Analysis of patients’ notes revealed only 7 (16%), admitted to hospital within 6 months of ACMP being in place, all of which were in keeping with the agreed individualised escalations.

**Discussion:** Appropriate use of geriatrician led ACMPs, within secondary care, for complex elderly frail patients, leads to significant reduction in admission & readmission rates. Notably, observed admission rate of this cohort within 1–6 months was significantly lower than national average (40–70%). Furthermore this approach improves care quality, facilitates better communication across healthcare sectors, encourages active cross-disciplinary working & enables implementation of patient/family’s wishes during EoL period.
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Withdrawing Life-maintaining Treatment (LMT) in an Elder Group: The Three-year Experiences of a Medical Center in Southern Taiwan

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Background: According to Taiwan’s law, emergent resuscitation is the physician’s legislative responsibility unless presenting with DNR. After the third amend of the Hospice and Palliative Ordinance in 2013, LMT in an unclear terminal patient could be withdrawn by only one closest family’s agreement. Many families would ask to withdraw the LMT if poor conscious recovery or the possibility of long term LMT dependent. Many studies revealed higher ICU admission rate and poor prognosis in an old population after LMT worldwide. It seems how to articulate the good death of our old is an important issue.

Aim: We want to figure out the characters of these patients and try to give some suggestions to help reduce these old patients suffering in their terminal year.

Method: Retrospect data from our hospice share care database from 2013 to 2015 June. We analysis the proportion of age over 65 year-old and their death causes, the duration between withdraw LMT and death.

Results: In a total 73 patients who received withdrawing LMT, 16 are over 80y/o and 37 are between 65–80 y/o. In the over 80 y/o group, the death causes are cancer(3/16), acute infection, cirrhosis, COPD, CKD, dementia, stroke and heart failure. In the 65–80 y/o group, the death causes are likely. Most of them died immediately after withdrawing LMT(almost are ventilator), and some died in one week.

Discussion/conclusion: According to our results, most patients received LMT over age 65 with severe underlying disease show poor prognosis. Because of they didn’t sign DNR permit before, doctors should do resuscitation according to law. We should re-thinking our elderly’s situation and how to pursue a peaceful death in their life last year. We suggest that promoting the advance directives, change the home care policy and the opt-in model about CPR in law may be the solutions.
The quality of End-of-Life Care in Long Term Care Facilities in Sweden 2013–2014

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Background: In Sweden, it is common for persons aged 65–79 to die in hospitals, while the oldest old, those over 80, more often die in Long Term Care Facilities (LTCF). In 2014 up to 40 % of all deaths in Sweden occurred in LTCF. Residents in LTCF are old, frail and usually have multiple chronic diseases which makes end-of-life care (EoLC) a challenge, this points to the importance to examine which EoLC that are provided there.

Aim: To describe EoLC in nursing homes in Sweden 2013–2014 and to examine if resident’s characteristics were associated with good EoLC.

Method: The study is a retrospective registry study based on the Swedish Register of Palliative Care (SRPC). All persons 65 years or older (n = 42813) recorded in the SRPC and who died in LTCF in 2013–2014 were included. To examine the quality of EoLC, seven indicators recommended by the Swedish National Board of Health and Welfare were used (0–7). The median was calculated (n = 5) and used to dichotomize the variable in poor EoLC (0–4) and good EoLC (5–7). A logistic regression analysis was made to examine the association between good EoLC and resident’s characteristics.

Results: All seven indicators were met in average 11% of the residents. Assessment of pain (28%) and symptoms (16%) were those indicators most rarely met. The probability of receiving good EoLC decreased by 3% for every year the resident stayed in LTCF. Consequently, older age groups were less likely to receive good EoLC, compared with the younger age group (OR 0.92 for 89–92 years vs. 64–83 years; OR 0.90 for 93–110 years vs. 64–83 years). The quality of EoLC was not significantly associated with gender or place of LTCF (Urban or Rural).

Conclusion: The results indicate that the older age groups are less likely to receive good EoLC. Also, the study illustrates the potential for using the indicators to improve EoLC in LTCF. This improvement is an urgent issue.
Evidence Base for Palliative Drug Treatment in the Last Days of Life – A Systematic Review

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Background: Opioids, anticholinergics, antipsychotics and anxiolytics are commonly prescribed for symptom relief in dying patients. We aimed to systematically review the efficacy and safety of drug treatment for symptom relief in dying patients.

Methods: Systematic literature review. Protocol was registered in PROSPERO, and the PRISMA guidelines followed. A systematic literature search was conducted in PubMed/MEDLINE, Embase, CINAHL, PsycINFO, Cochrane, ClinicalTrials.gov, and SveMed+ databases. We included intervention studies, cohort and case-control studies involving adult patients from any health care setting and diagnostic group, in their last days of life or considered dying, receiving drug treatment with an explicit palliative purpose, by any administration route. Systematic reviews were used for reference hand search. Primary outcomes were symptom control, adverse effects, and survival.

Preliminary results: Our search identified 3607 unique citations, from which 748 abstracts were screened, 62 full text articles assessed, and 8 studies included. Hand search identified two additional studies. Heterogeneity of studies impeded meta-analysis. Five studies examined the use of anticholinergics for death rattle (4 RCTs, 1 cohort study), four studied sedatives for dyspnea, anxiety, delirium or restlessness (2 RCTs, 2 cohort studies), one (cohort study) examined opioids for pain. Four studies reported on side effects, one reported comparatively on survival. Average number of patients in included studies was 106. Almost all patients had cancer, most commonly in a palliative care unit setting. Quality was rated “strong” in two articles, “moderate” in six, and “weak” in two articles.

Preliminary conclusion: Due to few studies, we cannot conclude regarding efficacy and safety of specific drugs. There is a lack of evidence based knowledge of drug treatment in the dying. Death rattle has been best studied.
Views of Future Care Planning in Patients Aged over 70 Years Old and Carers: A Framework for Qualitative Analysis through Clinical, Academic, Patient and Public Co-design

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Aims: To produce a framework exploring views of advance or future care planning (FCP) in patients aged over 70 and carers. Clark et al (2014) indicate that following a hospital admission in over 65 year olds, 1-year mortality is ~30%. In London, 1-year mortality is ~20% following emergency admission in over 70 year olds. Hospital admission may therefore act as trigger for a teaching moment, to understand wishes for future care.

Methods and design: The Collaborative co-designed a qualitative analysis of patient-led FCP for emergency admissions in patients aged 70+ years, inclusive of all diagnoses, for a cohort of 20+ inpatients and 20 carers.

Phase 1: co-design of semi-structured interviews and linguistic content with the patient group.

Phase 2: deliver the open pilot study.

Results: Outputs from iterative reflections with a patient and carer group and palliative care clinicians were incorporated by the research collaborative to produce the topic guide and linguistic structure for Phase 2.

Co-designed areas:
● Need for topic guided discussions

The 4 main themes:
1) an acceptable approach to FCP, including timing and terminology
2) significance of FCP to patients or carers as perceived benefits or harms
3) expectations of the content of FCP
4) expectations of whether to share FCP with medical or social contacts

Areas of difference:
● direct questioning for resuscitation orders
● need for formal assessment scales

Conclusions: Our phase 1 study identified:
i) An iterative methodology as an effective way of co-designing structured interviews agreed by patients and carers
ii) A framework for qualitative analysis of patient-led FCP for phase 2 work.
iii) Differences between patient and healthcare groups enabled changes to approach, and reflection on the need to retain formal scales.

Understanding FCP in the 70 years+ cohort is significant for improving individualised care, however as this is not a standard practice the topic guide co-design enables sensitive exploration of this area.
Reported Wishes and Values in Patients with Advanced Chronic Conditions (PACC) and Patients with Chronic Condition (PCC). Conversations about End of Life


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Background: Go Wish card game (GWG) is an advanced care planning tool developed to facilitate conversations about end-of-life (EOL). We have little knowledge of wishes and values in PACC and PCC.

Aims: To identify the main wishes and values of PACC and PCC in a conversation about EOL.

Methods: PACC and PACI admitted to the in-patient unit of intermediate care and long term care were recruited. Their competency was registered by Drane’s sliding scale (DSS). Sociodemographic data were recorded. We used the GWG as a tool to speak about EOL. Patients were asked to categorize these wishes as important or not important, which 10 wishes were most important, and to assess the usefulness and appropriate of the interview. A standard descriptive analysis was carried out by SPSS 21.0.

Results: 16 women and 7 men, average age was 82.39 ± 7.38. The DSS Levels were:
I (8.7%), II (52.2%) and III (39.1%).

PACC (13%); PCC (87%). The 10 wishes identified as most important to patients were: not being a burden to my family (91.3%); not being connected to machines (69.6%); to be free from pain (69.6%); to have my family with me (56.5%); to be at peace with God (56.5%); to maintain my dignity (56.5%); to trust my doctor (39.1%); to speak and be understood (39.1%); to be able to help others (39.1%) and not dying alone (34.8%).

The 10 least common wishes identified were: to know how my body will change (73.9%); to be mentally aware (65.2%); to have my financial affairs in order (65.2%); to die at home (65.2%); to remember personal accomplishments (65.2%); to take care of unfinished business with family and friends (60.9%); to meet with clergy or a chaplain (60.9%); to be able to talk about what death means (69.6%); stay at home (60.9%); eating and enjoying food (56.5%). The interview was useful in 91.3% and appropriate in 95.7%.

Conclusion: Not being a burden to my family and not being connected to machines were the most important wishes for the PACC and PCC. The GWG was a good tool for the conversation about EOL.
Symptom Control and End-of-Life Care in Spanish Nursing Homes: A Prospective Study

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Background: The elderly that live in nursing homes show numerous symptoms and chronic pathologies that are related to end of life.

Aim: Describe symptom control and end-of-life care provided in nursing homes. According to this study, end-of-life care has focused on symptom control and drug consumption, palliative care approach (lower use of therapeutic and diagnosis procedures) and frequency of decisions related to end-of-life.

Methods: Observational prospective study. 9 nursing homes of the Metropolitan District of Granada (Southern Spain) participated in this study. Full-time nurses selected advanced chronic illness patients according to Spanish Association of Palliative Care criteria. Symptom control was measured through Edmonton Symptom Assessment Scale, therapeutic and diagnosis procedures, and decisions related with end-of-life care were registered through ad hoc questionnaires. Data were collected at two different points: three months prior to death (beginning) and just before death (final).

Results: 31 patients were followed-up. Dementia (53.3%), hypertension (53.3%) were the most prevalent pathologies. More intense symptoms were fatigue (M=5.19;DT=2.85) and drowsiness (M=4.71;DT=3.02) at the beginning point, and anorexia (M=6.33;DT=3.80) and breathlessness (M=6.29;DT ± 2.78) just before death. Many invasive therapeutic procedures, like nasogastric feeding tubes (p=.012) and peripheral catheterization (p=.016), considerably increased just before death. Decisions related with end-of-life, like withholding diagnosis procedures (p=.00), or non-resuscitation orders (p=.031) considerably increased too.

Conclusion: More end-of-life care is needed in Spanish nursing homes. Nursing homes staff must be trained in discussing end-of-life decisions, and must reflect about withholding or withdrawing therapeutic procedures.
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Improving Quality of Living and Dying with Advanced Dementia

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Study aims: This presentation will provide an overview of:
(a) an innovative program, called Namaste Care, for residents who are dying with dementia; and
(b) a facility-wide education program that was conducted to launch the program.

Methods: This study used a multiple methods survey design to evaluate the education program that was conducted in two LTC homes in Canada; one in Ontario and Saskatchewan. The education program consisted of multiple sessions over a 2-day period for staff as well as an open public lecture for family, friends and others who were interested in the program. We collected survey data from 44 LTC staff (e.g., personal support workers, licensed nurses, recreation staff), 25 in Ontario and 19 in Saskatchewan; and 44 family members and others (n= 21 from Ontario, 23 from Saskatchewan).

Results: The majority of participants rated the training program as excellent, stating “it’s just basic human care”. All participants stated that they now understand the purpose of Namaste Care. Most participants stated that they learned how to interact with residents in the Namaste room and the types of programming that are offered. Similarly, participants who attended the public lecture stated that they were very satisfied with the education, stating that the public lecture helped them learn more about how the program can be implemented. Participants in both groups suggested having follow-up sessions with a ‘report back’ about how the program impacts resident outcomes.

Conclusions: These study findings support the use of a facility-wide educational program to help launch a new innovation in LTC.
A Gradual Slope to Death: End-of-Life Symptoms in Residents Dying in UK Nursing Homes

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Over the past decade, there has been a sizeable increase in the number of older people dying in nursing homes. Currently 22% of the UK population dies in a nursing home: most within 18 months of admission. There is little research about the nature of symptoms in this population & the limited evidence suggests that the dying trajectory may differ from other populations.

The aim is to describe the presence, frequency & intensity of physical symptoms of residents during the dying phase in nursing homes & explore common characteristics that present over time.

This prospective cohort study used the ESAS tool to collate demographic & symptom information from 157 participants during the final days of life. Descriptive statistics were used to present demographic & clinical characteristics. Associations between the observed and expected values of variables were evaluated using Pearson’s r correlation co-efficient. A multilevel logistic regression model (MLM) was employed to capture the relationship between changes in symptom level over time.

The 5 most common symptoms nearest to death were drowsiness, fatigue, anorexia, unresponsiveness & shortness of breath. A small number of associations between demographics, diagnoses & symptoms were observed. Those with a diagnosis of dementia had less fatigue and depression (p< .01) but no other significant distinctions. Through the MLM, significant differences were observed in the estimated rate of change in 4 symptoms (p< .05) (unresponsiveness, drowsiness, fatigue & anorexia).

The main symptoms occurring tended to relate to a general deteriorative condition suggesting that dying in nursing homes represents a gradual decline towards death. The limited associations between covariables indicate that those dying in nursing homes have similar symptoms despite different characteristics, and less acute symptoms that have been reported in other populations. This has implications for future symptom management and education for professionals.
Abstract number: P02-421
Abstract type: Poster Exhibition

Palliative Care Needs Assessment in a Geriatric Hospital

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Background: Introducing Palliative Care (PC) early in the course of serious and life limiting illnesses may improve quality of life and other patients and families relevant outcomes. PC should be delivered based on personalized needs assessment, rather than age, diagnosis or prognosis. However failure to identify PC needs is a common problem in health services, particularly in the elderly population.

Aims: Identify palliative care needs in patients admitted to a geriatric hospital and its complexity level. Compare patients with and without PC needs regarding sociodemographic variables, comorbidity and mortality.

Methods: A prospective descriptive study was conducted in a geriatric hospital. Patients were enrolled upon admission on 6 month period. PC needs were evaluated using SPICT, PC complexity was determined using the complexity indicators of the 2010 Portuguese PC National Plan. Sociodemographic variables, symptoms (ESAS), performance status (PPS) and comorbidity (CCI) were studied.

Results: 116 patients were included, mostly females (58%), with an average age of 75 y. PC needs were identified in 60% of the patients, half of which were complex PC needs. The patients with PC needs had an average PPS of 55%, ESAS was applicable in 60% of the patients with PC needs, and had a total average of 24.5. Age, sex distribution and days of hospital stay were not statistically different between patients with and without PC needs. Patients with PC needs had higher comorbidity score and higher mortality rate.

Discussion: High prevalence of PC needs, and palliative complexity was identified in this geriatric population. PC needs were highly associated to comorbidity and mortality, but not with sociodemographic variables. This reinforces the importance of systematically identifying PC needs, and implementing a multidisciplinary and integrated care plan. A specialized PC team should be available in institutions that provide medical care to the geriatric population.
Identifying Elderly Persons with Cancer in Need of Palliative Care [PC] Assessment in the ICU Setting: Comparison between ‘Discharge’ and ‘Death’ Subgroups

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Background: It’s in ICU environment where the act of “vulnerabilizing” occurs: certain decisions of “moral agents” (doctors) that contribute to the unnecessary increase of patients suffering. Based on an unmet demand for palliative care, it may create even greater distress in an ICU admission, without discussing possibilities of other approaches.

Aim: To identify in this “vulnerabilized” population admitted to ICU, issues that meet primary/secondary criteria for PC, comparing patients outcome subgroups.

Methods: Criteria for PC were correlated to clinical severity scores and functionality [PS], besides the amount of diagnostic/therapeutic resources used, then compared between ‘discharge’ and ‘death’ subgroups.

Results: 71 patients were enrolled, 39 died [55%]. Both groups showed no differences in age [P=0.49], length of stay [ICU,P=0.47;hospital,P=0.76], severity scores [SOFA,P=0.41;SAPS3,P=0.31], but KPS [P=0.012] and PPS [P=0.005] were lower in ‘death’ subgroup. When curative resources were compared, there was significant difference for ‘discharge’ subgroup [P=0.053], specially chemotherapy [P=0.018]. ‘Death’ subgroup received significantly more amine [P=0.011], artificial ventilation [P=0.005], enteral nutrition [P=0.003], as well as blood transfusion, tracheostomy, gastrostomy, and also had more cardiac arrest [P=0.016], CPR events [P=0.25]. Secondary criteria for PC [P=0.057], specially if ‘metastatic/locally advanced incurable cancer’ [P=0.012] and ‘ethical decisions [withdraw/hold] for obstinate therapy’ [P=0.006] were present, but also primary criteria such as ‘failure to thrive’ [P=0.039], ‘admission from long-term care facility’ [P=0.015] were significant to ‘death’ subgroup.

Conclusion: There is an urgent need to review the care offered to patients (specially in ICU environment), emphasizing the moral implications involved in conflicts associated with biotechnoscience-biopower binomial and the growing demand for PC on risk for dysthanasia.
Demographic and Socio-economic Characteristics of Residents Living and Dying in Nursing Homes in Six EU Countries: Results from the EU-funded PACE Study

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Background: Socio-economic status (SES) may have impact on resident’s admission to public or private nursing home (NH). In the frame of a cross-sectional study conducted within the PACE project (“Comparing the effectiveness of Palliative Care for Elderly people in long-term care facilities in Europe”) we carried out analysis to describe demographic characteristics and SES of deceased NH residents in Belgium (BL), Finland (FI), Italy (IT), Netherlands (NL), Poland (PL) and United Kingdom (UK).

Aims: To describe demographic and SES status of a sample of 840 deceased NH residents in 6 EU countries and examine its association with dying in public or non-public facility.

Methods: Data were collected in 2015 in a stratified random sample of 322 NHs. A total of 1707 residents were identified as having died over a 3 month period prior to contact with the NHs. For 1455 residents, the NH administrators identified a relative and sent out a questionnaire to them – 57.7% (840) relatives responded.

Results: Most of deceased residents were women (68.5%) and had lower education (78.1%). The oldest ones were in BE (87.2 ± 7.04), and the youngest in PL (82.0 ± 9.72). The highest proportion of residents in poor financial situation before admission was in IT (38.8%) and PL (13.7%), as well as residents who couldn’t afford to pay for their stay in NH (32.6% in PL and 23.6% in IT). In NL all residents were admitted to public NHs, while in UK most went to for-profit NHs. The residents’ SES was not associated with whether they died in public or non-public NHs in BE, IT and FI. In PL the residents with good financial resources had lower odds of being admitted to public NHs (OR=0.20; 95%CI: 0.04–0.96) than those with less resources.

Conclusion: We found no association between residents’ SES and dying in public or non-public NHs in BE, IT and FI. In PL limited access to NHs may mean that residents in better financial situation stay and die in non-public facilities.

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What is the Role of Community at the End of Life for People Dying in Advanced Age?

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Background: Rapidly ageing populations mean that dying an expected death in advanced age is now increasingly the norm in resource rich countries. New public health approaches to palliative care position communities as central to supporting dying people and their families. However, no previous research could be identified which explored the role of community for people dying in advanced age.

Methods: Post bereavement interviews were conducted with 58 family/whânau nominated before death to participate in the study by 52 people (20 Māori and 32 non-Māori) who died aged >80 years.

Analysis: A social constructionist framework informed a critical thematic analysis which also draw upon narrative methods. Techniques to enhance rigour included:
1) prolonged engagement in the field;
2) peer review and debriefing;
3) negative case analysis;
4) clarifying researcher bias;
5) member checking; and
6) rich, thick description.

Findings: There was limited evidence that community resources were drawn upon at end of life. Participants reported that, for most of the older people, social networks had been disrupted and diminished in advanced age due to the death of friends and peers, moving for retirement, health deterioration, giving up hobbies, and transitioning to live in aged care settings or with family. Also evident in many accounts was the older people’s active withdrawal from, and reluctance to accept help from, non-family networks.

Conclusion: Our findings differ from the limited available evidence within the palliative care literature, where community connections have been reported to be significant at end of life. This can partly be explained by the unique circumstances of dying in advanced age. There is an urgent need to explore ways in which communities can respond to the specific needs of the growing numbers of people dying in advanced age, as well as to further theorise key concepts underlying public health and palliative care approaches, including ‘community’.
Assessment of Renal Function in Elderly Palliative Care Patients – Differences between Estimation Equations

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Renal function impairment is common in elderly cancer patients. Accurate assessment of renal function is necessary for appropriate drug dosage. Several equations are used to estimate kidney function.

**Aims:**
1) to investigate the differences (Δ) in kidney function assessed with simplified Modification of Diet in Renal Disease (MDRD), Berlin Initiative Study (BIS1), and Cockcroft-Gault (CG) formulas in elderly palliative care patients;
2) to assess factors that may influence these differences.

**Methods:** A retrospective analysis of data of patients aged ≥ 70 admitted to a palliative care in-patient unit. The agreement between CG, MDRD and BIS1 equation was assessed with Bland-Altman analysis and weighted kappa statistic. Partial correlation analysis was used to analyze factors influencing the discordance.

**Results:** 174 patients (67 men; mean age 77.9±5.8 yrs) were enrolled. The mean ΔMDRD-CG was 18.6 (95% limits of agreement 55.3 and -18.2). The mean ΔBIS1-CG was 6.1 (25.7 and -13.5), and the mean ΔMDRD-BIS1 was 12.5 (40.6 and -15.6). The kappa statistics showed moderate agreement between MDRD and CG (kappa 0.55, P < 0.001) and substantial agreement between BIS1 and CG (0.71, P < 0.001), and between MDRD and BIS1 (0.73, P < 0.001) in staging using the National Kidney Foundation classification. 61 (35.1%) patients were differently staged using MDRD and CG, while approximately 20% of patients were differently staged with BIS1 and CG, and MDRD and BIS1. Serum creatinine (SCr) and body mass index (BMI) had the most important influence on variability of ΔMDRD-CG (partial R² 37.7% and 28.4%). Variability of ΔBIS1-CG was most influenced by BMI (34.8%), and variability of ΔMDRD-BIS1 by SCr (42.2%). Age had relatively low influence on differences between equations (3.1% - 9.5%).

**Conclusion:** There is a considerable disagreement between renal function estimation formulas, especially MDRD and CG. The magnitude of discrepancy increases with lower SCr, lower BMI, and higher age.
Symptom Prevalence, Severity and Palliative Care Needs Assessment Using the Patient Outcome Scale (POS) Tools in Elderly Patients Following a Hip Fracture


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Background: Ten percent of people with a hip fracture die within 1 month and about one-third within 12 months. At present there is a distinct lack of literature regarding the palliative care needs in this patient population.

Aim: To assess palliative care needs in elderly patients who are admitted with a fractured hip in the acute setting and were predicted to have an increased risk of 12 month mortality.

Methods: A cross sectional survey study was conducted, using the Patient Outcome Scale tools (POS and POS-S) to screen for palliative care needs in the population under study. Items were scored from 0 (best) to 4 (worst).

Results: Twenty one patients consented to participate in the study. The mean age was 89 years (range 85–94) and 76% (16/21) were female. The most common symptoms were pain and constipation; 76% (16/21) had moderate to severe pain in the previous 3 days, whilst 52% (11/21) reported having moderate to severe constipation. Assessment of mood revealed that 71% (15/21) had felt anxious and worried about their illness and treatment, and 24% (5/21) were anxious or worried most of the time. Ninety percent (19/21) felt their family and friends were anxious or worried about them and 29% (6/21) rated this as worried most of the time or always. The total mean Palliative Outcome Scale score was 10.8 (standard deviation = 4.41), suggesting mild to moderate palliative care needs. There were no dropouts in the study and patients found the POS tools acceptable.

Conclusion: This is the first study to describe the palliative care needs of elderly patients who have sustained a hip fracture. These results show that these patients have mild to moderate palliative care needs, across physical and psychological domains. The POS tools have been found to be an acceptable screening tool by patients and can therefore be used to assist clinical teams to identify care needs in this group of patients to help improve patient care.
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Profile of Elderly Patients under Palliative Care with Reports of Pain

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Introduction: Geriatric patients comprise presently the largest group of people needing palliative care (PC). It is believed that understanding the profile of elderly patients under PC and with reports of pain, will permit the outline of specific and focalized targets.

Objective: Describe the socio-demographic and epidemiological profile of hospitalized elderly patients under PC, with complaints of pain.

Methodology: A descriptive and quantitative study, performed with 22 elderly patients of ages equal or above 60 years, hospitalized in medical-clinic and surgical units of a large public hospital, in the city of Salvador-Bahia, Brazil, between March 1 and July 15, 2011. For the interviews, a questionnaire was used covering socio-demographic and economic variables, aspects related to self-rated health. Descriptive analyses were performed to characterize the profile of the participants through the distribution of univariate and bivariate frequencies and descriptive measures (average, standard and median deviation). The differences between the proportions of the self-rated health characteristics and the gender were verified through the Fischer’s Exact Chi-Squared test, at the level of 5% statistical significance. The STATA software version 8.0 was used for data analysis.

Results: There was a predominance of elderly patients of the male gender (55.6%), self-referred to as black (40.9%), married (50%), catholic (63.6%), average of 65.5 years of age, with low schooling level (72.7%) and low individual monthly income (50%). Most had performed the occupation of general services (28.6%) and perceived their health as being regular or very poor. The elderly patients were hospitalized for 30 days (59.1%), due to neuro-cardiovascular diseases (59,1%).

Conclusion: The results collaborate towards the preparation of nursing care plans guided towards the profile of the elderly patients under palliative care and with reports of pain.
Death in Intensive Care Units: The Experience of the Elderly

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Introduction: The occurrence of death is very present in the Intensive Care Unit (ICU). The experience of the severity of the disease associated to the sensation of the proximity of death can favor the development of stress and anxiety in hospitalized patients, especially in elderly people, which correspond to approximately 60% of the total amounts hospitalized in ICUs. The average age of patients hospitalized in ICUs in Brazil varies between 70 and 75 years, with a mortality rate of between 28% and 45%.

Objective: To analyze the experience of the elderly on death in Intensive Care Units.

Methodology: A qualitative study, performed in a public hospital of Salvador, Bahia, Brazil. There were fourteen participants, all elderly patients hospitalized in an ICU, during the period of January 2013 to May 2015. The data was collected by means of semi structured interviews and analyzed with the use of the statistical software Alceste (lexical analysis by context of a set of text segments), aimed at analyzing textual data. After analysis, the thematic category was identified: Death in Intensive care units: the experience of the elderly. The research complied with the recommended ethical criteria.

Results: It was identified that the experience of hospitalization in ICUs led the elderly to feel the proximity of death due to the association of this sector to the severity of the disease and the imminence of decease.

Discussion and conclusion: The proximity of death was the root of the fears and self-perception by critically ill patients. Thus, the experience in ICUs indicate the occurrence of stress, anxiety and fear among the elderly patients.
Sensations and Emotions Experienced by the Elderly in Palliative Care while Listening to Music

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Introduction: Music has stood out as a therapeutic tool in the field of health. Many studies have demonstrated the benefits of this technique, mainly for chronically ill patients and those performing varied surgical procedures.

Objective: To describe the reports of elderly people under palliative care on the sensations and emotions experienced while listening to music.

Methodology: An exploratory and descriptive study with a qualitative approach performed in a large sized public hospital in the city of Salvador-Bahia, Brazil. This is an excerpt from the doctorate thesis “Music as complementary therapy in the palliation of pain in hospitalized elderly patients: according to the Jean Watson theory”. There were 22 elderly patients participating, with ages equal to or above 60 years, submitted to three sessions of music, comprising three sets of instrumental music of different genres, during the period from March 1 to July 15, 2011. A guideline was used for the interview containing questions related to the object of the research. For analysis of the reports on the repercussion of listening to the musing during hospitalization the Minayo thematic analysis was used, based on the Jean Watson Transpersonal Theory.

Results: In general, during the three musical sessions, the discourse of the participants described sensations and emotions of: relief, relaxation, happiness, courage, tranquility, drowsiness, improvement of complaints regarding pain and respiration during the music session.

Conclusion: The results of this investigation reinforce the importance of using music in the care of the elderly patient under palliative care, permitting the expression of important feelings and emotions at the final moments of life.
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Pain Management for People with Dementia in Nursing Homes: Unrecognised Challenges

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Background: It is estimated that 19% to 83% of people with dementia (PwD) suffer with inadequately treated pain in the last months of life. A large number of employees who care for PwD in nursing homes lack expertise in assessing the patient’s complex needs such as pain.

Aims: The aim of this study is to identify care needs of PwD suffering from pain living in a nursing home.

Method: This study is part of an ongoing nurse led intervention study in Switzerland (German Clinical Trials Register: DRKS00009726), where nurses with different skill mix are individually trained how to assess, intervene and evaluate pain by an advanced nurse practitioner. The nursing documentation including case studies were singled out for this chart review using thematic content analysis. Two independent reviewers analysed according to a standard protocol, emerging themes were integrated into categories.

Results: Four main challenges in meeting care needs out of 35 nursing records documented were identified:

- **Recognition of medical emergencies:** it appeared to be very difficult for nurses to recognise a medical emergency (i.e. deep vein thrombosis) within the pain assessment.
- **Interdisciplinary communication:** barriers in exchanging information between nurses and GPs became evident based on scarce documentation.
- **Clinical assessment skills:** mastering the learned assessment skills proved to be difficult to achieve in the given time frame.
- **Prompt initiation of medical prescriptions:** it became noticeable that some medical prescriptions were not acted upon due to different reasons.

Discussion: The challenges thus care needs found in this study represent the complexity of pain management for people with dementia in nursing homes. The dissemination of these findings are important for quality improvement in nursing homes in terms of enhancement the patient’s safety.

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Palliative Care in Rural Age Care Facilities in Australia

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Purpose: The purpose of this paper is to present data in relation to the number of deaths in each age care facilities in the rural towns of Drouin and Warragul in the state of Victoria, Australia, in the period from January to September 2016. To distinguish the number of residents that have passed away in the facility and the number of residents who were transferred to hospital for terminal care and the reasons for being transferred.

Methods: Review of the medical records of the residents who have died from 1st January to 30th September 2016. Determine the place of death, either at the age care facility (ACF) or at the local hospital. Review of the residents files in the facilities.

Background: Warragul and Drouin are two semirural towns in the east of the state of Victoria, Australia. We have 3 aged care facilities with a small rural hospital.

Conclusion and discussion: Total number of deaths 68
Deaths in the ACFs 58 Deaths in hospital 10

Reasons for hospital transferred:
1. Serious fractures (due to falls)
2. Acute cardiac events
3. Serious respiratory tract infections
4. Acute cerebrovascular events
5. Transfer request by relatives.

There were 68 deaths in residents of 3 ACF
85% of the deaths occurred in the ACF.
15% of the deaths occurred in the hospital.

We have achieved this success by implementing the following strategies:
1. Education of ACF staff, nurses, carers and medical professionals.
2. Having access to all the equipment necessary to provide palliative care at the ACF.
3. Identifying early the patient that is deteriorating and likely to die in the near future and implementing the palliative care pathway protocol.
4. Close communication with relatives, informing them of the progression of the condition and with family meetings to discuss the needs of the patients and relatives.
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**Developing a Tool for Early Detection of Palliative Care Patients in Belgium: Palliative Care Indicator Tool (PICT)**

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**Background:** In June 2016, a bill was passed to broaden the definition of palliative care in Belgium. In the future, the provision of palliative care will be based on individual health care needs rather than on life expectancy. This stresses the importance of timely detecting patients who need palliative care.

**Aims:** To develop a tool to identify patients with palliative care needs and assess the severity of these needs, in order to refer patients to the optimal care setting.

**Methods:** The development of the tool was done in 4 phases:
- A literature study learned that the SPICT by Scott and Murray was the best tool for Belgium.
- Four focus group discussions were held to set criteria for the severity of health care needs.
- Face validity of the tool was assessed in a group of 16 physicians, after which it was adjusted.
- The tool was evaluated by 59 physicians who assessed 460 patients.

**Results:** The Palliative Care Indicator Tool (PICT) was developed. The first part screens for palliative care needs and consists of 3 filters. First filter is the surprise question, ‘would you be surprised if this patient would decease within 6 to 12 months?’, if no, the second filter applies. Second filter is the assessment of 7 frailty indicators, if at least 2 indicators apply, the third filter applies. The third filter assesses the incurable state of the patient. If 1 of 8 conditions apply, the patient is considered as palliative patient.

The 2nd part assesses the severity of the condition, with 3 possible outcomes. First, if life expectancy is below 3 months, patients are given a full statute. Second, if 1 of the severity criteria apply to the patient, he is given the advanced statute. If none of the criteria apply, he is given a basic statute.

**Conclusion:** The PICT is evaluated by physicians as a useful tool that applies to most of their patients. It may be used for early detection of palliative care needs (and thus prevalence studies) and the assessment of the severity of needs.
Geriatric Palliative Care: Reflections on an Emerging Field

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Background: The increasing life expectancy and the associated changes in end-of-life morbidity forecast challenges for the field of palliative care. The University Hospital Lausanne has therefore launched a Chair of Geriatric Palliative Care (GPC).

Objectives: To define the core concept of GPC and its ethical underpinnings, and to delineate its major challenges as well as strategies to tackle them.

Methods: We conducted a literature review and theoretical reflection oriented by an ethics of care perspective.

Results: GPC is not a new discipline, but a professional field at the intersection of two closely analogous specialties. Geriatric and palliative care are both highly multi-professional activities with distinctly patient- and family-centred activities aimed at improving quality of life, personal autonomy and social participation in the face of death. The synergies that result from joining these two specialties even exceed its proper patient population and may serve as a role model for collaboration in the increasingly fragmented medicine of today. As the severely ill elderly constitute a highly vulnerable group, their wellbeing depends on a notion of care that is multidimensional, oriented toward relational autonomy and sustainable. In this phase of life, close relationships of trust become crucial, which also shapes the attitudes and responsibilities expected from professional caregivers. The challenges that GPC faces include particularly the care and treatment decisions, both at the end-of-life and anticipating it. Tools that improve decision-making, such as advance care planning and decision aids, have to be studied across health care settings. Another priority is the sustainable enhancement of professional competencies, in particular with regard to communication and ethical skills.

Conclusion: The challenge of GPC is to develop and offer evidence-based strategies of management for the elderly population with severe and often life-limiting conditions.
Experiences of Ambulance in Palliative Care for Elderly People in Zagreb, Croatia

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Introduction: As the population in the world is getting older, it’s the same case in Zagreb, capital of Croatia. Number of people over 65 years rises from day to day. Elderly more often come down with malignan and other diseases. Services of palliative care aren’t developed – that role is being taken by Ambulance.

Aim: The goal is to show though the interventions of Ambulance the complexity and extent of the problems geriatric patients face with, and the need of implementation and integration of palliative care in health system.

Methods: The analyse of the performed interventions of Ambulance -Zagreb in 2014, 2015. With accent on interventions towards people older than 65 years, considering sex, diagnosis, reasons for calling, most common symptoms and the place where intervention ends.

Results: In the observed period conducted 153,248 interventions, 49% women, 47% men, 4% unspecified gender. For people over 65 years 42% interventions were conducted. Most common diagnosis are symptoms, abnormal clinical findings classified elsewhere 22%, diseases of the circulatory system 16%, injuries, poisoning and other consequences of external causes 13%, diseases of respiratory system 8%, mental disorders and behaviour 8%, neoplasms 4%. Reasons for calling: pain, fatigue, dyspnea, anorexia, cachexia. Over 70% of patients stay at home.

Conclusion: The city of Zagreb has almost a million inhabitants, 17, 3% of them are older than 65 years (61% women,39% men). ER is often the only service they can call (mobile, fast, easily accessible at any time), all though for their needs palliative care would be more appropriate. Sufferings are great and dignity of dying disrupted. Organizing service of palliative care and hospice in the city of Zagreb and Croatia is a major public health challenge and a priority.
Dementia and Advance Care Planning: Whose Decision?

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**Background:** Although people with severe dementia have complex physical and psychological need, the disease is not always recognised as terminal (Evans & Goodman, 2008). As a consequence, some people with dementia can receive undignified treatment and be in considerable, often unrecognised pain at the end of their life (Anquinet et al., 2013).

**Methods:** In this review the decisions which influence care at the end of life the following research questions guided the review process:

a. Who is involved in the decision-making process?

b. How are decisions made concerning EoLC and what is the outcome in facilitating a good death?

c. In what way do systemic factors impact upon EoLC.

**Results:** The studies reviewed demonstrate decision-making processes are a complex one involving multiple factors. Decision-making is not a one off-choice, but involves different individuals at different points of time of care both before and at the end of life, and in various sites of care.

**Conclusion:** There have been few examples of what it means to facilitate a good EoLC and a good death other than limiting treatment intensity. Yet suffering is reported here also in spite of clinicians intentions.
Being a Companion at a Natural Pathway towards Death

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Background: Dying in old age tends to be slow and characterized by frailty and bodily needs. In Sweden a large proportion of deaths occur in nursing homes where bodily care is foremost provided by assistant nurses (ANs) who have high school education. Due to lack of places, admission to a nursing home is seldom granted until the older person has complex care needs, meeting death within a year.

Aim: The aim of the study was to describe ANs experiences of providing bodily care to older persons during the last time of their lives in a nursing home.

Method: The study had a qualitative design. Data was collected by individual interviews with ANs (n=7). The transcribed interviews were analyzed using an inductive qualitative content analysis.

Results: In the analysis one main theme emerged; “Being a companion at a natural pathway towards death”. The ANs perceived dying at old age expected as a natural end to a long life. This meant not to hinder what happened, but to be pliable to bodily signs of gradual deterioration of the older person, using intuition, experience and teamwork. The bodily care strived to relieve oppressive symptoms and increase quality of life. This was made possible by teamwork with a holistic approach meaning that bodily care was not only to care for the body, but the whole person. Thus, ANs also described a wish to bring a sense of security and well-being to the older person by being present, creating an atmosphere of closeness outgoing from a companionship built upon a mutual and familiar relationship.

Conclusion: ANs strived to supply a bodily care aimed to strengthen the older persons self-image. This goal was closely linked to a person-centred palliative care that highlights self-image as fundamental to health, wellbeing and a good death. This may indicate a need of further education in palliative care in order to strengthen the ANs as professionals but also to develop an evidence-based bodily care.
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**A Medical Geriatric Unit in Long-term Care as the Best Point of Care for Chronically Ill and Dying Patients**

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**Background and aims:** Longevity and very old age are causing unstable disorders with increasing need of specialized medical care among geriatric patients. This study aims to determine the benefits of a medical geriatric unit (MG) in long-term care within the Geriatric Health Care Centers Graz (GGZ) linked with three other care facilities (palliative care facilities in hospitals, hospice, and nursing homes) in the metropolitan area.

**Methods:** A retrospective research of routine data sets was conducted. Selected key figures of about 4000 patients and routine data in the years 2011 and 2015 had been compared in the area of Graz.

**Results:** Compared with the three care units (palliative care facilities in hospitals, hospice, and nursing homes) in terms of quality of supply and cost efficiency, the MG is the best point of care for chronically ill and dying patients. Moreover, the main findings confirm a clear difference between the target groups within the four care facilities, giving each one its importance. Furthermore, economic data showed that the costs for treatment in an acute care hospital is about four times the costs for treatment in the medical geriatric unit of the GGZ.

**Conclusion:** A personalized medical, psychosocial and nursing care gains more and more importance but therefore requires a demand-oriented allocation to the particular care unit. However, divergent financing models between social and health care systems are causing problems to do so. It is therefore recommended to develop an adjusted financial model meeting the needs of chronically ill and dying patients.
Profile of Sensibility of Staphylococcus aureus Isolated from Saliva, among Patients of Two Cancer Centers

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Oncologic patients, especially those in palliative care generally have immunosuppression, and therefore, are more susceptible to antibiotic therapies. Excessive use of antibiotics and for long periods of time are toxic, which can cause significant adverse effects, also inducing the emergence of resistant microorganisms, an increase in morbidity and mortality, an increase in associated infections and consequently increasing costs associated to the provision of health care. Antimicrobial resistance in the intra-hospital environment is a threat to public health and compromises proper patient treatment. This study aims to compare the microbial sensitivity profile of Staphylococcus aureus isolated from saliva, among patients of two cancer centers. A cross-sectional study with prospective data collection was conducted with 118 cancer patients respecting the inclusion criteria, and the compilation of data will occur in three stages: 1. collection form filling, 2. application of free and informed consent and 3. collecting saliva samples of patients and processing the samples.

Significant difference were found in Staphylococcus aureus sensitivity profile patients in oncology and palliative care patients in a cancer center, with great importance to the rational use of antibiotics in patients under palliative care, providing improved quality of life and control of appearance microbial resistance, preventing the development of infection by microorganisms multiresistant.
An Innovative and Comprehensive Signposting Tool to Support Care of the Dying Person

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Background: The Introduction of the Priorities of Care for the Dying Person 2014 in the UK describes the Duties and Responsibilities for Health and Care Staff when caring for dying people. It aims to achieve good care in the last few days of life and highlights key areas for staff to consider in the management of patients who are recognised as entering the final stage of their lives. It ensures patients and families are the centre of care. A Care Home Vanguard in collaboration with the Supportive Care Home (SCH) Team who provide End of life Care (EOLC) support and education to the care homes in a Borough of London.

To improve this learning a poster was developed to help signpost Care Homes to local services that could support them with these five national priorities. The poster was designed by a Health Innovation Exchange.

Aim: The poster was designed to provide guidance to care home staff regarding local EOLC services.

By highlighting local Multi Disciplinary Team resources it can empower staff to initiate the national priorities of care for the dying person earlier.

Method: An expert panel reviewed the National Priorities of Care Document and adapted this into a signposting tool. This tool was introduced at a local care home forum and was further disseminated by the SCH team to all care homes. The tool is now used as a practical resource for care home staff.

Results: Initial findings confirm that care home staff have found the signposting tool beneficial as an EOLC resource. There has been interest from other health care settings and there are currently plans to adapt and introduce this tool in a Community Nursing Service.

Conclusion: An innovative and comprehensive EOLC resource tool that underpins national guidance for a local population.
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“Dignified Life Closure” in Nursing Home Patients in Southern Spain

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Background: Little is known in Spain, about specific end-of-life care provided in nursing homes. “Dignified Life Closure” is an expected outcome for nursing interventions included in the Nursing Outcome Classification (NOC) and that could be used to measure some aspects of end-of-life care.

Aim: Describe how nursing home nurses rate the indicators of the NOC “Dignified Life Closure” in advanced chronic illness patients.

Methods: Observational/descriptive study. Patients of 9 nursing homes belonging to the Metropolitan District of Granada (Southern Spain) participated in this study. Data were collected by full-time nurses of each center, and patients were selected patients according to Spanish Association of Palliative Care criteria, for advanced chronic illness. Sociodemographic and clinical data were also recorded. The 25 indicators of the NOC “Dignified Dying” were rated in a 1–5 Likert scale, where 1 was “never demonstrated” and 5 “consistently demonstrated”. A descriptive analysis was performed using SPSS 22.0.

Results: Data were collected from 70 patients (Mean age=83.3), mostly of them women (63%) and cognitive impaired (59%). Overall, the best rated indicators were “The patient remember his life” (M=3.30;SD=1.54) and “Sharing emotions with others” (M=3.26;SD=1.58) and the worst rated were “Control organ donation decisions” (M=1.56;SD=1.36) and “Participates in funeral planning” (M=1.55;SD=1.261). For most of the indicators of the NOC (21/25), values were statistically lower for cognitive impaired patients (p=.00). Non-response rate was high in several indicators linked to post-mortem decisions.

Discussion: NOC “Dignified Life Closure” can be used to measure some aspects of end-of-life care, but there some severe limitations for using it in cognitive impaired. Spanish nursing home nurses must be trained in discussing end-of-life decisions.
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The Need for Legal Support for Patients and Families

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Background: Our palliative care (PC) service is developed in a resource restrained environment and there is a bigger emphasis on the social component of the service. Our social workers have frequently stressed the lack of legal support for the beneficiaries and a project was approved to develop such services. The project included an initial research.

Purpose: To understand the experiences of patients and families in PC on how their legal needs have been addressed and identify potential solutions for offering legal support.

Method: Phenomenological qualitative study conducted September 2015–July 2016. Data collected through semi-structured interview. Interviews were recorded, transcribed verbatim and analyzed by 2 researches through open coding.

Results: 30 interviews – patients (11) and carers (19) were performed. The study participants felt strongly the existence of barriers at various levels in the system for obtaining rights, bureaucracy. Subjects believe that the problems they face are due to: communication deficit with officials in state institutions, disinterest and lack of involvement of authority, lack of periods of respite, financial problems, marginalization and issues due to the diagnosis of disease chronic progressive. Following solutions were identified: a lawyer attached to PC services/hospitals who can advice the family, the development of information materials and education sessions with lawyers attending, the existence of a central reference point which includes all state institutions, tax deduction adjustments of policies (for ex permanent handicap certificate for those who have no chance of recovery).

Conclusions: PC services need to include legal advice and counseling as part of the services offered in order to mediate communication with relevant institutions and allow patients and family members to experience good quality of life.
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The Impact of Socialization on Children Who Dealt with an Incurable Disease in their Family

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Introduction: Palliative care doesn’t stop at taking care of the needs of the patient, but also offers care and support to their families. Usually, children who take care of a relative (parent, sibling) diagnosed with an incurable disease live with a hidden suffering. Our Foundation offers these children the opportunity to take part in various events, such as the annual summer camp, that has been going on for the last 10 years. These camps aim to take the patients’ children or siblings out of their delicate environment, even if the patient himself has deceased.

Purpose: The review of the role which the summer camps play in covering both the need to socialize and the need of counseling that children who deal with an incurable disease in their family have.

Method: Retrospective study about the children’s participation at the summer camps in the last 10 years, by analyzing a series of documents from the camps: participation form, written feedbacks given by the children and evaluation forms filled out by the children.

Results: During 2006 - 2015, 10 summer camps were organized for these children, with various themes and in various locations. A total of 293 children took part at the summer camps, from which 138 were boys and 155 were girls. 58% of the children involved had one of their parents diagnosed with an incurable disease and 42% of them had a sibling in such a condition. 44.02% (129) of children lived in the rural area.

Main subjects: The emotional impact of the camp and the positive feelings that these children experienced, confronting one’s fears, developing new abilities and least but not last bonding friendships as a result of teamwork. Also, a small number of children wish to do volunteer work in the upcoming camps.

Conclusions: These summer camps aim to take the children out of their environment, to relax them, to offer emotional and spiritual support and to stimulate creativity.
Frontline Direct Care Workers
Experiences of Providing Domiciliary Care towards the End of Life: A Systematic Literature Review and Narrative Synthesis

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Background: An ageing population heralds a greater demand for palliative and end-of-life care. Many people approaching the end of life rely on domiciliary care services provided by a para-professional workforce. Despite low pay and status, these workers provide personal and social care to people at a difficult time in their lives. Little is known about the impact of this work on the workers themselves or how they are trained, supervised and supported.

Methods: A systematic search was conducted in six databases. All study designs were included. Titles and abstracts of retrieved papers were screened by two researchers working independently. Findings were analysed using a narrative synthesis approach.

Results: Of 747 retrieved references, 12 papers from six countries in four continents were selected for inclusion in the review. Few studies dealt directly with the experiences of direct care workers themselves. Most considered them as part of multi-professional care networks with many focusing on issues relating to the professionals involved in the teams under consideration. Internationally and within nations, workers job titles varied and in some cases obscured job role. Where this role was clear, there was much overlap between domestic, personal, social and health related tasks. There was little evidence of a consistent approach to training and supporting staff involved in care towards the end of life and a paucity of 'voice' for these workers in published studies.

Conclusion: The experiences of direct care workers in palliative homecare is poorly studied. There is considerable variability in how workers are named, the work they do, and who they report to. More research that privileges the voice of these workers and identifies the impact on them of caring for those approaching the end of life is required so that employing agencies may consider how to improve the training, supervision and support of this essential frontline workforce.

Lancaster University funded
Palliative Care and a Socio-Educative Institute: The Valais-Swiss Experience

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Aim: To show the importance of a palliative care mobile ambulatory team in the overall support of terminally ill mentally disabled patients.

Design: We will be using a small group of patients (reports of 4 patients) to show the role of a palliative care mobile unit in the overall medical support of psychiatric and handicapped patients with terminal disease. This report will outline the multi-disciplinary interaction between institutions for adults with psychiatric and severe intellectual disability and an ambulatory palliative care team.

Participants: The Palliative Care Department of Martigny Valais/Switzerland and private institutions for adults with severe intellectual and psychiatric disability.

Results: The feed-back from the care takers will give answers to the following questions:

Does the intervention of a palliative care ambulatory unit allow more comfort for these patients?

Does it reduce the anxiety of social workers, families, the general practitioner and the nursing medical team? Does it reduce hospitalizations for these patients?

This report will outline the work of a mobile palliative care unit in Martigny/Switzerland to allow management optimization of these patients.

Conclusions: In order to have a patient benefit it is important to have an excellent collaboration and coordination between a multi-disciplinary palliative care department and those responsible for the primary care of terminally ill patients with a mental handicap. This vulnerable group of patients is primarily cared for by the socio-educational workers, their family, nursing and medical staff. As a palliative care ambulatory unit our task is to make sure that these patients are not uprooted from their stable environment and we implement tools that allow us to assess symptom management and comfort.
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Creating a Space to Talk about the Characteristics of Substitute Decision Makers during Discussions about Advance Care Planning (ACP). The Value of Social Work Follow-up Meetings during this Process in the Hemodialysis Unit

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Background: ACP is beneficial for the patients and caregivers as well as the interprofessional health care teams. During the ACP discussions patients identify the need to learn more about the role of their appointed substitute decision makers if and when they are not able to direct their care. They also reflect on the knowledge and skills needed to be an effective substitute decision maker as well as their own ability to discuss with potential substitute decision makers, matters related to their quality of life, wishes, values and their expected treatment outcomes. Patients frequently ask for social work support to facilitate conversations of such nature with those they consider that need to be aware and involved, and that they value the most.

Social care and education enables patients to become more aware of the consequences of sharing their notion of quality of life with their family and substitute decision makers. The ACP process has a positive impact on their ability to direct their care and manage their own health.

Goal: Describe the benefits and impact of social work follow-up meetings during the process of ACP

Approach / Method: An Eighteen months analysis all ACP discussions  
Scripting  
Narrative Therapy

Results: The majority of the patients report feeling validated during this process and state that they are confident that their wishes will be respected. In many cases having a safe space to have conversations with caregivers will impact patients’ ability to complete advance directives that have been well discussed with their families.

Lessons learned: Patients report feeling more empowered and knowledgeable about their health, rights and options after having different social care meetings to support their communication with their relatives/caregivers. Some caregivers and patients state that they experience less anxiety and better emotional outcomes when they had positive ACP discussions and AD in place, as their communications concerns are significantly reduced.
Palliative Care DayCenter – Expectations and Service Use

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Introduction: Our palliative day care center (PCDC) is one of the 2 day care center existing in the country and has the role to deliver care and be model for service development in the country. Up to 10 patients attend daily. Due to increase awareness and demand policies concerning length of stay and discharge were reviewed.

Aim: To understand how our PCDC is serving the needs of the patients enrolled and the impact of the new policy.

Method: Quantitative prospective observational study, data collected with purposely designed, self administered questionnaire with 19 items. Anonymity insured, Alpha Cronbach 0.7880.

Results: All 50 patients (RR 100%) of the PCDC responded; 78% women; 78% urban patients; age: 54% 56–70y, 24% 41–55 y, 16% over 71y, 6% under 40y; Frequency of attending: weekly 66%, every 2nd week 10%, monthly 24%; At the enrollment 96% discussed the objectives of care and contractual arrangements; 60% believed they will find more about their disease, 56% that their pain can be controlled; 28% associated hospice with terminal care; 32% feared they will be judged by their friends, 22% the emotional impact on seeing other suffering, Expectation at enrollment versus subsequent service use: nursing 54%/v100%, medical 96%/98%, social 84%/98%, volunteer services 2%/94% religious 82%/92%, psychological 80%/88%, transport 0%/84%, Kineto-therapy 62%/76%. As successful interventions: symptom management and help in understanding their disease scored highest (84%), alleviation of spiritual suffering and obtaining social rights (72%); improving relations 54%, remove of fear 56% and isolation 48%. Negative impact of new discharge policy: fear of abandonment and social isolation 70%, rejection 40%, frustration 36%.

Conclusion: The center is exceeding the expectations of patients in all areas of care, still low awareness of role of nurses, volunteers and transport service offered by PCDC. Negative impact of new policy in the social area.
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The Psycho-social Presence in Palliative Care: Comparing the Social Work Role between Hospital and Hospice Multi-disciplinary Team

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Aim: Multi-disciplinary work is integral to palliative care and professions from different knowledge areas and skills sets must work cohesively for the best interests of the patient. There is still progress to be made in how psycho-social care is delivered in what are often medicalised environments. This study aimed to review the purpose and effectiveness of the social work role in a palliative care team in both hospice and hospital settings to reflect the impact on quantity and quality of referrals to a palliative care service when there is a full time psycho-social presence.

Methods: Data was collected from the 6 months prior to when the social work role was in place and during the 6 month placement, gathering information about number of referrals, nature of referrals and evidence of joint working. Both the hospice and hospital environments are set in inner London areas.

Results: Both settings had an increase in referrals with the addition of a full time social worker in the team however there were differences in the quality of referral. The referrals were also considered within the context of the number of overall referrals received to the wider multi-disciplinary teams and also by the contrasting nature of the services overall in hospice palliative care and hospital palliative care. The data is currently being processed and collated fully.

Conclusion: Psychosocial care is concerned with the psychological and emotional well-being of the patient and their significant others and includes a wide range of issues that can be practical, social, psychological, emotional or spiritual. There can often be a conflict between this area and the more medicalised and physical aspects of patient care but this study continues to evidence that psycho-social needs are fundamental considerations in the lives of those dealing with a terminal or life limiting condition.
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**Dying for Better Care in Dementia**  
**Improving End-of-Life Care for People with Dementia and Reducing Hospitalisation Using the Gold Standards Framework (GSF) Dementia Care Training Programme**

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**Aim:** Dementia is now the biggest cause of death for women in the UK, and the importance of proactive quality end-of-life care for people with dementia is increasingly recognised. People with dementia are at greater risk of inappropriate hospitalisation and interventions, sometimes causing worsening disorientation, distress, morbidity and mortality. Care for people with dementia in hospital wards also poses particular challenges for hospital staff, sometimes leading to inappropriate over-use of medication and sedatives. The GSF Dementia Care Programme focusses on a proactive person-centred approach to End-of-life care, aiming for reduced hospitalisation. It was initially supported by a Government grant.

**Method:** The 4 modular online course with 2 interactive workshops is offered to frontline staff working with people with dementia. It includes:

1. Awareness of the impact on the person and their families and person-centred care.  
2. Communication and Advance Care Planning with people with dementia.  
3. Assessment and management of pain and distress in people with dementia.  
4. Means to reduce inappropriate hospitalisation with more living and dying in their usual place of residence.

Evaluation includes before and after measures, both quantitative and qualitative.

**Result:** We report on the outcomes of over 100 learners in different settings related to changes in knowledge, understanding, confidence, skills and practice in dementia care.

**Conclusion:** The programme shows improvements in awareness and confidence of staff in caring for people with dementia towards the end of their life, and in the four key areas of improving outcomes. Staff are able to better identify deterioration in a person with dementia as they approach the end of their life with improved communication skills. The programme has been reported to effect the care of the wider team, changing the ethos and attitudes within the organisation. This work is helping to put UK Government policy into practice.
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Cultural Diversity in End-of-Life Care among Minority Population in the United States

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The underutilization of end-of-life services by minority populations has been a growing concern in research and in palliative care practice as society becomes more diverse. This has become important in that the palliative care may improve quality of life of patients and their family.

This study aimed to examine and profile the knowledge, understanding, and utilization of end-of-life services/programs among minority population.

A cross-sectional, quantitative survey was conducted, targeting African, Latino, and Korean Americans adults from the age of twenty-one to over eighty-five years of age from Northwest Ohio in the United States. A total of 342 adults were participated in this study.

Using multivariate ANOVA, the data was analyzed on the effects of age and ethnic differences regarding advance directives, spiritual and cultural values regarding death and dying, language barriers, and lack of information related to hospice care.

Result showed that there are significantly ethnic and age differences in advance directives including living will and power of attorney. Religious belief appeared a common factor to impact all three ethnic groups’ decision of end-of-life care. Korean Americans were more likely to have difficulties in communicating with health care providers and need a translator than the other groups. Regarding utilization of the hospice services, Korean Americans are more likely to use hospice services when they have a terminal illness than African Americans and Latino Americans. As people get older and have a terminal illness, they are more likely to use hospice services. Hispanic Americans had more conversations with their family members regarding their wishes for end-of-life care than the other two groups. Cultural competency and age specific approaches, along with outreach and education programs around advance care planning for minorities, are suggested.
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The Impact of Social Work Care and Interprofessional Collaboration on Patients with Disabilities, from Diagnosis to Advance Care Planning and Palliative Care in the Hemodialysis Unit

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Background: It is important to provide patients with different abilities and literacy levels, sensitive and clear information to explore their understanding of their illness and treatment. ACP conversations must start in the early stages of the patients’ treatment to reduce the levels of stress on patients and their families. To deliver inclusive and holistic care to these patient populations, we need to assess them and have well planned ACP discussions. Sufficient time must be allocated for these assessments to provide opportunity for the professionals from different disciplines to identify and address concerns and ideas that the patients might have. Patients display better understanding about their renal diets, hemodialysis and available options after having ACP discussions.

Patients also report that they feel more comfortable appointing their power of attorney (POA) for personal care and expressing their wishes after having ACP discussions. Some patients state that it is beneficial for them to use “scripts” at the beginning of this process to practice how to talk to their relatives and friends about their wishes.

Objectives: Share the experiences and outcomes of creative interprofessional care during the process of Advance Care planning. Discuss the benefits of ACP for patients with different abilities.

Methods: Materials written in a simple language Patients and families education Conversations framed as ongoing process Interprofessional and interinstitutional collaboration Analysis of all ACP discussions held.

Results: ACP strategies appear to have a positive impact and enhance the quality of life of patients and their families.

Conclusion: Advance Care Planning promotes patients self-determination, autonomy and empowerment by supporting their leading role over their treatment plan. People with disabilities like other patient populations benefit from ACP as this process is used to ensure that the interprofessional health care provided is consistent with their wishes, goals and values.
Activities for Patient Support in Cancer Support House of Ishikawa Prefecture

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**Background:** In Japan, the Basic Plan to Promote Cancer Control Programs, launched in June 2007, was revised in June 2012. It defines the basic concept of cancer control and aims to promote comprehensive and well-planed cancer control in Japan. It also provides a model for developing the Prefectural Plan to Promote Cancer Control. In addition to two overall goals, Reduction of cancer deaths and Reduction of burden and improvement of quality of life among cancer patients and their families, the third goal – building a society in which cancer patients can live peacefully – was added to the revised plan. In 2013, the Plan in Ishikawa Prefecture was also revised, and Cancer Support House, in accordance with the 3rd goal, was established in the middle of Kanazawa City (Prefectural Capital) as a commissioned project to our hospital from Ishikawa Prefecture.

**Nature of services:**
1. Management of peer salon,
2. Consultation for worries of patients and their families,
3. Events and lectures (to go out well with cancer or to get along with medical professions),
4. Maintenance of library,
5. Training of volunteers,
6. Building a network of relevant organization.

Furthermore, we work on support for activities of nursing students and patient groups, and study meeting about cancer and employment.

**Results:** The total number of users is an ever increasing trend. Monthly average is 204 people in 2015, 297 in 2016. The breakdown of that is as follows – patients: 50%, families: 12%, others: 38%. The way of use is various. Someone takes part in specific program with a sense of purpose, the other seeks a chance of interaction and going out, and only drops in for a chat.

**Conclusion:** Key word in Cancer Support House is not medicine but life. To build a society in which cancer patients can live peacefully, we aim to deepen the understanding for cancer patients and their families living in community.
Valuing Clinical Supervision in Palliative and End-of-Life Care

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Clinical supervision is becoming recognised as an essential way of supporting people, across professions, working in palliative and end-of-life care. It provides a safety valve as well as a vehicle for personal growth and development. Whilst the benefits of supervision for workers is becoming clearer there is little research on the affect that supervision has on the ability of the worker to relate to, and engage with, the person in receipt of these services. The authors are engaged in providing supervision in these settings and seek to discover whether supervision enables the patient voice to be heard in all its nuanced communication. One of the areas under consideration for instance is – does supervision enhance our capacity to listen to deeper expressions of psychological and emotional pain? Can people’s deepest darkest fears be acknowledged? Fears such as what may happen at the point of death, after death or other issues that may be troubling, such as secrets that may not have been spoken or unresolved grief that needs discussion. We will present a preliminary evaluation of a supervision service in which we will begin to address the following: what behaviour might professionals engage in to minimise the impact of these issues for people at the end of life and what factors may deflect someone’s intention of sharing their inner world with us.

Take home message – not only does supervision support people working in this demanding field it has the potential to make a difference to a patient’s experience of dying through the people supporting them.
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The Work of the Social Worker in Palliative Care Situations in France

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The work of the social worker in palliative care situations is often little known.

Clinical social worker in a unit possessing identified palliative care beds within a French hospital, I would like to raise awareness to the work of the social worker in palliative care situations in France.

Providing informations on: The training

Interventions concerning the patient and his relatives, will be illustrated by the means of three relevant situations.

Other kinds of interventions: means used to raise awareness to the work, counsel to other team.

In conclusion: the main part of the work of the social worker: counsel on social assistance law, psychosocial care and transfer to other care facilities. This part of the work requires the acceptance of the limits the disease can impose on the social worker’s action.

The less frequent part: participating in trainings to raise awareness to the work of the social worker in palliative care situations and counsel to the mobile palliative care team.

The work of the social worker requires a teamwork and partnership. It is why it seems important to get to know each others.
Impact of Volunteer Befrienders on Quality of Life, Loneliness and Social Support: A Wait List Randomised Trial (ELSA)

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Background: Volunteers are central to the provision of end-of-life care services. Volunteer befriending services could reduce isolation, meet emotional needs and maintain a sense of community connectedness. Studies show patients and volunteers value these services, but no study has yet investigated their outcomes.

Aim: To evaluate the effectiveness of receiving care from a volunteer befriending service plus usual care at improving quality of life (QoL) than usual care alone for adults in the last year of life.

Methods:

Design: A multi-centre wait-list controlled trial, with participants randomly allocated to intervention (immediate intervention receipt) or wait list arm (four week wait).

Intervention: Volunteers provided tailored face to face support including befriending, practical support and signposting to services.

Participants: estimated to be in their last year of life. Setting: 11 end-of-life care providers in England. Data collection: at baseline, 4, 8 (12) weeks: WHO QOL BREF, Loneliness scale, mMOS-SS, social networks.

Analysis: Intention to treat analysis includes fitting a linear mixed effect model to each outcome variable at 4, 8 and 12 weeks. ISRCTN 12929812.

Results: 196 adults (61% (n=109) female), mean age 72. No significant difference found in outcomes at 4 weeks. Rate of change of QoL showed trends in favour of the intervention as evidenced by treatment interaction results: physical domain (b= 3.98 (CI -0.38 to 8.34), psychological domain (b=2.59 [CI -2.24 to 7.43], environmental domain (b= 3.9 [-4.13 to 4.91]).

Adjusted analyses to control for hours of volunteer input found significantly less decrease in physical QoL in the intervention group (slope (b) 4.43 (CI 0.10 to 8.76).

Conclusion: Any intervention effect is likely to be in reducing rate of decline in QoL; future research should focus on ‘dose’ to maximise likely impact. Clinicians can confidently refer to volunteer services at the end of life. Funder: UK Cabinet Office.
Hospice Satisfaction Data from The Netherlands: How to Evaluate Care Offered by Volunteers?

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Literature shows that the more hours volunteers spend per patient in care focused roles, the more often care is scored as excellent. What does this mean for reflection on quality of volunteers’ contribution to palliative care? When can their contribution be called satisfactory, good or excellent? This research presents data on satisfaction of hospice patients’ family members. In 2015 230 satisfaction questionnaires were received of hospice clients’ family members via 10 hospices. Until July 2016 another 65 respondents filled in the questionnaire. The satisfaction data were gathered by VPTZ Nederland (national umbrella organisation of volunteers). Respondents were recruited by coordinators of the hospices. Questionnaires were sent by email to surviving relatives six weeks after the patients’ passing away. The inventory used consists of 32 questions on 7 axes: information, communication, eating and drinking, medical care. Also questions about spiritual care, after care and privacy were included.

Data show extreme satisfaction on psychosocial and spiritual care, privacy and communication. Medical care was rated a little lower. Some respondents were negative about collaboration among volunteers and with professional care givers. Also negative remarks about medication were made. The open questions provide insight in the concerns of relatives. We analyse the data for the whole group and per year and search for variations between hospices.

In the discussion we step by step reflect on the value of such data to asses quality of care in hospices. We present a (conceptual) search of how quality of volunteering in care focused roles in palliative care can be evaluated. What is the value of measuring satisfaction and to what extent could Quality of Life be a good alternative? Which clues can be found in other European countries when it comes to identifying concepts or questionnaires to evaluate quality of volunteering in hospice organisations?
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On Staying a Flexible Stranger. Hospice Volunteers in End-of-Life Care for People with Dementia

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Background: Hospice volunteers play a key role in palliative care in Germany. There are approximately 80,000 involved in the care for the dying. Due to the demographic development, they have eventually become an important source of care for people with dementia.

Aims: The aim of the study was to get, from the perspective of the volunteers, a clearer understanding of what the assignment of hospice volunteers in end-of-life care for people with dementia is all about.

Methods: The main method leading the research process based on general principles of grounded theory methodology. The data was received through in-depth interviews with hospice volunteers. 17 hospice volunteers of eight mobile hospices were included in the study. Led by a theoretical sampling, empirical data was collected through structured in-depth interviews. The participants reported a duration of the care assignments between 2.5 hours and six years. The interviews were recorded, then transcribed and then analyzed until theoretical saturation was assessed.

Results: Initial results indicate that the volunteers can be very satisfied with their service. It seems that this highly depends on their flexibility in tasks to perform. They show a great variety of strategies in managing unpredictable situations, which they report to occur a lot. Furthermore, there seems to be a link between the volunteers reported satisfaction and being (and staying) a stranger to the care-recipient. Those volunteers who knew the care recipient prior to their service (neighbour, carer etc.) and those who stayed in close contact to the relatives of the care-recipient, reported more burdensome episodes.

Conclusion: The initial results show, that hospice volunteering in end-of-life care for people with dementia can be as satisfying as for a person without dementia. But those volunteers who were familiar with the care-recipient or the relatives, were less flexible in dealing with difficult situations and less satisfied with their service.
The Role and Motivation of Volunteers in Hospice and Palliative Care in Europe

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**Background:** Volunteers are an essential part of hospice work and palliative care. In spite of the volunteers’ central position and increasing relevance, until now only limited data exists about volunteering in hospice and palliative care in Europe.

**Aim:** The aim of this study is to determine the role and motivation, as well as tasks, training and the challenges facing volunteering in hospice and palliative care in Europe.

**Methods:** The study was carried out in two phases and in collaboration with the Task Force on Volunteering of the European Association for Palliative Care (EAPC). During the first phase, three different questionnaires were created. The first questionnaire targeted ‘volunteers’, the second one ‘volunteer coordinators’ and the third one an ‘expert group’. During the second phase, the questionnaires were distributed via an email link. The participants could complete the questionnaire either on SurveyMonkey or as Word file. The data collected from the questionnaires was stored in an electronic database. Descriptive and evaluative evaluation was performed, using the SPSS program.

**Results:** The response within the expert group consisted of 254 questionnaires. The experts considered the main tasks of volunteers as emotional care and shared activities with the patient. In contrast medical care was rarely mentioned. Expert opinion suggests that volunteers’ motivation was mainly characterised by altruism rather than personal gain or obligation. Furthermore 129 questionnaires were completed by volunteers and 68 by volunteer coordinators. Their data is yet to be analysed.

**Conclusions:** The obtained information will be used to determine structures and requirements for volunteer work. The data will also be used to identify differences between countries and to formulate hypotheses concerning why this is the case. The study will then identify opportunities to improve practice, with an emphasis on practices that promote and support the expansion of volunteer work.
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Reaching Out: Volunteer Outside Service

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Aim: Volunteers ensure high-quality experience for hospice users. Building on existing practice and promoting future excellence, we train volunteer workforce to support patients and families in end of life (EoL) choices, in own home/hospital, particularly if alone. Volunteers, aligned to hospice vision and values complement and ‘fill gaps’ in existing services.

Approach: A willing, confident, flexible, health & social care experienced, volunteer team, able to respond to changing demand, recruited to work unsupervised in people’s homes and a bespoke training programme addressed expressed anxieties. Hospice at Home is ideally placed to promote the initiative; identify/assess potential patients (those for discharge from specialist palliative care (SPC) input, who would still benefit from regular hospice support for self/family) and co-ordinate volunteers. Patients seamlessly allocated volunteer visits and SPC as condition dictates. Uniformed volunteers, with lone worker devices, start and finish at hospice, have current patient information to avoid ‘surprises’ on arrival at patient’s home, clear guidelines to follow if difficulties encountered and are debriefed on return. They undertake light household duties, provide companionship and are not expected to undertake personal/clinical care.

Results: 10–14 volunteers made 500 home/hospital VOS visits, report feeling valued and fulfilled, privileged to be involved in lives of people at an important time and proud to make a difference. Hospice staff feel that, despite required time and support, they have integrated well into existing team.

Conclusion: Volunteers, integral to package of care, meet complex, challenging patient and family needs. Younger volunteers needed, due to demographic profile of current volunteer workforce. Aim to support more people dying in hospital and communicate with secondary care colleagues to ensure professional boundaries respected. Volunteer training and retention, ensures continuity of a reportedly worthwhile valuable service.
Together against the Wind: A Research on the Contribution and Appreciation of Buddies from a Buddy Care Program and the Collaboration Between Formal Care and Buddy Care to the Benefit of Palliative Patients at Home

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**Background:** This research includes a buddy care program and a homecare group. The target groups of these institutions are palliative patients who reside at home. The problem is that palliative patients at home are confronted with a retreating government, changes in legislation as of January 1\(^{st}\) 2015, cutbacks in homecare on function support, an increase of private care management and decisions regarding the end of life. For GP’s and district nurses the workload has increased. The buddy care program is confronted with an increase in applications, while the applications become more complex.

**Aims:** The aim of the research is recognition of the buddy care program and optimal collaboration between formal care and buddy care involved with palliative patients at home.

**Methods:**
- A literature review on two concepts: ‘Four dimensional palliative care’ and ‘collaboration between formal and informal care’.
- An analysis of evaluations from patients of the buddy care program.
- 8 interviews with buddies participating in the program.
- 3 interviews with professionals of a homecare group.
- 1 focus group consisting of 2 buddy care coordinators, 1 nurse practitioner in training, and the manager.

**Results:** The buddies in the buddy care program offer social emotional support to patients who in general have a small social network. It can be concluded that the buddies are well appreciated by the involved parties. Buddies fulfill their role in the psychosocial and spiritual dimensions. In the collaboration between the buddy care and the formal care there is tension on whether or not the buddy is part of the care network of the patient.

**Conclusion and discussion:** The most important recommendations are that buddy care, within the 3 active dimensions, is going to strengthen the approach of buddies towards patients and will continue research into the impeding factors of the cooperation of the formal care and the tension between life and system world.
The Challenges of Volunteer Management in the Country Where the Palliative Care System Is Still Developing

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The aim of this paper is to explain challenges faced by volunteer managers in Croatia, a country where the palliative care system is still developing.

These barriers are drawn on the experience of Mobile Team of Volunteers in Palliative Care in Zagreb that has seven years of experience. Working environment of this team is compared to the working environment of volunteers in the UK and in Austria.

In the UK and Austria volunteer coordinator is located in hospice. On that way staff acceptance and understanding of volunteering are greater, communication between members of the multidisciplinary team is easier and integration with the professional team is more effective. In Zagreb, there is no hospice, there are only palliative care sections within hospitals. For palliative care at home there are two professional teams, consisting of doctor and nurse, supported by the national health insurance. Mobile Team of Volunteers in Palliative Care is NGO. Volunteer coordinator is social worker employed full-time. Mobile Team of Volunteers cooperate with those professional teams adding service of social worker and volunteers. On that way palliative patient get multidisciplinary support. But locations of those teams are different and more effort must be done to get effective communication between the members of the team providing care for same patient and to have effective integration of professional with volunteer team. Although in all three observed countries the costs of volunteers are covered from donations, fundraising in UK and Austria is easier because fundraising team work together with hospice fundraising team. Also, strong history of volunteering in this sector in the UK and Austria strengthened community support. Mobile Team of Volunteers raises funds independently and is faced with poor community support.

Although in Croatia a lot of barriers for volunteering in palliative care request creativity, visible progress makes us optimistic and give strength to continue.
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