Abstracts of the 8th World Research Congress of the European Association for Palliative Care (EAPC)

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EAPC2014: Invited Speakers

Abstract number: INV1
Abstract type: Invited Speaker

Opioids in Palliative Care: How Can Research Lead to a Better Clinical Practice

Caraceni A.1,2
1Fondazione IRCCS Istituto Nazionale Tumori Milano, Palliative Care, Pain Therapy, Rehabilitation, Milan, Italy, 2Norwegian University of Science and Technology (NTNU), Trondheim, Norway

The medical use of opioids in palliative care has been an original contribution to the whole of medicine derived from the hospice experience, first disseminated by Cicely Saunders, Robert Twycross, Geoffrey Hanks at the beginning of opioid clinical pharmacology. The use of opium, the discovery of opium alkaloids, the synthesis of new effective opioid molecules, the identification and cloning of the opioid receptors unravel a fascinating history which has greatly improved our understanding of how opioids work and how they can be used in the clinic to treat pain. The initial demonstration that morphine was effective and safe when given orally occurred together with an interest in opioid pharmacology aiming at the identification of the “ideal” opioid drug preserving the analgesic effect and devoided of other undesired effects. At that time the analgesic trial methodology, established by R. Houde and others, allowed to identify equianalgesic opioid tables, and already highlighted individual differences in opioid responses. PK/PD studies associated with an enormous clinical experience allowed, K. Foley, R. Portenoy and C. Inturrisi to contribute to the concept of “opioid responsiveness” which today is still an incredibly useful concept. The study of “opioid responsiveness” based on the new developments of genetics, pharmacology and on a renewed ability to classify pain conditions and patients subjective responses is key to find an answer to the limitations of opioid pharmacotherapy for chronic pain in all clinical conditions. How and why do opioids fail to adequately control pain in some patients? Will we be able to develop analgesics as effective as opioids and without the limitations due to the development of tolerance, side effects and addiction? We are confronted with these questions since the early stage of opioid pharmacology. I am addressing these questions in this lecture to honor the memory of Vittorio Ventafidda who pioneered the use of opioid for cancer pain.

Abstract number: INV2
Abstract type: Invited Speaker

“Finding Ways to Hope, Seeing Beauty”

Frank A.W.

University of Calgary, Sociology, Calgary, AB, Canada

One reason healthcare professionals need stories is to undo what professional discourse does too well: it simplifies the complex. Professionals confront complexities that require shorthand representation, and so jargon has a useful beginning. But then these words take on lives of their own, seducing professionals into believing such words adequately express realities. We need stories to restore the complexities, or better yet, the messiness of care. We need stories to enable professionals to feel the confusions, absurdities, and occasional heroism of patients and their families. Jargon neatens this messiness; stories intensify it.

This presentation tells part of the story of my mother’s final hospitalization and entry into a palliative-care program. Gradually, my father takes over the story, which becomes about his confusions, desires, and sadness. I hope the story makes unseen worlds of care more visible.

Abstract number: INV3
Abstract type: Invited Speaker

Metaphors at the End of Life: Results from a Large Study

Semino E.

Lancaster University, Department of Linguistics and English Language, Lancaster, United Kingdom

This talk presents the goals, methods and selected findings of the project ‘Metaphor in End-of-Life Care’ at Lancaster University (funded by the UK’s Economic and Social Research Council; grant number: ES/J007927/1; http://ucrel.lancs.ac.uk/melc/). The project is concerned with the use of metaphor by members of three stakeholder groups involved in end-of-life care: patients, unpaid family carers and healthcare professionals. Qualitative and quantitative methods are combined to analyse the metaphors used in a 1.5-million-word corpus consisting of interviews and contributions to online fora by members of all three groups. The controversial ‘war’ metaphor in relation to (terminal)
illness is revisited by exploring the ways in which it is used in the data. ‘War’ metaphors, and ‘violence’ metaphors more generally, are used by members of all three stakeholder groups. There are similarities in the frequency and type of metaphors employed by patients and carers, whilst the professionals’ metaphor use is somewhat different. More specifically, patients have been found to use a variety of ‘violence’ metaphors to talk about a wide range of experiences. Although there is evidence that these metaphors can have demoralising and disempowering effects, it has been found that they can sometimes have a positive function, such as expressing personal determination and mutual solidarity. It is therefore argued that a blanket condemnation of ‘violence’ metaphors in the context of (terminal) illness should be replaced by a more nuanced understanding of the advantages and disadvantages of different types and uses of ‘violence’ metaphors in different contexts and by different stakeholders.

Abstract number: INV4
Abstract type: Invited Speaker

Analysis of Narratives and Discourses Used by Family Carers of Older People with Dementia Living in Nursing Homes

Hennings J.
Lancaster University, Division of Health Research, Lancaster, United Kingdom

Background: From a social constructionist stance knowledge is constructed in the light of experience and meaning created through social interaction. Narration is a form of social action through which people enact their sense of who they are in relationships. Stories built over time are personal resources through which continuity is maintained. The research process is acknowledged to be interactive and subjective. This presentation aims to describe the use of narrative inquiry to illicit in depth accounts using narrative methodology.

Research aim: To explore spouse caregivers’ accounts of having a partner with advanced dementia in a nursing home.

Study population: Spouse caregivers (7 women & 3 men) of people with dementia nearing the end of life were recruited from nursing homes in Northern England.

Methods: Narrative accounts were elicited during three sequential interviews over six months, and through diary methods. Consent was an ongoing process. Rigorous analytical reflexivity was practiced by the researcher to maintain transparency. Narratives were recorded and transcribed verbatim. Key stories and metaphors were identified. Research participants read an earlier report and gave feedback.

Results: Through narrative and metaphor analysis the overarching or grand narrative of liminality was discovered. Participants spoke and wrote of their ambiguous position with loss of status and at times invisibility in society. Within a climate of transition and loss, caregivers were shown to be working hard to maintain continuity and support social identity both for their spouses and themselves.

Conclusions: New understanding of the role and status of spouse caregivers in this setting has been made possible as a result of the methodology adopted.

Abstract number: INV5
Abstract type: Invited Speaker

Prognostication in Advanced Cancer
Alonso-Babarro A.
Hospital Universitario La Paz, Palliative Care Unit, Madrid, Spain

Survival prediction for end stage cancer patients is a key task in Palliative Medicine. First of all, it allows appropriate selection of patients for palliative care programs. Second, it helps to determine the most appropriate care in the best possible setting. Third, it facilitates determinate goals of care and decision making by the health care team as well as by patients and families. Finally, patients and families wish to know.

There are a large number of variables that have been studied to predict survival in advanced cancer patients:

1. Clinician prediction of survival: Physicians’ estimates of a patient’s life expectancies are correlated with their actual survival times, but they are imprecise and often inaccurate.
2. Clinical factors: The single most important predictive factor in cancer is performance status and functional ability. A number of clinical signs and symptoms have been proved to be associated with life expectancy: delirium, dyspnea, weakness and dysphagia anorexia-cachexia syndrome.
3. Laboratory tests: The most frequently associated abnormalities with low survival include hypoalbuminaemia, leukocytosis, lymphocytopenia, elevated LDH and elevated C-reactive protein.
4. Prognostic Scores: The Palliative Prognostic Score (PaP-S) has been validated in several countries, in various settings and in different disease phases. Recent studies show the PaP-S performance improves if information about PPS and delirium is incorporated. Other prognosis scores included PPI and nomograms.

We recommend the routine use of a prognostic tool by palliative care clinicians. But no matter what we do, there will always be some uncertainty in prognosis. Prognostication should not include exclusively foreseeing but also foretelling, disclosure of information to
patients and families. We believe that at least as much attention should be paid to clinicians’ communication about the uncertainty associated with prognostication as to the search for better prognostic models.

**Abstract number:** INV6  
**Abstract type:** Invited Speaker  
**Research on Prognosis: What’s Next?**  
**Glare P.**  
Memorial Sloan Kettering Cancer Center, New York, NY, United States

Prognosis is an important yet challenging clinical skill which palliative care (PC) clinicians should work to master. While prognoses can be offered for any outcome of an illness, the main focus to date in PC has been on predicting survival. There are three elements of survival prediction for which competency is required: making the prediction, communicating the prediction, and using the prediction during the clinical decision-making (CDM) process. The evidence base for each of these domains has grown in the past 10 years, although utilization of prognostic information in CDM has received much less attention than the other two. Advances in statistical computing have allowed creation of mathematical models that take the guess work out of predicting, and examples will be given by other speakers in this session. Communications research has explored the variability in patients’ prognostic informational needs, and how to deliver predictions effectively yet sensitively. Future research topics to expand the evidence base might include: identifying novel predictive factors; improving the predictive output generated by models; developing models for other populations, e.g. pre-hospice; novel communication techniques; prognosis, uncertainty and decision making; predicting outcomes other than survival. Some of the methodologic challenges that might arise while undertaking this kind of research will also be discussed.

**Abstract number:** INV7  
**Abstract type:** Invited Speaker  
**How Can we Predict which Patients are at Risk of Imminent Death?**  
**Stone P.**  
University College London (UCL), Marie Curie Palliative Care Research Unit, London, United Kingdom

Good terminal care requires clinicians to recognise which patients are approaching the end of their lives and are at risk of imminent death. A failure to recognise that death is imminent might mean that patients are treated inappropriately or that patients (and their families) are denied an opportunity to adequately prepare for the end of their lives. Conversely there is a risk that incorrect labelling of someone as “dying” could lead to potentially life-prolonging treatments being denied or withdrawn. Concerns have sometimes been expressed that diagnosing “dying” might become a self-fulfilling prophecy.

Relatively little empirical research has been undertaken to predict which palliative care patients are at risk of imminent death (i.e. “hours” or “days” as opposed to “weeks” or “months”). Studies suggest that clinicians are more accurate at predicting imminent death than intermediate or longer term survival. Many different factors have been proposed as potential prognostic indicators of imminent death including: breathing pattern, respiratory secretions, general decline, conscious level, skin appearance, oral intake, emotional state and other factors. Whether clinicians actually use these factors or, if they do, the relative weighting that they give them when formulating a prognosis is not known. No actuarial tools have been specifically designed to predict imminent death in palliative care patients. However the Palliative Performance Scale (PPS) assesses many of these domains and approximately 50% of patients with a PPS of < 10% die within 24 hours.

Future research should focus on identifying how “expert” clinicians make prognostic judgments and how this skill can be taught to novices. It will also be important to identify whether actuarial models can improve the accuracy and/or the consistency of clinician estimates. Finally, since no approach can be 100% accurate, it is important to investigate models of clinical decision making under conditions of uncertainty.

**Abstract number:** INV8  
**Abstract type:** Invited Speaker  
**Obtaining an International PhD in Palliative Care: A Social Sciences Research Perspective from Euro Impact, an FP7 Marie Curie Initial Training Program**  
**Deliens L.**  
1,2  
1 Vrije Universiteit Brussel, Brussel, Belgium, 2 VU University Medical Center, EMGO Institute for Health and Care Research, Amsterdam, Netherlands

As a PhD student in palliative care research, your training is focused on the skills needed to become an “independent” researcher. This implies that you have the skills to choose an appropriate research problem, develop it into good research questions, choose a suitable research design, draft an adequate protocol, obtain all required approvals, conduct the study, and successful report at good conferences and in good scientific journals. These skills should enable you after your PhD graduation to develop your own
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research in an independent way. Successfully graduating and obtaining your PhD will open additional possibilities for developing your career in palliative care research.

However, PhD systems and training trajectories vary across countries and even across universities within a country. Furthermore, the research domain of palliative care is a very complex domain, making use of very different research designs, and research methodologies. Hence, training PhD students in an international program preparing them for a future research career in their (future) country is very challenging. Therefore, an advanced development and training plan is preferred.

In this presentation we will address the question “How to successfully build an international PhD program in palliative care?”

Abstract number: INV9
Abstract type: Invited Speaker

Obtaining an International PhD in Palliative Care: A Biomedical Research Perspective from the European Palliative Care Research Centre

Haugen D.F.1,2

1Norwegian University of Science and Technology, European Palliative Care Research Centre, Faculty of Medicine, Trondheim, Norway, 2Haukeland University Hospital, Regional Centre of Excellence for Palliative Care, Western Norway, Bergen, Norway

The first comprehensive survey of end-of-life care research in Europe was performed as part of the EU-funded PRISMA project in 2009. The results showed that the majority of research groups were small and scattered, with no overall coordination. A clear need for a formalised higher education in biomedical palliative care (PC) research was identified.

When the European Palliative Care Research Centre (PRC) was established later the same year, the partners committed themselves to establish an international PhD program to foster an international learning environment with mentors, education in research methodology, and structured collaboration.

The international PhD program in PC admits candidates with different professional backgrounds, but has a biomedical emphasis in line with the research priorities of the PRC. The main research areas are translational research, development of guidelines, and symptom assessment and management in cancer patients, focusing on a few major symptoms. The 13 core collaborating centres provide expertise in planning and running of clinical trials, with efficient trial offices.

The PhD program is established at the Norwegian University of Science and Technology in Trondheim, and all students must be admitted there. However, cotutelle agreements and joint degrees are possible. A financial plan is required upon admission. The program is governed by an international council. By Feb 2014, 15 candidates have been admitted, 3 have completed their PhDs.

“Introduction to PC research - theoretical, practical, ethical and methodological aspects” is the only mandatory course of the program to date. This 2-week intensive course takes place in Trondheim and Edinburgh each autumn. The course is open to anyone qualified to do a PhD in palliative care.

Entering the International PhD program of the PRC gives opportunities for training in PC research and being part of an international research environment, with tutors from different countries and institutions.

Abstract number: INV10
Abstract type: Invited Speaker

An Academic Palliative Care Research Career: Skills, Competence, Career Choices and Luck?

Higginson I.J.

King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, London, United Kingdom

You have completed your MSc and/or PhD and now want to move to or have even won an academic job. Congratulations. How do you survive? Even in the best supported fields this is hard. In palliative care, which as a Cinderella field generally gets less than 0.5% of research funding, it is exceptionally hard. For this it’s important to know the principles that are required for general academia and then a few more besides.

In any field a new faculty member is expected to be active in research, to be a good teacher, to help the department, to be visible in the profession and to achieve professional recognition. If you are clinically qualified you also usually have to deliver clinical care. The relative importance of these depends on the university. And it starts before you get to this position. This session will consider:

- How to win good academic jobs - what do you need to have on your CV - where should you have studied and worked, what papers and grants should you have got? This thinking can start as far back as MSc, PhD. What experience will be most useful to you?
- You can’t get your dream job in academia, what can you do in the mean time?
- How to succeed in an academic job - peer review grants, high quality papers, developing a distinct but collaborative portfolio, teaching are all important - in what mix?
• The need to plan long term, but also to be flexible and fast (always keeping that grant proposal you didn’t get in your pocket)
• Finding the things that are most fun for you - you will need to work long hours, so what motivates you, what will make you work harder?

Abstract number: INV11
Abstract type: Invited Speaker

Older patients and Cancer Palliative Care
Van Den Noortgate N.J.
Ghent University Hospital, Geriatric Medicine, Ghent, Belgium

In Western Europe more than one third of cancers are diagnosed in people aged 75 years and older. Taking into account the in 2050 expected threefold increase of this population and the recent evolution in less toxic anticancer treatments like biological treatments, the challenge will be to offer an adequate and up to date anticancer treatment for older patients.

Although most studies report undertreatment of this age group and ageism should be avoided, there is also the risk of overtreatment of palliative patients, resulting in low quality of life due to toxicity of anticancer treatment. Treatment should be based both on the profile of the older patient but also on the wishes and needs of the person himself. A careful exploration through a comprehensive geriatric assessment completed with an exploration of the wishes and needs of the patient is the start of a successful palliative anticancer treatment. For a robust, high functioning older patient, the same therapy as in young people should be offered. In case of an active anticancer treatment, adaptation of therapy to decreased organ function like renal function, interaction with concomitant drug therapy and prevention of complications or specific geriatric syndromes should be considered. For a frail, highly dependent older patient, no anticancer treatment should be considered and good symptomatic palliative care should be offered. For the vulnerable or frail patient, individual and tailored anticancer therapy should be considered together with support for present or expected geriatric syndromes. These aspects will be further discussed in a state of the art lecture.

Abstract number: INV12
Abstract type: Invited Speaker

Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE): An Epidemiologic Study of Hospice Care for Older Adults
Casarett D.J.
University of Pennsylvania, Medicine, Philadelphia, PA, United States

Older adults constitute a large and growing proportion of the population using hospice at the end of life in the United States. However, the data available to guide the care of older patients in hospice is very limited. Most empirical palliative care data, and particularly data from randomized controlled trials, come from studies in other populations. This creates significant challenges for health care providers who must extrapolate evidence from very different, and younger, populations.

Research in a hospice setting can be very difficult, particularly for older adults. Hospice research in the US raises significant challenges because patients are typically referred to hospice very late in the course of illness. Nationally, half of patients are referred in the last three weeks of life, and one third are referred in the last week. Therefore, patients in hospice are often very near the end of life, which created practical difficulties of recruitment and data collection, as well as ethical concerns about consent and burdensome data collection.

The overarching goal of the CHOICE network (Coalition of Hospices Organized to Investigate Comparative Effectiveness) is to use electronic medical records to provide data that can be used to define safe and effective care. CHOICE studies utilize descriptive methods including propensity score matching, to define best practices without relying on randomized controlled trials. Currently CHOICE has 13 hospice members, with a combined database of 165,000 patients spanning five years.

This presentation will describe the formation of the CHOICE network, its structure and organization, and the results of initial studies to define best practices regarding nursing visit patterns and intensity of care.

Abstract number: INV13
Abstract type: Invited Speaker

Ethical Dimensions to Palliative Care for Frail Older Persons
Hertogh C.M.
VU University Medical Center, EMGO+ Institute, Amsterdam, Netherlands

Ethics is about doing the right things and doing them good. Frequently, ethical issues in palliative care are narrowed down to questions related to (medical) decision making at the end of life. This presentation is focused more broadly on care giving in the last stage of life for frail older persons suffering from advanced chronic disease and multimorbidity. With regard to palliative care for this patient group, defining its ethical dimension first of all means that we need to have a clear conception of geriatric palliative care and how it relates to palliative care in general. The popular definition that views palliative care as complementary to life prolonging therapy is inadequate in this respect because for older persons...
Abstract number: INV14
Abstract type: Invited Speaker

Developing Research Methodologies that Can Reliably Examine the Quality of End of Life Care

Currow D.C.
Flinders University, Discipline, Palliative and Supportive Services, Adelaide, Australia

Developing research methodologies to evaluate the quality of end of life care brings out key challenges created by the structure of hospice / palliative care services worldwide: services rely on referrals from other parts of the health and social systems; no universally accepted criteria for referral (or discharge) from specialist services; and difficulty identifying the whole population with life-limiting illnesses. The first research challenge is therefore to ‘see’ the whole of the population at the end of life. Having identified the population who are facing an expected death, are services seeing the people with the most complex needs?

What measures of quality should be used? In addition to the measures of good health care that should be in place for every clinical service, measures specific to hospice / palliative care should include outcome (not just process) measures at three levels:

- health service (How much variation in clinical outcomes is acceptable in hospice / palliative care?); and
- health system (How are hospice / palliative care services helping to be part of the solution for health systems’ problems? How do hospice / palliative care services create the most useful interface with their referring services?).

Given the wide variation in the people referred to specialist services, the next research challenge is to ensure that any comparisons are of similar patient (or caregiver) populations (rather than at a health system or service level) to optimise comparability.

Having defined useful measures for similar groups of patients, data can then be aggregated to service and system level measures. Ultimately, what further research do we need to do to convince the communities that we serve that we are improving the health of our communities because of their investment in hospice / palliative care services?

Abstract number: INV15
Abstract type: Invited Speaker

Early Researcher Award: “My Contribution to Palliative Care Research”

Van den Block L.1,2
1Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Vrije Universiteit Brussel, Department of Family Medicine and Chronic Care, Brussels, Belgium

As Master in Clinical Psychology with PhD in Medical Social Sciences, my research in the End-of-Life Care Research Group (Vrije Universiteit Brussel) Belgium focuses on performing epidemiological research in a national and international perspective aimed at monitoring and improving palliative care. It is interdisciplinary in nature, focusing on palliative care in the community and palliative care for older people including frailty and dementia, hence bridging between long term care, primary care, geriatrics and palliative care. I am also involved in developing a European multidisciplinary, multi-professional research training framework as executive coordinator of EURO IMPACT, a Marie Curie Initial Training Network (FP7/2007-2013,GAnr [264697]).

I was the first to use an existing public health surveillance network -Belgian Sentinel Network of General Practitioners- to monitor people’s final months of life, measuring across setting and disease. Since 2009, I am coordinating the EUROSENTIMELC study, a voluntary EU collaboration (BE, NL, IT, SP, FR) monitoring quality of end-of-life care on a population-based level using such representative GP networks. The consortium developed a
core set of quality indicators for primary palliative care currently being tested (2013-2014).

Chairing the research line on palliative care for older people, I supervised a large-scale representative study on Dying Well with Dementia in Nursing Homes in Belgium. We described the clinical complications and problems experienced at the end of life of people with dementia, and a comparison with analogous data from the Netherlands showed important country differences in the level of discomfort while dying. Based on this work, we started a new EU project PACE (FP7/2007-2013, GAnr[603111]) performing comparative effectiveness research in long term care facilities in Europe (BE, NL, UK, IT, PL, FI) and evaluating the effectiveness of introducing an early integrated palliative care approach.

Abstract number: INV16
Abstract type: Invited Speaker

Experiences from an International Study on Symptom Treatment in Palliative Care: The European Palliative Care Cancer Symptom Study (EPCCS)

Hjermstad M.J. 1,2
1Oslo University Hospital, Ullevål, Regional Centre for Excellence in Palliative Care, Department of Oncology, Oslo, Norway, 2European Palliative Care Research Center, Department of Cancer Research and Molecular Medicine, Norwegian University of Science and Technology, Trondheim, Norway

Background: Palliative care (PC) populations differ substantially within and between countries, as do palliative care services and their organisation. Even if WHO states that PC is applicable early in the course of illness, many PC centres do not see patients until the very last stages of disease.

Objectives: The EPCCS aims to examine and compare PC population characteristics in a large international sample in relation to organisational data; to follow symptom prevalence and intensity over time; and to work towards a standardized way of assessing frequent symptoms.

Methods: PC cancer patients, ≥18 yrs, with metastatic/disseminated disease were recruited when coming for treatment or follow-up. They were followed on site every 4 weeks, up to 3 months, or until death, with a brief set of patient reported outcomes; ESAS, questions on pain, appetite and functions etc. Study personnel registered a core set of medical data, cognitive function and performance status (KPS). Data was registered by computers or on paper, according to the centres’ wishes. A web survey was used to collect data on organisational issues. Eligible patients, who were not included, were also registered.

Results: 32 centres (hospitals, hospices, nursing homes) in 12 countries recruited more than 1500 patients from April-12 to Sept-13. Attrition was high, appr. 36% had 3 registrations. GI and breast cancers were most common (28%/19%). Median age was 66 (22-96), median KPS 70 (10-100), >80% had metastastic disease, 57% received opioids. Average pain intensity (0-10) was 3 (SD 2.8), tiredness 4.5 (SD 3). 40% were undergoing chemotherapy.

Conclusion: High attrition over time is expected in PC studies. The use of a core set of patient self-report data, standardized registrations of medical data, and a log of non-participating patients may reduce the biases from low compliance. We believe this study provides valuable information about important aspects of and variations in cancer PC in many countries.

Abstract number: INV17
Abstract type: Invited Speaker

International Comparative Public Health Research on End-of-Life Care: Where are we Now, Where Will we Go?

Cohen J.
Vrije Universiteit Brussel, End-of-Life Care Research Group, Brussel, Belgium

Most end-of-life care research is using a health service and bedside approach, particularly focusing on the patient - professional caregiver relationship and targeting possible improvement through health service or occupational intervention. This approach may make successful contributions at an individual level, but may be inadequate to address problems on a population level. Demographic, epidemiological, and sociological changes increasingly ask for a public health or population approach to end-of-life care.

A public health research approach to end-of-life care is concerned with the quality of end of life of populations, not just the individuals within them, and uses different research methodologies to describe and understand circumstances of dying at a population level.

This presentation discusses experiences with cross-national public health end-of-life care research so as to illustrate the possibilities of applying a public health perspective and to draft the state of affairs. It discusses three different types of research methodologies and designs:

1) Death certificate data which provide a useful source to study place of death and associated factors at a population level:

2) Surveys using death certificates as a sampling frame, allowing examination of various circumstances of death and the final days:

3) Administrative health care claims data to describe patterns of formal health care and medication use and costs in the final days, weeks and months.
The limitations of the applied research designs will be discussed, including that the role and experiences of family carers and other relevant non-professional agents remains under-investigated. These limitations indicate some of the future challenges for the public health end-of-life care research agenda. One particular future challenge is to go beyond the descriptive and understanding level and develop evidence-based public health interventions aimed at optimizing the circumstances of the dying and all those involved.

**Abstract number:** INV18  
**Abstract type:** Invited Speaker  

**Experiences from International Qualitative Research:**  
**The UNBIASED Study**  
Rietjens J.1, Seymour J.2

1Erasmus MC, Department of Public Health, Rotterdam, Netherlands, 2University of Nottingham, School of Health Sciences, Nottingham, United Kingdom

The use of continuous sedation to relieve the burden of severe suffering is often the subject of heavy debate. These debates often focus on its use, intentions, risks and significance of this practice in palliative care delivery. There are also questions about how to explain international variation in the use of the practice. The UNBIASED study (UK Netherlands Belgium International Sedation Study) is a collaboration between research teams in UK, Belgium and the Netherlands. With the funding from several national agencies (like the Economic and Social Research Council (UK), the Research Foundation Flanders and the Netherlands Organisation for Scientific Research) we conducted an in-depth qualitative case study of the use of this practice in the three countries.

The aim of the UNBIASED study is to examine the experiences of physicians, nurses and bereaved relatives with the use of continuous sedation in end-of-life care for cancer patients and to identify and explain differences in reported practice between UK, Belgian and Dutch practitioners. The study was conducted in hospitals, the domestic home and in palliative care units.

We studied 84 cases involving face-to-face interviews with 57 physicians, 73 nurses and 38 relatives. Recruitment to interviews commenced in January 2011 and was completed by May 2012. All audiotaped interviews were transcribed verbatim, and all data that could identify the participants were removed. The Belgian and Dutch interviews were translated into English by a professional translation agency and checked for accuracy.

In my presentation, I will discuss the benefits and caveats of designing and conducting this large scale qualitative international study. I will also talk about our experiences with analyzing the transcripts and reporting about its results.

**Abstract number:** INV19  
**Abstract type:** Invited Speaker  

**Research on Culture and Values in Palliative Care - the Experience of PRISMA**  
Evans N.1, Pool R.2, Higginson I.J.3, Harding R.3, Gysels M.2,3

1EMGO+ Institute, VU University Medical Center, Department of Public and Occupational Health, Palliative Care Expertise Center, Amsterdam, Netherlands, 2Centre for Social Science and Global Health, University of Amsterdam, Amsterdam, Netherlands, 3Cicely Saunders Institute, King’s College London, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

The priorities and preferences of patients and their families are at the heart of patient-centred palliative care. Attitudes towards and preferences for end-of-life care however are strongly influenced by cultural background and this becomes particularly apparent in cross-cultural research. Through exploring perceptions, experiences and behaviour of patients and health care professionals, qualitative research has the potential to provide insight into how culture influences end-of-life care discourse and practice. Current research on culture and the end of life in Europe is however disparate: often known only to those in specialist fields and frequently unavailable to policy makers and practitioners.

‘PRISMA’, a three-year FP7-funded programme, aimed to inform best practice and harmonise research in end-of-life care for cancer patients across Europe. The programme incorporated a workpackage exploring cultural differences in understanding and prioritising end-of-life care, and how this is articulated in, and influences, research. This workpackage informed and underpinned other areas of PRISMA that addressed outcome measurement and public and clinical priorities in end-of-life care.

To collate and analyse the research and expertise on culture and end-of-life care in Europe, a three-part approach was taken. This consisted of: broad reviews on socio-cultural issues in end-of-life care in the seven participating European countries; a widely disseminated expert questionnaire on meanings and definitions of end-of-life care; and a conference and expert workshop to identify priorities for research.

In this session, I outline how, within PRISMA’s workpackage on culture and end-of-life care, the concept of culture was operationalised. I also summarize the main findings from the workpackage, and describe how insights
Research on Culture and Values in Palliative Care - the Experience with the Cancer Locus of Control Scale

Mystakidou K.
University of Athens, School of Medicine, Areteion Hospital, Pain Relief and Palliative Care Unit, Radiology, Athens, Greece

Statement of Aims/Research Questions: To assess the psychometric properties of the Greek-Cancer Locus of Control Scale (G-CLOC). In two other studies the objectives were: to evaluate the associations between depression, sense of control, cognitive functioning in elderly cancer patients and the correlation between depression, sense of control and cancer-related symptoms in patients ≤65 years old.

Presentation of Methods: In the first study 140 advanced cancer patients participated. Confirmatory factor analysis, reliability and construct validity were conducted. In the second study, univariate and multivariate analyses assessed the relationship between sense of control with depression and cognitive functioning in 86 elderly patients. Then, 70 patients ≤65 years old were analysed for the relationships between G-CLOC, depression and symptoms as well as the factors that might influence depression.

Presentation of results: G-CLOC consisted of three subscales: ‘Control over the Course of Cancer’, ‘Control over the Cause of Cancer’, ‘Religious Control’. The homogeneity of the subscales were satisfactory (α coefficient: 0.713-0.786) as well as test-retest reliability, interscale and inter-item correlations (p< 0.0005, p< 0.05, respectively). The second study revealed: higher perceived control over the ‘course of illness’ and lower perceived control over the ‘cause of illness’ associated with depressive symptoms (p< 0.0005). In the third study, poor quality of life, sense of control, anxiety, fatigue, anorexia, dyspnoea, and sleep disturbances were correlated to depressive symptomatology (p=001).

Conclusions: G-CLOC is a reliable and valid instrument. Elderly cancer patients’ sense of control orientation over the course of illness and the cause of illness predicted the levels of depressive symptoms. In younger patients, ‘control in the course of cancer’, quality of life and cancer-related distressing symptoms might influence depressive symptoms in advanced stages of cancer.

Research on Culture and Values in Palliative Care: Lessons from the World Values Survey

Diez-Nicolas J.
Universidad Europea de Madrid, Research in Social Sciences and Security, Villaviciosa de Odón, Spain

The World Values Survey is an international comparative project that focuses on the study of social, economic, political and cultural values in countries all over the world. It has conducted six waves in 1981, 1990, 1995, 2000, 2005 and 2010, covering more than 100 countries with a great variety of economic development levels, political systems and cultural systems. One of the main hypothesis (Inglehart) has been that for the most part of Human history populations lived under conditions of economic and personal insecurity, which led to values systems based on survival-scarcity values and traditional values. Industrialization and modernization changed this situation, increasing personal and economic security, which led to a new values system based on self-expression values and legal-rational values. Increasing security led to a process of post-modernization characterized by decreasing importance of authority and increasing importance of the individual’s welfare. More recently, increasing insecurity, both economic and personal, seems to be leading to a certain reversal of values again towards higher concern for security in all realms of life. Changes in values’ systems, obviously, also affect people’s concerns about values regarding health, well-being, life, pain, illness and related concepts as palliative care.

Do we always need randomised studies in order to have good evidence?

Costantini M.
IRCCS Arcispedale S. Maria Nuova, Reggio Emilia, Italy

Enriched Enrolment: Definition and Effects in Pain Trials

Straube S.1, Derry S.2, Moore R.A.2

1University Medical Center Göttingen, Institute of Occupational, Social and Environmental Medicine, Göttingen, Germany, 2University of Oxford, Pain Research and Nuffield Division of Anaesthetics, Nuffield Department of Neurosciences, Oxford, United Kingdom
**Aims:** To discuss the concept of enriched enrolment (EE) with particular reference to pain trials. Specifically, to provide a simple scheme to define categories of EE and to investigate its effects.

**Methods:** Narrative literature review.

**Results:** Under circumstances where only a minority of patients with a given condition benefit from an intervention, classical (non-enriched) randomised controlled trials (RCTs) may not demonstrate a beneficial effect of active treatment over placebo because the positive response in that minority may be diluted when treatment group average results are compared and it may be difficult to demonstrate statistical significance. EE offers a possible solution: when the trial population is enriched in responders before randomisation, a treatment effect should be more prominent. EE may be particularly useful when the treatment effect variability is large (only few patients are responders) and the within-patient variability is small (initial responders stay responders over time). EE, if present, can be defined as partial or complete, depending on whether some or all trial participants are known to be responders; when no method capable of producing an enrichment is used in trials, they are non-enriched. Partial EE, particularly when the degree of enrichment is low, has not been shown to produce results substantially different from non-EE. EE with randomised withdrawal (EERW) is a form of complete EE that can be difficult to compare to classical RCTs because different trial outcomes are used. Bearing that in mind, as far as efficacy outcomes are concerned, EERW and non-EERW trials seem to produce similar results. Limitations of using EE include a lack of generalisability to the overall (non-enriched) diseased population.

**Conclusion:** EE is a noteworthy feature of trial methodology, though with limitations and not always with a clearly demonstrable benefit. Publications resulting from trials with EE should therefore state that EE was used.

**Abstract number:** INV24

**Abstract type:** Invited Speaker

**Is There a Place for Qualitative Research in Evidence-based Medicine?**

**Flemming K.**

The University of York, Department of Health Sciences, York, United Kingdom

There is a growing appreciation that health-care needs to be evaluated and informed through a variety of research methods and that it is clinical uncertainty or policy requirements that need to drive evaluation, rather than an allegiance to a particular research methodology. The aim of evidence-based medicine (EBM) is to reduce uncertainty in clinical decision making by incorporating appropriate, current research evidence in decision making processes.

What constitutes ‘best evidence’ is dependent on the question being asked. Critics of EBM have focused on a perceived over-emphasis on randomized controlled trials and systematic reviews, citing a privileging of ‘science’ over other forms of knowledge in clinical decision making. Whilst qualitative research did not feature prominently in the early development of EBM, more recently it has started to contribute in a number of traditional and more novel ways.

The ability to answer complex questions is crucial in the evaluation of palliative care. It is essential to understand not only which treatments are effective in palliative care, but also how the context of delivery can influence implementation. Improving the quality and relevance of research by ensuring that the methods employed answer clinical questions in their totality can help ease the ongoing and dynamic tension surrounding the role of research in palliative care, the maintenance of an ethical stance and developing an evidence-base for practice. Good quality evidence is needed on which base future interventions, but at the same time researchers need to remain sensitive about involving people (and their families) in research when they are facing the end of their lives.

This presentation will explore the role of qualitative research in enhancing the ‘E’ in EBM for palliative care, as a primary research method, through its use in mixed-methods research and its role in evidence synthesis through Cochrane Reviews and beyond.

**Abstract number:** INV25

**Abstract type:** Invited Speaker

**COMBAT Study - Computer Based Assessment and Treatment: A Computerized Clinical Decision Support System for Evaluation and Treatment of Pain and Other Cancer Related Symptoms**

**Raj S.**

**Klepstad P.**

**Brunelli C.**

**Loge J.H.**

**Kaasa S.**

1Norwegian University of Science and Technology (NTNU), European Palliative Care Research Centre, Faculty of Medicine, Trondheim, Norway

2St. Olavs Hospital, University Hospital of Trondheim, Department of Oncology, Trondheim, Norway

3Department of Anaesthesiology and Emergency Medicine, St. Olavs Hospital, University Hospital of Trondheim, Trondheim, Norway

4Fondazione IRCCS Instituto Nazionale dei Tumori, Palliative Care, Pain Therapy and Rehabilitation Unit, Milan, Italy

5Oslo University Hospital, National Resource Centre for Late Effects after Cancer Treatment, Oslo, Norway

COMBAT (Computer Based Assessment and Treatment) is a prospective cohort study with two consecu-
tive study periods recruiting cancer outpatients with pain intensity of at least 4 or higher on a 10-point numerical rating scale. The primary aim of the study was to evaluate the efficacy of a clinical computerized decision support system (CCDSS) on pain intensity. The secondary aims were to evaluate the impact of this system on other cancer related symptoms and opioid consumption. The CCDSS employed in this study was developed in close collaboration between clinicians, pain researchers and computer engineers. In the first study period patients received symptom assessment and treatment as usual. In the second study period the CCDSS system was employed. After inclusion patients completed an electronic questionnaire on an iPad minutes before consultation. After completion this information was wirelessly transferred to the desktop computer applied by the clinician and was available for the clinician in advance of consultation. The data was presented to the clinician both as a summary of the most important symptoms including an electronic body map as well as a more detailed outline of symptoms. Additionally this system provided decision support on key symptoms including treatment of pain. The results from this study will be presented at 8th World Research Congress of the EAPC.

Abstract number: INV26
Abstract type: Invited Speaker

A Nationwide Registry in Palliative Care: Development and Results

Ostgathe C.

University Erlangen, Palliative Medicine, Erlangen, Germany

In 2011 the National Hospice and Palliative Care Registry (NHPR) has been launched in Germany. In this central registry minimal datasets of specialized inpatient (hospices / palliative care units) and home care services are merged. The minimal data sets have been defined and continuously redefined over the last 15 years using scientific methodology by multiprofessional experts of the two major associations in the field (German Association for Palliative Medicine and German Hospice and Palliative Care Association). These minimal data sets consist of information on patients and their disease, on symptoms and problems as well as on organization of care in the beginning and at the end of treatment. All German services are invited to take part in an annual three months census. Data is pseudonymised and processed centrally and can be integrated from different documentation software as a standardized interface has been programmed. The information is fed back to all the participating services and can be used for benchmarking in terms of structure-, process- und outcome quality and for research. Between 2011 and 2013 overall 132 services have participated in the NHPR and data of 6577 patients was integrated. First quality indicators have been developed and calculated.

Abstract number: INV27
Abstract type: Invited Speaker

What are the Most Relevant Indicators to Classify a Palliative Care Population for Quality Assurance and Research

Currow D.

Flinders University, Palliative and Supportive Services, Adelaide, Australia

Ideally, the process of identifying whole populations requires the work to be independent of diagnosis and prognosis. Instead, parameters need to be based around the presence of a progressive, life-limiting illness.

The denominator for the consideration is the whole population of people who are dying, not simply those who are referred to specialist palliative care services.

At a clinical level (evaluating quality) requires a definition of the population being served. Given that resource utilisation and needs are largely independent of prognosis and diagnosis, other measures must be used. This includes not only the patient but also family and friends as caregivers and health professionals. Needs-based assessment tools that evaluate all three groups can also help to serve as ways of describing key demographic factors associated with hospice / palliative care populations.

For patients specifically, clinical factors include diagnosis, a measure of the level of function and potentially also phase.

In research, given variations in access to services and in differing burdens of life-limiting illnesses, it is important to add key demographic factors when considering whole populations: age; gender; a measure of socio-economic status; caregiver availability; health and social support resources; and a measure of geography.

Together these factors can give a composite view of whole populations for measuring clinical quality, access to services and for describing populations in hospice / palliative care research.

Abstract number: INV28
Abstract type: Invited Speaker

Mechanisms of CIBP using animal models and relevant parallel clinical paradigms

Mantyh P.

University of Arizona, Tucson, United States
Abstract number: INV29
Abstract type: Invited Speaker

Bone Metastases: A Complex Soup of Neurochemical Medication. Pharmacological Manipulation

Hoskin P.
Mount Vernon Hospital, Cancer Centre, Northwood, United Kingdom

The process of bone metastases and invasion is dependent upon a cascade of biochemical responses resulting in osteoclast activation. This includes interleukins, parathyroid related proteins, prostaglandins, macrophage activating proteins (MIF1), and cholecalciferols. Activation of T cells is also seen. Many of these agents work through the receptor activator of nuclear factor kb ligand (RANKL). Bone pain arising from this process is partly due to chemical stimulation of large pain fibres, together with the effects of mechanical stresses within the bone.

The treatment of metastatic bone pain is multimodality. Non steroidal anti-inflammatory drugs exploiting their prostaglandin synthetase inhibition are usually first line drugs. Bisphosphonates have as their main mode of action profound osteoclast inhibiting activity. In the metastatic setting they reduce the incidence of skeletal related events and there is now evidence that they are equivalent to radiotherapy in achieving pain control. Denosumab, an inhibitor of RANKL is now established as an effective prophylactic agent in metastatic bone disease and results in improved quality of life and pain scores.

For persistent local pain radiotherapy is considered the gold standard treatment but its mechanism of action remains elusive. Indirect evidence from radiotherapy studies suggests that tumour shrinkage is not needed for pain control. It may have a direct effect upon the host environment resulting in a reduction in chemical mediators of pain and osteoclast activation. There is some evidence for this from the pattern of change of bone markers after radiotherapy. Low dose radiation will also affect neural transmission in animal models and the combination of radiotherapy with drugs such as pregabalin will be discussed further in this session.

Abstract number: INV30
Abstract type: Invited Speaker

Bench to Bedside: translation of pain relief in animal models to the clinic, including radiotherapy and pregabalin study results and role of novel treatments such as denosumab

Fallon M.
University of Edinburgh, Edinburgh, United Kingdom

Cancer Induced Bone Pain (CIBP) is the most common type of pain in cancer, is a clinical challenge and has a major impact on quality of life.

Work in CIBP through both an animal model and translational paradigm, has increased the understanding of the pathophysiology of CIBP. This has highlighted that the underlying neurobiological mechanisms are unique and distinct from neuropathic and inflammatory pain. Peripheral changes occur at the site of the bony metastasis, where the tumour microenvironment is affected by a complex interaction between tumour-related factors, immune cell activity, alterations in somatosensory processing and bone metabolism. This greater understanding has led to research in key areas such as biomarkers of response to radiotherapy (XRT) and the possible use of novel drugs in CIBP.

A prospective study (n=45) by our group examined a range of clinical biomarkers in receiving XRT for CIBP, focussing on Quantitative Sensory Testing. Patients with altered sensation to cool (25°C) and warm (40°C) stimuli, in the skin overlying the area of CIBP were six times (OR 6.1, p<0.05) more likely to respond to radiotherapy. In terms of therapeutics for CIBP, we have completed a randomised double blind placebo controlled trial examining pregabalin (n=233), in combination with XRT in CIBP. The preliminary findings of this study will be presented along with areas where further research is needed such as RANKL inhibitors.

Abstract number: INV31
Abstract type: Invited Speaker

MRSA in Specialist Palliative Care: Should we Be Concerned?

Gleeson A.B., Larkin P., O’Sullivan N., Walsh C.

1Aneurin Bevan University Health Board, Palliative Medicine, Gwenf, United Kingdom, 2University College Dublin, UCD School of Nursing, Midwifery and Health Systems, Dublin, Ireland, 3Our Lady’s Children’s Hospital, Microbiology, Dublin, Ireland, 4Trinity College Dublin, Statistics, Dublin, Ireland

Aims: To determine the impact of Meticillin-Resistant Staphylococcus aureus (MRSA) in the specialist palliative care setting. Specific aims: 1. Determine prevalence, risk factors and MRSA eradication success in one hospice. 2. Assess the impact of an MRSA diagnosis on patients and family members.

Methods: The study included: (1) A prospective study in which data was collected for all admissions to a 36 bed hospice for 18 months. Demographic data, MRSA screening data, and clinical outcome data were collected. Data relating to use of the MRSA eradication protocol was also collected. (2) An in-depth interview study to explore the impact of MRSA on patients with advanced cancer and their family members (n=18). Framework Analysis was used.

Results: (1) MRSA screening results available for 580 admissions (95%). The prevalence and incidence of MRSA colonisation were 10.67% and 1.84%, respectively.
There was no significant survival difference in the MRSA positive group, while MRSA positive patients had a significantly longer length of stay (p< 0.01) and more infection episodes (p< 0.01). Risk factors for MRSA colonisation included: admission from hospital (p< 0.01), Waterlow pressure ulcer risk (p< 0.01), palliative performance score (PPS) (p< 0.01), and mental status (p< 0.01). MRSA eradication success was 8.1% (6/74). (2) In the interview study, four themes emerged: the magnitude of the psychological impact of an MRSA diagnosis; the need for effective communication of the MRSA diagnosis; the enigmatic nature of MRSA; and lessons to guide the future care of MRSA patients.

Conclusion: MRSA has a significant impact in the palliative care setting. Early and careful explanation about MRSA can help patients and their families to cope better with it. The psychological impact may be more significant than the clinical impact. Future MRSA policy development for use in palliative care settings must target the minimisation of the negative connotations linked to MRSA colonisation.

Abstract number: INV32
Abstract type: Invited Speaker

Diagnosing Dying - Development of a Research Tool
Eychmueller S.1, Domeisen Benedetti F.2, Forster M.3
1Universitätsspital Bern Inselspital, Palliativzentrum, Bern, Switzerland, 2Cantonal Hospital St. Gallen, Center for Palliative Care, St.Gallen, Switzerland, 3Cantonal Hospital St. Gallen, St.Gallen, Switzerland

Background: The recent debate on the Liverpool Care Pathway in UK demonstrates the many challenges we are confronted with while offering support and care in this vulnerable last phase of life. The same is especially true while conducting research on the issue of diagnosing dying.

Strategy: Based on results of the European collaboration on optimizing care of the dying (OPCARE9) a three step approach was initiated in an international, multicenter, prospective observational trial to finally come out with a clinical tool that may assist clinicians in recognizing the dying phase more accurately compared to unstructured clinical judgement only: a) prospective testing of a set of criteria/categories as results from OPCARE9; b) statistical analysis and composition of a final set of criteria and definition of a clinical process for recognizing dying (“Diagnosing dying DD) clinical tool”), and c) prospective testing of the DD-tool for sensitivity and specificity.

Results: There have been many practical and some ethical challenges throughout the process. The final instrument consists only of two categories of symptoms/observations (out of initially 9 categories). An intense educational approach in order to avoid misuse is mandatory, and interprofessional team functioning plays an enormous role in terms of safety and best communication while applying the clinical tool. First results show rather high sensitivity of the DD-tool when used in skilled teams.

Abstract number: INV33
Abstract type: Invited Speaker

Non-pharmacological Caregiving Activities at the End of Life: An International Qualitative Study
Lindqvist O.1,2,3, Tishelman C.1, Lundh Hagelin C.4, Lundquist G.1, Sauter S.5, Fürst C.J.6,8, Rasmussen B.H.2, on behalf of OPCARE9
1Karolinska Institutet, Learning, Informatics, Management and Ethics, Stockholm, Sweden, 2Umeå University, Nursing, Umeå, Sweden, 3Västerbotten County Council, AHS Västerbotten, Umeå, Sweden, 4Sophiahemmet University College, Stockholm, Sweden, 5County Council of Dalarna, Palliative Team Västerbergslagen, Ludvika, Sweden, 6Research and Development Unit in Palliative Care, Stockholms Sjukhem Foundation, Stockholm, Sweden, 7Lund University and Region Skåne, Palliativt Utvecklingscentrum, Lund, Sweden, 8Karolinska Institutet, Oncology-Pathology, Stockholm, Sweden

This presentation is based on work conducted in OPCARE9, an EU 7th framework project (2008-2011) aiming to optimize cancer care in the end-of-life, which included of 7 European countries, Argentina and New Zealand. Sweden in collaboration with Slovenia was responsible for a work package on “Complementary Comfort Care”, operationalized as: Non-pharmacological caregiving activities (NPCA), Pharmacological interventions, and spiritual/existential support. An initial perusal of NPCA in palliative care literature, clarified that it was not well represented. We therefore conducted a scoping exercise to identify the variety of NPCA performed in the last days of life. We used a free-listing technique—a modified anthropological approach. After Swedish pilot testing, a representative from each OPCARE9 country was asked to perform a brainstorming activity with at least one palliative care unit in his/her country, discussing which interventions and activities staff carried out with patients and families during the last days and hours of life. A first list of activities was generated, using spoken language, with descriptions in as much detail as possible. Staff was requested to add activities to the lists for 3-4 more weeks. Nine-hundred eighty-five NPCAs were listed by 16 units in the 9 countries and analysed using computer-assisted qualitative data analysis software (NVivo 8). In this presentation both expected and unexpected results of the study will be discussed, as well as pros and cons of using free-listing in this manner. The presentation will conclude with discussion of what this study has had for implications for future research.
Plenary session I

Abstract number: PL1
Abstract type: Plenary

Reducing the Psychological Distress of Family Caregivers of Home Based Palliative Care Patients: Longer Term Effects from a Randomised Controlled Trial

Hudson P.1,2, Trauer T.1,4, Kelly B.3, O’Connor M.6, Thomas T.1, Zordan R.1, Summers M.7
1St Vincent’s Hospital/The University of Melbourne, Centre for Palliative Care, Fitzroy, Australia, 2Queens University, Belfast, United Kingdom, 3St Vincent’s Hospital, Melbourne, Australia, 4University of Melbourne, Melbourne, Australia, 5University of Newcastle, Newcastle, Australia, 6Curtin University, Perth, Australia, 7Assistive Technology Suppliers Australasian Inc, Parramatta, Australia

Background: Best practice in palliative care incorporates comprehensive support of family caregivers since many of them experience burden and distress. However, systematically implemented evidence-based psychological support initiatives are few.

Aim: We evaluated a one-to-one psycho-educational intervention aimed at mitigating the distress of caregivers of patients with advanced cancer receiving home-based palliative care. We hypothesised that primary caregivers receiving this intervention would report decreased distress.

Methods: The study consisted of a randomised controlled trial comparing two versions of the intervention (one face-to-face home visit plus telephone calls versus two visits) across four sites in Australia. Recruitment to the one visit condition was 57; the two visit condition 93, and the control: 148. We previously reported non-significant changes in distress between Times 1 (baseline) and 2 (one week post-intervention), but significant gains in caregivers’ sense of competence and preparedness for the role. Here, we report changes in distress between Times 1 and 3 (8 weeks post death).

Results: There was significantly less worsening in distress scores between Times 1 and 3 in the two intervention groups combined than in the Control group. The 1 visit plus telephone calls intervention effect was significant but the two visit intervention was not. The results, particularly the one visit condition, are consistent with the aim of the intervention to confer some protection against the rise in distress observed in the Control group.

Implications/conclusions: These results support existing evidence demonstrating that relatively short psycho-educational interventions can help family caregivers who are supporting a dying relative. The sustained benefit during the bereavement period may also have positive resource implications, which should be explored in subsequent research.

Abstract number: PL2
Abstract type: Plenary

Cross-cultural Validation of an EORTC Measure of Spiritual Wellbeing (SWB)

1Brunel University, School of Health Sciences & Social Care, London, United Kingdom, 2Mount Vernon Cancer Centre, Lynda Jackson Macmillan Centre, Northwood, United Kingdom, 3University of Sydney, Patricia Ritchie Centre for Cancer Care and Research, Sydney, Australia, 4Hospital of Navarre, Department of Oncology, Pamplona, Spain, 5Institut Curie, Psychiatry and Psycho-Oncology Unit, Paris, France, 6San’ Andrea Hospital, Sapienza University, Psychology Unit, Dept of Oncological Sciences, Rome, Italy, 7St Gemma’s Hospice, Academic Unit of Palliative Care, Leeds, United Kingdom, 8Shengjing Hospital of China Medical University, Palliative Ward, Shenyang, China, 9Instituto Oncologico Fundacion Arturo Lopez Perez, Calidad de Vida, Santiago, Chile, 10Saitama International Medical Center, Department of Respiratory Medicine, Hidaka City, Japan, 11Academic Medical Center, University of Amsterdam, Medical Oncology, Amsterdam, Netherlands, 12Instituto Nacional de Cancerologia, Division de Investigacion Clinica, Mexico City, Mexico, 13Iranian Institute for Health Science Research, Tehran University Medical School, Mental Health, Tehran, Iran, Islamic Republic of, 14University of Agder & Sorlandet Hospital, Faculty of Health and Sport Sciences, Kristiansand, Norway, 15Az. ULSS 3, Psycho-Oncology Service/Palliative Care Unit, Bassano del Grappa, Italy, 16National Cancer Centre Singapore, Palliative Medicine, Singapore, Singapore

Background and aims: No existing measures of spiritual wellbeing (SWB) have been developed cross culturally.
However, in 2002 the EORTC Quality of Life (QL) Group began an international study to develop a measure of SWB for palliative patients. We initially hypothesised 3 domains of SWB, and developed items accordingly. Data collection for Phase IV field-testing and validation of the measure was completed in July 2013.

**Method:** Participants completed a 36-item provisional measure and then a structured debriefing interview exploring the suitability of items. EORTC QLQ-C15-PAL, socio-demographic and clinical data were collected, and test-retest data from a sub-group of patients. We assessed the structure of the domain scales using Principal Component Analysis (PCA) and Rasch analysis and explored further validity using known group comparisons.

**Results:** 458 patients from 14 countries on 4 continents took part. 188 were Christian, 50 Muslim, 23 Buddhist, and 158 followed no religion or belief system. All items showed good distribution of scores across response categories. 275 patients (60%) did not find any items problematic, but small percentages of respondents found 6 items difficult. Combining patient feedback with PCA and Rasch analysis led to deletion of a few items for the final measure. We identified 4 distinct domains which explain 53% of the variance. No remarkable differential item functioning (DIF) was found for age, sex, geographical region or respondents’ belief in a God. Goodness of fit measures were within expected guidelines. Global SWB correlated weakly with global QL.

**Conclusions:** This new EORTC measure of SWB for palliative patients is now available for use in research and clinical practice, and has a role as both a measurement and an intervention tool. Future studies will specifically recruit and explore the perceptions of people in minority religious and/or ethnic communities not already represented in this diverse sample.

**Plenary session II**

**Abstract number:** PL3  
**Abstract type:** Plenary

**Opioid Prescriptions for Cancer Patients in the Last Year of Life. A Pharmacoepidemiological Study of Changes over Time**

_Brelin S._1, _Loge J.H._2,3, _Skurtveit S._4, _Johannessen T.B._5, _Aass N._6,7, _Ottesen S._6, _Fredheim O.M._6, _Hjermstad M.J._8,9,10  

1Oslo, University Hospital, Regional Centre for Excellence in Palliative Care, Department of Oncology, Oslo, Norway, 2Oslo University Hospital, National Resource Centre for Late Effects after Cancer Treatment, Oslo, Norway, 3University of Oslo, Department of Behavioral Sciences, Oslo, Norway, 4Institute of Public Health, Department of Pharmacoepidemiology, Division of Epidemiology, Oslo, Norway, 5Cancer Registry of Norway, Oslo, Norway, 6Oslo University Hospital, Regional Centre for Excellence in Palliative Care, Department of Oncology, Oslo, Norway, 7University of Oslo, Faculty of Medicine, Oslo, Norway, 8Norwegian University of Science and Technology (NTNU), Faculty of Medicine, Department of Circulation and Imaging, Trondheim, Norway, 9Oslo University Hospital, Ullevål, Regional Centre for Excellence in Palliative Care, Department of Oncology, Oslo, Norway, 10European Palliative Care Research Centre (PRC), Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Trondheim, Norway

Opioids are well established as the main pharmacological treatment for moderate-to-severe cancer pain, according to guidelines for cancer pain management. Few studies have examined the prescription prevalence (PP) of Step2; low-potency drugs and Step3 higher-potency drugs over time.

**Objective:**

1) examine if prescription rates of opioids to Norwegian cancer patients in their last year of life changed from 2005 to 2009,

2) examine the association between medical and socio-demographic factors and opioid prescriptions.

**Methods:** Two nationwide, complete registries were combined; the national cancer registry and the national prescription database. The latter contains details on all medical prescriptions issued for patients who are not hospitalized. Relevant socio-demographic data were retrieved from the national statistics bureau.

**Results:** The study population consisted of 44,579 adults. The opioid PP was 78% overall; 74-82%; being 38.5% and 40.8% for step2 and 3 respectively. 25% (10,968 patients) had both Step2 and Step3 opioids in the last year of life. Younger age, long disease duration, prostate or pancreatic cancer and disseminated disease at diagnosis gave higher odds for opioids. The proportion who received opioids increased from 2005 to 2009, while the mean individual amount of DDDs (defined daily dosage) declined. The PP of morphine declined; 29-27.3%, as did paracetamol-codeine combinations; 37.2 -29.0%. Tramadol increased; 11.5-14.5%, but Oxycodone was the dominating opioid in the period; 39.8-48.5), while the PP for Fentanyl remained stable; 17%.

**Conclusions:** The overall PP of opioids for Norwegian cancer patients in their last year of life increased from 2005 (74%) to 2009 (82%), and the DDDS declined, probably due to the higher PP. Paracetamol was used by almost half the opioid receivers, in line with the WHO ladder. Oxycodone was the most frequently prescribed opioid, despite higher cost and no proven superior effect compared to other strong opioids.
Plenary session III

Abstract number: PL4
Abstract type: Plenary

Improvements in Quality of End-of-Life Care in Sweden - Updated Results from the Swedish Register of Palliative Care

**Lundström S.**, **Fransson G.**

1Stockholms Sjukhem Foundation, Palliative Medicine, Stockholm, Sweden, 2Swedish Register of Palliative Care, Kalmar, Sweden

**Background and aims:** The Swedish Register of Palliative Care (SRPC) aims to improve end-of-life care by means of collecting and analysing data on quality indicators related to care during the last week of life for all expected deaths in Sweden. With a coverage exceeding 70% of all deaths in more than 50% of the municipalities in the country, the register now has the ability to present robust data on quality-of-end of life care on a national level. The aim of this study was to give an update on important outcome measures collected by the register.

**Methods:** Aggregated data from the web based end-of-life questionnaire (30 questions) that is answered by health-care providers after the patient has died was analysed using descriptive statistics.

**Results:** The national coverage has increased continuously since the start in 2005 and during 2012 a total of 57,410 deaths were registered by 5080 different health care units. This corresponds to 62% of all deaths in the country with 83% of the registrations made after expected deaths. Eighty-five percent of all cancer deaths were registered in SRPC and the distribution of places of care during the last week in life for cancer patients was 25% for each of hospitals, nursing homes, palliative in-patient units and own home. Approximately 25% of all cancer patients were reported to have difficult pain (NRS > 6) on at least one occasion during last week in life, irrespective of type of care unit. Aggregated analysis of four parameters - proportion of patients having had a physician lead documented discussion about transition to end-of-life care, having prescription of as needed medications for anxiety, and being assessed for pain and oral health during last week in life - showed a mean improvement of 5% over the whole country during the last year with variations seen between different parts of the country.

**Conclusion:** A national quality register is a feasible and important tool when monitoring quality of end-of-life care.

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Abstract number: PL5
Abstract type: Plenary

Are Advance Directives Associated with Better Hospice Care? Results of A Prospective Cohort Study

**Casarett D.**, **Ache K.**, **Harrold J.**, **Harris P.**, **Dougherty M.**

1University of Pennsylvania, Philadelphia, PA, United States, 2Suncoast Hospice, Largo, FL, United States, 3Community Hospice, Lancaster, PA, United States, 4Hospice of Kansas City, Kansas City, KS, United States

**Background:** A general consensus supports the use of advance directives to ensure that patients with serious illnesses receive care that is consistent with their preferences. However, it is not known how the presence of an advance directive influences patients’ care during later stages of illness, after enrollment in hospice.

**Objectives:** To define the population of patients who have an advance directive at the time of hospice enrollment and to determine whether these patients have patterns of care and outcomes that are different than those without advance directives.

**Design:** Electronic health record-based retrospective cohort study, with propensity score adjusted analysis.

**Setting:** Three hospice programs in the United States.

**Participants:** 49,370 patients who were admitted to hospice between January 1, 2008 and May 15, 2012.

**Main outcome measures:** Timing of hospice enrollment prior to death, rates of voluntary withdrawal from hospice, and site of death.

**Preliminary results:** Most patients (35,968/49,370; 73%) had advance directives at the time of hospice enrollment. These patients had a longer stay in hospice (median 29 vs. 15 days) and longer survival prior to death (adjusted hazard ratio: 0.62; 95% CI 0.58-0.66; p< 0.001). They were also less likely to die within the first week after hospice enrollment (24.3% vs. 33.2%; adjusted OR: 0.83, 95% CI 0.78-0.88; p< 0.001). Patients with advance directives were also less likely to leave hospice voluntarily (2.2% vs. 3.4%; adjusted OR: 0.82, 95% CI 0.74-0.90; p=0.003), and more likely to die in a private home or nursing home vs. an inpatient unit (15.3% vs. 25.8%; adjusted OR: 0.82, 95% CI 0.77-0.87; p< 0.001).

**Conclusions:** Patients with advance directives were enrolled in hospice for a longer period of time prior to their death and have outcomes, such as death at home, which are more consistent with the principles of hospice care.
Palliative Medicine
28(6)

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Pain

Abstract number: FC1
Abstract type: Oral

Exploring the Relationships between Pain Intensity, Pain Burden and the Need for Pain Relief in a National Sample

Johnsen A.T.1, Petersen M.A.1, Pedersen L.1, Groenvold M.1,2

1Bispebjerg Hospital, Palliative Medicine, Copenhagen, Denmark, 2Copenhagen University, Institute of Public Health, Copenhagen, Denmark

Aim: To explore the relationships between three different questionnaire-based assessments of the patients’ need for pain relief.

Method: Patients were selected from 56 hospital departments across Denmark based on their birthday, and included if they had advanced cancer (stage three or four) or haematological malignancies. The questionnaire contained items assessing a) the patients’ pain intensity (i.e. how much pain) assessed with EORTC QLQ-C30, b) the experienced pain problem burden (i.e. how much was pain a problem) assessed with the three-levels-of-needs-questionnaire (3LNQ), and c) the patients’ need for additional help in relation to pain, also assessed with the 3LNQ.

Results: Questionnaires were sent to 2364 patients, and 1447 filled them in. Regarding pain intensity, 7% had very much, 17% quite a bit, 27% a little and 49% not at all. All most identical frequencies were found for pain problem burden, and the two items were highly correlated (spearman correlation: 0.85). Regarding the patients’ need for additional help, 47% had no pain and thus, help was irrelevant, 28% experienced a met need, 3% had no wish for help, and 23% had an unmet need. The likelihood that patients had an unmet need was bigger the more pain intensity they had (polychoric correlation: 0.56), and a receiver operating curve (ROC) showed that pain intensity did predict the patients’ need for additional help (AUC: 0.76) quite well. However, 48% of patients with very much pain did not have an unmet need, and 16% of patients having an unmet need stated that they had no pain.

Conclusion: The majority of patients who experienced pain intensity also experienced pain problem burden, thus little difference exist between assessing these two dimensions. Pain intensity predict the patients’ need for additional help quite well. However, some patients experience an unmet need despite having no pain, or experience no need for help despite having much pain.

Abstract number: FC2
Abstract type: Oral

Storage, Disposal and Utilization of Opioids among Cancer Outpatients


MD Anderson Cancer Center, Houston, TX, United States

Background: Prescription opioid abuse is an epidemic in the US. Of the abusers, 75% obtain the opioid from a friend or relative, which may be related to improper opioid storage and disposal practices. Our aim was to determine patients’ practices of opioid use, storage, and disposal.

Methods: We surveyed 300 cancer outpatients presenting to our Supportive Care Center and collected information regarding opioid use, storage, and disposal along with patient characteristics and scores on Cut-down, Annoyed, Guilty, Eye-opener (CAGE) questionnaire for alcoholism. Sharing or losing their opioids was defined as an unsafe use.

Results: Median age was 57 years; 53% female, 72% white, and 63% were married. Most (89%) had advanced cancer, and lung cancer was the most common (22%). CAGE was positive in 19%, 9% had history of illicit drug use, and 36% lived with adult/young adult children. 19% stored opioids in the open, 69% kept opioids hidden but unlocked, and 9% locked their opioids. Patients with history of CAGE positivity (P=.007), illicit drug use (.0002), smoking (P=.03), and those living with adult children (P=.004) were more likely to keep their opioids locked. 66% were unaware of proper opioid disposal methods. 46% had unused opioids at home. 26% indulged in unsafe use by sharing (9%) or losing (17%) their opioids. 39% were unaware that their opioid could be fatal when taken by others. Compared with married patients, those who were never married [OR=2.92; 95% CI 1.48-5.77], separated [OR=11.38; 1.52-112.5], or divorced [OR=1.27; 0.55-2.91] had higher odds of unsafe use (P=.006). CAGE positivity (40% vs. 21%,P=.003) and illicit drug use (42% vs. 23%,P=.031) were significant predictors of unsafe use.

Conclusion: An alarming proportion of patients improperly and unsafely use, store, and dispose of opioids. Patient education and creation of more drug take back programs may reduce availability of prescription opioids for potential abuse. More research is needed in this area.
Abstract number: FC3
Abstract type: Oral

Prevalence of Opioid-related Adverse Events in Cancer Pain: Analysis of Discrepancy between Investigator- and Patient-reported Prevalence

Koh S.

The Catholic University of Korea, Department of Internal Medicine, Seoul, Korea, Republic of

Introduction: Although opioid therapy has been the mainstay of treatment for cancer pain, the prevalence of opioid-related adverse events (AEs) has not been reported in Korea.

Objectives: The study aimed to investigate the prevalence of opioid-related AEs amongst cancer pain patients and compare the difference in AEs reported by investigators and patients.

Methods: A cross-sectional analysis of patients’ charts and questionnaires from 30 teaching hospitals was performed. Clinical characteristics and prevalence for AEs were assessed.

Results: Of the 2,395 patients recruited, the most common opioid-related AEs as reported by investigators were constipation (29.7%), dry mouth (17.2%), and somnolence (14.7%). Patients, however, reported common AEs as dry mouth (61.1%), asthenia (52.2%), somnolence (49.4%) and constipation (49.2%). In addition to the difference in prevalence rates, results indicated a wide discrepancy in reporting of AEs between patients and investigators. Rates of patient-reported AEs which were not reported at all by investigators were as follows: dry mouth 1,054 (44%), asthenia 1,040 (43%), somnolence 831 (35%), and constipation 489 (20%). On the contrary, the differences in rates of AEs reported by investigators and not reported by patients were extremely small.

Conclusions: The study demonstrates the magnitude of discrepancy in reporting opioid-related adverse events between physicians and patients which highlights the importance of patient-reported outcomes. There is a need for improved assessment of patients’ AEs, not only to actively manage AEs, but also to improve patients’ pain and quality of life pertinent to cancer pain.

Abstract number: FC4
Abstract type: Oral

Efficacy and Safety of Methadone as a Second-line Opioid for Cancer Pain


Institut Català d’Oncologia, IDIBELL, Palliative Care Service, L’Hospitalet de Llobregat, Spain

Aims: To evaluate the efficacy & safety of methadone (MTD) as a second-line opioid in advanced cancer patients (pts) 14 and 28 days after rotation.

Material and methods: Prospective efficacy & safety study at days 3, 7, 14, 21 & 28 after MTD rotation. The Brief Pain Inventory (BPI) was used to assess pain & CTCAS v3.0 for toxicity. Categorical data were compared using Pearson’s χ² & Fisher’s exact test. Means of continuous variables were compared using Student’s t-test (normal distributions), and Mann-Whitney and Kruskal-Wallis test (non-normal distributions).

Results: A total of 145 pts (67% men) were included after informed consent was obtained. Mean age was 59. M1 was 79%, mean PPS 70%, and PaP score “A” 75%. ECS-CP pain poor prognosis criteria was 87%. Pre-rotation opioids were: Fentanyl (56%); morphine (19%); oxycodone (15%); Buprenorphine (8%), and other (2%). Rotation opioid ratio was DDEMO (mg) 194.4: MTD, 24.2 (8:1). Pts in follow up, by day: day 3 (94%); 7 (79%); 9 (68%); 14 (59%); 21 (45%); and 28 (38%).

Mean differences from day 0 to 14 (86 pts) were: average pain (5.6 vs 3.0; P < 0.0001); worst pain (8.3 vs 5.0 (P < 0.0001); no. of rescue doses (4.3 vs 1.7; P < 0.0001); side effects (0.29 vs 0.30; P = 0.91); MTD PO mg/d (24.2 vs 27.1; P = 0.01).

Mean differences from day 0 to 28 (55 pts) were: average pain (5.6 vs 2.3; P < 0.0001); worst pain (8.2 vs 4.0; P < 0.0001); no. of rescue doses (3.8 vs 1.2; P < 0.0001); pain interference (6.6 vs 2.5; P < 0.0001); side effects (0.28 vs 0.28; P = 0.86); MTD PO mg/d (24.5 vs 26.4; P = 0.206). Missing pts were due to clinical deterioration/death (49%), analgesic procedures (25%), lost follow up (13%), voluntary withdrawal (9%), and other (3%).

Conclusions: In a sample of advanced cancer pts with poor pain prognosis, the use of MTD as a 2nd line opioid resulted in a rapid, safe, and sustained analgesia. The high rate of missing pts is attributable to the expected disease course, with < 10% due to voluntary abandonment.

Funding: FIS ECO08/00234

Abstract number: FC5
Abstract type: Oral

Barriers to Accessing Opioid Medicines: An Analysis of Legislation of 11 Eastern European Countries


1Utrecht University, Utrecht Institute for Pharmaceutical Sciences, Division of Pharmacoepidemiology & Clinical Pharmacology, Utrecht, Netherlands, 2Lisman Legal Life Sciences, Nieuwerbrug, Netherlands, 3University Hospital Bonn, Department of Palliative Medicine, Bonn, Germany, 4Malteser Hospital Bonn, Centre for Palliative...
Research Aims: Overregulation of opioids contributes to limited access to opioid medicines. The ATOME project focuses on lifting barriers to accessing opioids in 12 selected Eastern-European countries, including barriers in legislation. This study aimed at identifying barriers in national legislation of the 12 participating countries.

Methods: A template focusing on nine categories (prescribing, dispensing, usage, manufacturing, trade and distribution, penalties, affordability, language and other) was developed to identify barriers to accessing opioids in legislation. Three reviewers analysed selected legislation using this template; the results were discussed until consensus was reached.

Results: National legislation was analysed from 11 of the 12 ATOME countries (Bulgaria, Cyprus, Estonia, Greece, Hungary, Latvia, Lithuania, Serbia, Slovakia, Slovenia and Turkey). Potential barriers to access were found in all 11 countries in 6-9 of the 9 categories. Each country showed barriers in the categories ‘prescribing’, ‘dispensing’, ‘usage’, ‘trade and distribution’ and ‘language’, while the total number of barriers in a category varied from 1 (Cyprus, dispensing) to 50 (Greece, prescribing). Most barriers were identified for prescribing, dispensing, and language. Prescribing restrictions and administrative requirements were the most common barriers identified in the category ‘prescribing’, with individual differences in the level of impediment e.g. a prescription validity of 5 days (Hungary, Lithuania, Slovakia, Slovenia) or 13 weeks (Cyprus), and the usage of special prescription forms in duplicate (Greece, Serbia and Slovenia) or triplicate (Bulgaria, Estonia, Slovakia and Turkey).

Conclusion: The review procedure developed for this research proved to be useful for the identification of potential legal barriers. Additional research is needed to assess the direct impact of these barriers on the accessibility of opioid medicines in medical practice.

Aim: Based on AGREE II (appraisal of guidelines for research & evaluation) guidelines need to reflect current research and should be regularly updated. The evidence-based recommendations from the EAPC on the use of opioid analgesics in the treatment of cancer pain were published in 2012 and are now going to be revised and updated. The new guidelines will also be integrated with a series of new topics in order to broaden their scope to “Cancer pain management”. The protocol for searching and summarizing available evidence is reported.

Methods and design: Systematic reviews and meta-analyses will be carried out by independent reviewers in order to summarize the evidence on the following relevant outcomes associated with analgesic treatment in cancer pain: efficacy on pain intensity and on pain burden, side effects and patient’s satisfaction with treatment. Among new topics added: use of “bisphosphonates”, “radionuclides”, “radiotherapy” and “chemotherapy”, “invasive interventions” and “pain assessment and classification”. The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) system will be applied to evaluate confidence on an outcome-by-outcome basis. Searches will be carried out on different databases (MedLine, EMBASE, CINAHL, Cochrane) up to January 31st 2014. Evidence from randomized controlled trials should be preferred but, because of the paucity of studies available for some of the topics, no limits regarding study design will be a priori established.

Conclusion: Appropriate methodology and rigorous strategies in the guideline development process are important for the successful implementation of the resulting recommendations. Updated new and more comprehensive guidelines will facilitate evidence-based management of patients with pain due to cancer, will identify key points for further research and will constitute an international benchmark.

Communication and information

Aim: Life-sustaining Treatment Preferences: Social Support More Important than Health?

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“Medical Aid in Dying”: Healthcare Professionals’ Comprehension of a Possible New Practice at the End-of-Life

Marcoux I.1,2,3, Arseneault C.2,4, Blanchette A.2,4, Toupin M.2,4, Youssef J.2,4, Boivin A.2,4

1University of Ottawa, Interdisciplinary School of Health Sciences, Ottawa, ON, Canada, 2Centre de Recherche Hôpital Charles-Le Moyne, Longueuil, QC, Canada, 3Centre for Research and Intervention on Suicide and Euthanasia, Montreal, QC, Canada, 4University of Sherbrooke, Longueuil, QC, Canada

Recently, a large public consultation on dying with dignity was initiated by the government of Quebec (Canada). Subsequent recommendations ranged from larger access to palliative care to having access to “medical aid in dying” under specific conditions. The aim of this study was to investigate healthcare professionals’ comprehension of this new concept. Two hundred and seventy-one nurses and physicians, recruited through continuing professional training, completed a questionnaire (response rate = 88%). Six clinical scenarios were developed with three sources of variation:

1. the act committed (treatment withdrawal, prescription or administration of drugs according to types and dosage);
2. the presence or absence of a request;
3. the medical justification of the act according to symptoms relief.

We asked healthcare professionals what types of medical acts they considered being “medical aid in dying”, we took into account professionals’ characteristics (sex, types of practice, years since the last diploma, experience with end-of-life care), and discussed responses based on the current legal status of each practice. Scenarios describing actual legal medical acts, namely use of medication adjusted to symptom control and treatment withdrawal, were considered as being “medical aid in dying” by 38% to 62% of professionals respectively. For actual illegal practices, from 67% to 76% of respondents consider the use of potentially lethal drugs beyond symptoms relief (opioid alone or barbiturate with neuromuscular blockade), at the patient or relatives’ request, as “medical aid in dying”. Regression results showed that those with experience with end-of-life care were 2.4 less likely to label all the scenarios as being “medical aid in dying” (p<0.05). Despite a large democratic public consultation, better education is needed for those who would be at the frontline of legal changes.

Abstract number: FC8
Abstract type: Oral

What Do Cancer Patients and Members of Ethical Review Boards in Norway Consider Important Elements in Informed Consent Documents?

Berger O.1,2, Sand K.1, Johansen I.1,3, Loge J.H.4,5, Kaasa S.1,2, Grønberg B.H.1,3

1Norwegian University of Science and Technology (NTNU), European Palliative Care Research Centre
Aims: Length and content of Informed Consent Documents (ICDs) in clinical trials have more than doubled last decades. In Norway, Regional Committees for Medical and Health Research Ethics (REC) approve ICDs according to national and international guidelines. The aim of this study was to investigate how the members of these committees and cancer patients evaluate the relevance of information elements found in ICDs.

Material and methods: This was a cross-sectional, exploratory study. By using the Delphi technique, an expert group developed a questionnaire for asking the participants how they rated the importance of 31 information elements, and whether they were familiar with or considered 7 commonly used terms/phrases in ICDs as difficult to understand. All the 123 members of the Norwegian REC-s and 200 consecutively cancer patients treated at the outpatient cancer clinic at St. Olav’s Hospital, Trondheim University Hospital, Norway, received the questionnaire. Group comparisons were conducted using Chi Square and Fisher’s exact test. Significance level was defined at p< .01 due to multiple testing.

Results: The committee members (n = 81) and patients (n =104) rated the majority of the information elements as important (95%). Few rated any of the information elements as not important (3.5%). Subgroup analysis revealed no statistically relevant differences among patients or REC-membors between patients and REC-membors. The patients were not familiar with all terms commonly found in ICDs, and the REC-membors were not able to predict which. The patients rated the information elements as more important if they were familiar with the terms used in the respective elements.

Conclusions: The participants rated almost all information elements important to include in ICDs, suggesting that ICDs cannot necessarily be shortened. Explaining all terms used in ICDs appears to be an important part of the information process.

Abstract number: FC10
Abstract type: Oral

Being Told about the Imminent Death of a Parent: A Nationwide Study of Cancer-bereaved Youths’ Opinions and Experiences

Bylund Grenklo T.1,2, Uggla C.3, Kreicbergs U.4,5, Valdimarsdóttir U.A.6, Nyberg T.1, Steineck G.1,7, Fürst C.J.8,9

1Karolinska Institutet, Clinical Cancer Epidemiology, Stockholm, Sweden, 2Stockholms Sjukhem Foundation, Stockholm, Sweden, 3Karolinska University Hospital, Stockholm, Sweden, 4Södertörn University College, Stockholm, Sweden, 5Karolinska Institutet, Dept of Women’s and Children’s Health, Stockholm, Sweden, 6University of Iceland, Centre of Public Health Sciences, Reykjavik, Iceland, 7Sahlgrenska Academy, Division of Clinical Cancer Epidemiology, Gothenburg, Sweden, 8Lund University, Dept of Oncology, Lund, Sweden, 9Karolinska Institutet, Dept Oncology Pathology, Stockholm, Sweden

Aim: The aim was to investigate the opinions and experiences of cancer-bereaved teenage children on being told about a parent’s imminent death from cancer.

Method: A nationwide population-based survey including 622 of 851 (73%) youths aged 18 to 25 who six to nine years earlier as teenagers aged 13 to 16 had lost a parent to cancer. Participants responded to questions about their opinion on and experiences of being told when the parent’s death was imminent, about perceived barriers to such communication and at what point in time they realized that death was imminent.

Result: In 595 out of 610 (98%) cancer-bereaved youths opinions, teenage children should be informed when the parents death was imminent (i.e., a matter of hours or days, not weeks). Three-hundred sixty-seven (60%) stated that they had received this information. In this group, 62% reported to have been told by the parents and 11% by parents together with health-care professionals. Prevalent reasons for why the child and parents didn’t talk about imminent death the final week of the ill parent’s life were that one (n=106) or both (n=25) of the parents together with the teenager had pretended that the illness wasn’t that serious, or that none of the parents had been aware that death in fact was imminent (n=80). Two days before the loss 36% of teenagers had realized that death was imminent. Twenty three percent realized this only a couple of hours before the loss.

Conclusion: Parentently cancer-bereaved youth in Sweden believe that teenagers should be informed when a parent’s death is imminent (a matter of hours or days) yet many are not told and do not realize what is about to happen until very late.

Abstract number: FC11
Abstract type: Oral

Developing, Implementing and Evaluating a Psycho-educational Intervention for the Management of Cachexia in Advanced Cancer

Porter S.1,2, Reid J.1,2, Santin O.1, Scott D.1, EPACaCC Study Group
Aims: To develop, implement and evaluate a psycho-educational intervention for patients with advanced cancer who have cachexia and their lay carers.

Background: At present, there is no standardized supportive healthcare intervention in current practice that targets the psychosocial impact of cachexia on advanced cancer patients and their lay carers. This paper reports on the development of an intervention that is currently being trialled.

Design: The MRC framework for the development and evaluation of complex healthcare interventions.

Methods: Multiple methods were used. Pre-clinical phase: qualitative studies with patients and lay carers (interpretive phenomenology), and professional carers (symbolic interactionism). Phase I: systematic reviews, qualitative results and discussions with expert panels to model the intervention. Phase II: pilot study. Phase III: a pragmatic multicentre randomized controlled trial to test the intervention. Phase IV: prospective follow-up.

Interpretation: The MRC framework facilitated the rigorous assessment of the psycho-social needs of patients and their carers and allowed us to incorporate these findings into the development and evaluation of an intervention which both recognizes (though pre-clinical and Phase I) and responds (through Phase II-IV) to these needs.

Funding: DHSSPSNI HSC R&D Division (qualitative study of patients and carers).

DELNI (qualitative study of professionals).

Queen’s University Belfast Centre for Health Improvement (modelling and development of intervention).

All-Ireland Institute for Hospice and Palliative Care (pilot study and RCT).

Abstract number: FC12

Abstract type: Oral

Family Conferences: A Survey of Palliative Care Health Providers in France

Barberet C.1, Filbet M.1, Ruer M.1, Ledoux M.1, Perceau E.1, Font-Truchet C.2, Vallet F.3, Rhondali W.4, Dav R.4, Bruera E.3

1CHU Lyon Sud (CHLS), Palliative Medicine, Pierre-Bénite, France, 2Centre Hospitalier de Bourg-Saint-Maurice, Bourg-Saint-Maurice, France, 3Centre Hospitalier William-Morey, Chalon-sur-Saône, France, 4M.D. Anderson Cancer Center at Houston, Palliative Care, Houston, TX, United States

Family conferences are conducted to assist with end-of-life discussions and discharge planning. Our aim was to explore the perceptions of palliative care providers of the benefits of family conferences in France.

Methods: We performed a cross-sectional descriptive survey with every French PCU (n=113). We asked 4 members of the interdisciplinary team (physician, senior nurse, psychologist and social worker) active in each PCU at the time of the survey to answer.

Results: We obtained 276/452 (61%) responses from 91 units (81%). 272/276 (99%) healthcare providers (HCP) reported conducting family conferences in clinical practice. Only 13 (5%) HCP reported to follow a structured protocol. The majority of HCP reported that palliative care physician (n=225, 82%), nurse (n=219, 79%) and psychologist (n=181, 66%) should participate. 106/452 HCP (45%) reported that patients were not invited to participate. The 3 main goals of family conferences identified by HCP were to allow family members to express their feelings (n=240; 87%), to identify family caregivers (n=233; 84%), and discuss patient’s plan of care (n=219; 79%). The 3 main indications for family conferences were patients with terminal illness (n=216; 78%), at the request of the family (n=208; 75%) and if a terminal sedation was required (n=189; 69%). We found significant differences for the family conference’s primary goals and indications between the 4 disciplines.

Conclusion: The vast majority of HCP in PCU conduct family conferences. Most have no structured protocol, half have no patient participation and there was a significant variation in the primary indications and goals among disciplines.

End-of-life care I

Abstract number: FC13

Abstract type: Oral

Changes in the Personal Dignity of Nursing Home Residents: A Longitudinal Qualitative Interview Study

Oosterveld-Vlug M.G.1, Pasman H.R.W.1, Van Gennip I.E.1, Willems D.L.2, Onwuteaka-Philipsen B.D.1

1EMGO Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Department of Public and Occupational Health, Amsterdam, Netherlands, 2Section of Medical Ethics, Academic Medical Center, Department of General Practice, Amsterdam, Netherlands

Aims: Most nursing home residents spend the remainder of their life, until death, within a nursing home. As preserving
dignity is an important aim of the care given here, insight in the way residents experience their dignity throughout their entire admission period is valuable. We aimed to investigate if and how nursing home residents' personal dignity changes over the course of time, and what contributes to this.

**Methods:** A longitudinal qualitative study was designed, in which multiple in-depth interviews, with an interval of 6 months, were carried out with 22 residents of the general medical wards of four nursing homes in The Netherlands. Transcripts were analyzed following the principles of thematic analysis.

**Results:** From admission onwards, some residents experienced an improved sense of dignity, while others experienced a downward trend, a fluctuating one or no change at all. Two mechanisms were especially important for a nursing home resident to maintain or regain personal dignity: the feeling that one is in control of his life and the feeling that one is regarded as a worthwhile person. The acquirement of both feelings could be supported by

1. finding a way to cope with one’s situation;
2. getting acquainted with the new living structures in the nursing home and therefore feeling more at ease;
3. physical improvement (with or without an electric wheelchair);
4. being socially involved with nursing home staff, other residents and relatives and;
5. being amongst disabled others and therefore less prone to exposures of disrespect from the outer world.

**Conclusion:** Although the direction in which a resident’s personal dignity develops is also dependent on someone’s character and coping capacities, nursing home staff can contribute to dignity by creating optimal conditions to help a nursing home resident recover feelings of control and of being regarded as a worthwhile person.

**Main source of funding:** The Netherlands Organisation for Scientific Research (NWO).

**Abstract number:** FC14
**Abstract type:** Oral

**General Practitioners’ and Nurses’ Descriptions of their Collaboration, Roles and Responsibilities during the Process of Continuous Sedation until Death at Home in Three European Countries**

Anquinet L.1, Rietiens J.1,2, Mathers N.3, Seymour J.4, van der Heide A.2, Deliens L.1,3, UNBIASED

1Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Erasmus MC, Public Health, Rotterdam, Netherlands, 3University of Sheffield, Academic Unit of Primary Medical Care, Sheffield, United Kingdom, 4University of Nottingham, Nottingham, United Kingdom, 5VUmc, EMGO Institute, Amsterdam, Netherlands

**Research aims:** Continuous sedation until death (CSUD) requires a multidisciplinary team approach, with adequate collaboration and communication. However, it is unknown how general practitioners (GPs) and home care nurses experience being involved in the use of sedation at home. We aim to present case-based GP and nurse descriptions of their collaboration, roles and responsibilities during the process of CSUD at home in Belgium, the Netherlands and the UK.

**Study population:** 25 GPs and 26 nurses closely involved in the care of 29 adult cancer patients who received CSUD at home in Belgium, the Netherlands and the UK.

**Design and methods:** Qualitative case study design, based on face-to-face interviews. Methods of statistical analysis The interviews were transcribed verbatim and analyzed with the help of qualitative analysis software (NVIVO 9).

**Results:** We found that in Belgium and the Netherlands it was the GP who typically took the final decision to use CSUD whereas in the UK it was predominantly the nurse who both encouraged the GP to prescribe anticipatory medication and decided when to use the prescription. Nurses in the three countries reported that they commonly perform and monitor CSUD in the absence of the GP which they reported to experience as emotionally burdensome.

**Conclusions:** We have found variety between the countries studied regarding the decision making and provision of CSUD at home. These differences may among others be due to different organizational contexts in the three countries such as the use of anticipatory medication in the UK.

**Funding:** This work was supported by funding from the Economic and Social Research Council (UK) (grant no: RES-062-23-2078), Research Foundation Flanders (BE), the Flemish Cancer Association (BE), the Research Council of Ghent University (BE), the Netherlands Organisation for Scientific Research (NL) and the Netherlands Organisation for Health Research and Development (NL).

**Abstract number:** FC15
**Abstract type:** Oral


Rietiens J.1, Onwuteaka-Philipsen B.2, Swart S.1, van Delden J.3, van der Heide A.1

1Erasmus MC, Public Health, Rotterdam, Netherlands, 2VUmc, EMGO Institute, Amsterdam, Netherlands, 3UMCU, Julius Centrum, Utrecht, Netherlands
**Research aims:** In the Netherlands, the frequency of continuous deep sedation until death (CDS) has risen from 8.2% of all deaths in 2005 to 12.5% in 2010. We aim to describe the practice of CDS in 2010 and compare it with 2005.

**Study population:** Dutch physicians from all specialties.

**Study design and methods:** Nationwide questionnaire study about random samples of deaths reported to the central death registry in 2010 and 2005. Reporting physicians received a questionnaire about the medical decisions that preceded the patient’s death.

**Method of statistical analysis:** Descriptive statistics.

**Results:** 74% (n=6263) responded in 2010 and 78% (n=6860) in 2005. The increased use of CDS was most pronounced among GPs (7.4% in 2005 and 12.0% in 2010), and patients with pulmonary disease (6% of sedated patients in 2005 and 10% in 2010) and nervous system disease (4% of sedated patients in 2005 and 9% in 2010). In 2010, CDS was induced by benzodiazepines in 93%, compared to 83% in 2005. In 2010, in 40%, CDS was used with the (co-)intention of hastening death, and in 31% (compared to 26% in 2005) the physician estimated that the medical decision-making preceding death had hastened death to some extent. The use of palliative consultation prior to the use of CDS increased from 9% in 2005 to 20% in 2010. In both years, in 9% the use of CDS was preceded by a patient’s request for euthanasia that was not carried out.

**Conclusions:** The increase in the use of CDS in the Netherlands is most substantial among GPs, and for patients with pulmonary and nervous system diseases. It is increasingly performed with benzodiazepines and after palliative consultation, which is according to guideline recommendations. In the Netherlands, the relief of suffering through the use of CDS -often to the extent that life shortening cannot be precluded- has become an increasing part of contemporary end-of-life care.

**Main source of funding:** ZonMw.

**Abstract number:** FC16

**Abstract type:** Oral

**Improving the End of Life Care for People with Advanced Dementia and their Informal Carers: A Method of Developing a Complex Intervention Using a Whole Systems UK Wide Approach**

*Jones L.*, *Harrington J.*, *Lord K.*, *Davis S.*, *Chan D.*, *Vickerstaff V.*, *Scott S.*, *Candy B.*, *Round J.*, *Sampson E.L.*

UCL, Mental Health Sciences, London, United Kingdom

**Background:** We aimed to develop a complex intervention to improve end of life care (EOLC) for people with advanced dementia and their carers. We collected data from 4 sources: literature review; qualitative data from health and social care professionals, carers and people with early dementia; quantitative data from people with advanced dementia and their carers; review of UK health and social care policy documents.

**Method and results:** To develop the intervention we synthesised these data. 49 emerging statements were considered in workshops with health and social care professionals across UK to achieve consensus using the RAND Appropriateness Method (RAM) to develop components of the intervention.

1. Prior to workshops we sent invitees the RAM form consisting of 49 statements and asked them to rate these on a scale of 1-9 for appropriateness.
2. At the workshops statements rated as ‘uncertain’ or ‘inappropriate’ were discussed and all 49 items were rated again.
3. Analysis resulted in the retention of 29 statements rated as appropriate.
4. Post workshop attendees were sent the RAM form and asked to rate 29 statements for necessity.

All 29 statements were rated as necessary and retained then mapped onto impact theories (Grol 2007) comprised of individual, social interaction, organisational or political/economic context, and categorised as enablers and barriers for an intervention.

Three core intervention components emerged:

1. Integrated systems and approaches to the delivery of care-operational plan
2. Education, training and support for health and social care professionals and carers - utilisation plan
3. Political and economic context dependent on reimbursement and contracting through CCG commissioning.

**Discussion:** The next phase is to pilot components 1 and 2 of the intervention in a naturalistic experiment in one inner city and one suburban locality at different stages of development for services for EOLC for people with dementia and their carers.

**Abstract number:** FC17

**Abstract type:** Oral

**Respite Care for Patients with Neuro-degenerative Diseases. A Grounded Theory Study**

*Laverty D.V.*, *Arber A.*, *Faithfull S.*

1St Joseph’s Hospice, London, United Kingdom, 2University of Surrey, Faculty of Health & Medical Sciences, Guildford, United Kingdom

**Background:** Palliative care in the United Kingdom plays an important role in supporting patients and their
Aims: To determine what patients and their carers understand by the term ‘Respite’, what patients and carers gain from a respite admission, who accesses respite and how sources of funding affect decision making.

Methodology: A qualitative, constructivist grounded theory approach using 15 in-depth interviews with carers and patients who had experience of respite care.

Data collection: An audit of respite provision and uptake was undertaken prior to the interviews which were conducted over a period of eighteen months. Purposive, selective sampling was used, with a shift to theoretical sampling as concepts and codes begin to emerge. Patients and carers were recruited from a specialist centre, one hospice and a community based team within the south east of England.

Analysis: Conducted using thematic coding methods, memos and constant comparison, involving collapsing of codes to create major themes/categories which then could be divided into sub categories until data saturation occurred.

Results: Emerging themes of tensions & responsibilities, surveillance of care, a mutual beneficial arrangement, a therapeutic intervention, routine and the fight for information and referral. People accessing respite tend to be of a higher social class and this is easier once care funding is ascertained.

Conclusions: Centre on developing a pathway for patients/carers and professionals to determine avenues of referral for respite care, information of respite facilities and handover mechanisms as carers are very uncertain about handing over their loved one to respite services as experiences of respite are so mixed.

Abstract number: FC18
Abstract type: Oral

End-of-Life Care in Nursing Homes: Results from a Retrospective Cross-sectional Study in France

MORIN L., Aubry R., DéHPAD Group

French National Observatory on End of Life Care, Paris, France

Aims: Nursing homes have become a frequent place of death for the elderly in France: in 2011, 12.3% of all death occur in a residential facility. However, we lack nationwide population-based data to describe and assess the circumstances of the final weeks of life. This study aims to describe the care delivery process at the end of life and to target areas of improvement.

Methods: A cross-sectional, retrospective survey was conducted in all nursing homes in France. Using a paper standardized form, attending physicians were asked to describe the organization of end-of-life care in their facility and to report the place of death of all residents who died in 2012. Additionally, participants were asked to identify residents who had died non-suddenly amongst the five most recent death cases which occurred within the nursing home, and to collect detailed information about their last two weeks of life.

Results: 3705 nursing homes participated in this study (response rate: 53%), representative of all elderly care home facilities in France. 13.9% of them have a night-shift nurse and 29.5% have a palliative care consultant nurse. 20.3% of all attending physicians have had no training in palliative care. 25.3% of all deaths (n=70,606) occur in a hospital. The situation of 15,276 residents who died non-suddenly in their facility were analysed. During the last two weeks of life, 54.2% received step-3 pain treatments, 39.7% were concerned by a decision to withhold or withdraw life-sustaining treatments, and 23.4% were transferred at least once to an emergency department. In the last week of life, 23.5% suffered from severe physical symptoms. Finally, during the last 24 hours before death, 6.7% suffered from very intense pain symptoms and 4.3% triggered a call for an ambulance. Only 23.4% of them were able to communicate.

Conclusion: Despite its limitations, this study gives a nationwide unprecedented insight on end-of-life care in elderly care homes.

Assessment, measurement and research methodology I

Abstract number: FC19
Abstract type: Oral

Enda ponnu mone (My dear son): Methodological Challenges in Researching Older Ethnic Minorities in End of Life Care

Ramasamy Venkatasalu M.

University of Bedfordshire, Department of Healthcare, Aylesbury, United Kingdom

Background: Older people from ethnic minorities tend to under-use available palliative and end of life care services. However, limited research is focused about their experiences, preferences and attitudes towards end of life care due issues around ‘hard to reach and research’ these minority ethnic groups in end of life care studies.

Aim: This paper explores the methodological challenges of researching ethnic minorities in end of life care from our study that aimed to examine views and perceptions about end of life issues among older South Asians living in East London.
Methodology: After gaining ethical approval, five focus groups and 29 in-depth, semi-structured interviews were conducted with total of 55 older South Asian adults (24 men and 31 women). Participants from six South Asian ethnic groups were recruited through 11 local community organisations. Tape recorded multilingual data were translated and transcribed into English. Constructive grounded theory used as a data analysis approach.

Results: We experienced two key issues; researcher centred issues including English as second language, identity, age and gender and process centred issues including recruitment, ‘protective’ interpreters, and presence of dominant voices during data collection.

Conclusion: Despite our study innovatively used a multilingual, multicultural and multi-religious approach and importantly, using an ‘insider’ approach, various methodological challenges posed as a threat for data contamination. We conclude that end of life care researchers who focus with ethnic minority population needs to strictly adhere reflexivity mechanisms and gain support from field notes and memo-writing to enhance data trustworthiness.

Abstract number: FC20
Abstract type: Oral
Is the “Surprise” Question a Useful Trigger to Predict those Advanced Cancer Patients who Could Benefit from Early Palliative Care? A Prospective Study among General Practitioners

Bolognesi D.1, Moroni M.2, Zocchi D.1, Abernethy A.3, Rondelli R.1, Savorani G.3, Salera M.3, Dall’Olio F. G.1, Galli G.3, Biasco G.1, on behalf of the SUQ-P Group

1Fondazione Isabella Seràgnoli, Bologna, Italy, 2Fondazione Hospice Seràgnoli, Bologna, Italy, 3Azienda USL Bologna, Bologna, Italy, 4Duke Cancer Care Research Program, Duke University School of Medicine, Durham, NC, United States, 5Giorgio Prodi’ Center for Cancer Research, Alma Mater Studiorum, University of Bologna, Bologna, Italy, 6Academy of Science of Palliative Medicine, Bologna, Italy

Background: Several studies stress the importance of timing in the activation of Palliative Care (PC). The “surprise” question (SQ) “Would you be surprised if this patient dies in the next year?” - was a suggested prognostic tool to identify patients who should receive priority for PC. In this study the SQ has been proposed to a group of general practitioners (GPs), who often have in charge cancer patients all along the disease history.

Aim: This observational study aims to determine the prognostic accuracy of GPs by means of the SQ, answered according to their clinical impression of the patient.

Design: Prospective cohort study.

Participants and methods: Between December 2011 and February 2012, 42 of 50 randomly selected GPs prospectively classified 231 stage IV cancer patients. Lymphoma, leukaemia and skin malignancy were excluded. One year later they were asked to report about the patients’ status. The collected data were divided in two groups according to the answer to the SQ. Univariate and Multivariate Proportional Hazard Regression Models were used to identify prognostic factors influencing the risk of death at 1 year.

Results: 126 patients were classified into the “No” (not surprised) group, 105 into the “Yes” (surprised) group.

After 1 year, 104 (45.0%) patients had died: 87 (83.7%) of them were in the “No” group. The sensitivity of the SQ was 69.3% and the specificity was 83.6%. PPV was 83.8% and the NPV was 69.0%. The SQ was significantly related to patient’s status at 1 year.

Conclusions: The accuracy of the prediction of survival of cancer patients by SQ was very high when used by physicians involved in the patients’ care all along the disease history. Although performed on a relatively selected group of physicians, the study suggests that the “surprise” question in the hand of GPs could be a reliable tool for a timely identification of patients who could benefit from early PC.

Funding: This research received no specific grant from any funding agency.

Abstract number: FC21
Abstract type: Oral
A New Prognostic Score for Medical Treatment of Malignant Obstruction

Vieito Villar M.1, Martinez Lago N.1, Baron Duarte F.J.1, Rodriguez Lopez C.1, Vidal Insua Y.1, Candamio Folgar S.1, Neto Galbiza I.2, Lopez Lopez R.1

1Hospital Clínico Santiago de Compostela, Medical Oncology, Santiago de Compostela, Spain, 2Hospital da Luz, Lisboa, Portugal

Aims: Define using clinical parameters which patients with bowel obstruction derive the most benefit from medical treatment.

Methods: Retrospective analysis of 114 consecutive cancer patients treated at our institution from 2008-2010 for a first episode of bowel obstruction. A multivariate analysis of clinical variables influencing survival, resolution of symptoms, days of hospitalization and discharge was performed.

Results: Four clinical variables were statistically associated with survival (p< 0.005 multivariate Cox regression): presence of ascites, delirium and low conscience level, a non gynaecological-non intestinal primary, and known metastatic disease at admission. Three variables were correlated
with resolution of symptoms (p<0.05 Chi Square): a PS score of less than 3, absence of progressive disease, and a non gynaecological-non intestinal primary. Using this variables we generated a 4 item score with an AUC of 0.751 and a 6 item score with an AUC of 0.775. Using a threshold of 2 risk factors permitted us to categorize 51.7% and 45.6% of the patients respectively as low risk patients. The four item score allowed us to predict the resolution of symptoms with sensitivity of 74.5 and a specificity of 68%. The median overall survival in patients with a low risk score was 14 weeks versus 2 weeks for high risk (p<0.05 log rank test) and the median length of hospitalization was 15 vs 52 days (p<0.005 log rank test). For the 6 items score the results were comparable with no improved power to predict any of the outcomes.

**Conclusion:** Not all the patients with bowel obstruction treated medically have the same prognosis. Although it is necessary to perform a prospective validation of this results, a score of 4 items based in clinical variables could be useful to make informed decisions about earlier referral to palliative care and even stratify patients in clinical trials.

**Abstract number:** FC22

**Abstract type:** Oral

**The Usefulness of EuroQol and McGill Quality of Life Questionnaires in Palliative Care In-patients**

*Deskur-Smielecka E.1,2, Kotlinska-Lemieszek A.1,2, Stelcer B.3, Wieczorowska-Tobis K.1*

**Aim:** To assess the feasibility and validity of EuroQoL (EQ-5D), a generic health-related QoL instrument, as compared to the McGill Quality of Life Questionnaire (MQOL) in palliative care in-patients.

**Material and methods:** Of 125 consecutive patients with advanced cancer admitted to a palliative care ward, 66 (53%) were disqualified because of very poor general status (Karnofsky performance status, KPS ≤ 30) or severe cognitive impairment. Ten subjects refused to participate. In the remaining 49 patients EQ-5D and MQOL questionnaires were completed in random order. Three additional questions about patients’ perception of each tool (time of completion, clarity and burden) were asked. Spearman rank correlations between EQ-5D and MQOL items were performed.

**Results:** 17 men and 32 women (mean age 63±11.3 yrs) completed QoL questionnaires. Median KPS was 50. Both instruments had little respondent burden; however, patients perceived EQ-5D as faster and clearer tool than MQOL. It showed moderate correlations with corresponding domains in MQOL.

### Table 1.

<table>
<thead>
<tr>
<th>EuroQoL items</th>
<th>MQOL items</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Global QoL</td>
</tr>
<tr>
<td>Problems with mobility</td>
<td>-0.178</td>
</tr>
<tr>
<td>Problems with self-care</td>
<td>-0.079</td>
</tr>
<tr>
<td>Problems with usual activity</td>
<td>-0.172</td>
</tr>
<tr>
<td>Pain/discomfort</td>
<td>-0.146</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>-0.288*</td>
</tr>
<tr>
<td>Health state (visual analogue scale)</td>
<td>0.262</td>
</tr>
</tbody>
</table>

**Conclusions:** Assessment of QoL was unfeasible in significant number of palliative care in-patients. EQ-5D was perceived as faster and clearer tool than MQOL. It showed moderate correlations with corresponding domains in MQOL.

**Abstract number:** FC23

**Abstract type:** Oral

**Palliative Sedation Therapy (PST) Guidelines. Findings from a Systematic Review and Quality Assessment**
**Schildmann F.K.¹, Schildmann J.A.², Dietz I.¹³**

¹Klinikum der Universität München, Campus Großhadern, Klinik und Poliklinik für Palliativmedizin, München, Germany, ²Ruhr-University Bochum, Institute for Medical Ethics and History of Medicine, NRW Junior Research Group ‘Medical Ethics at the End of Life: Norm and Empiricism’, Bochum, Germany, ³Klinikum der Universität München, Campus Großhadern, Klinik für Anaesthesiologie, München, Germany

**Aim:** The aim of this paper was to systematically review published PST guidelines with a focus on their quality and recommendations on drug selection and dosage to inform about and discuss differences in available PST guidance.

**Methods:** A literature search was performed in CINAHL, Cochrane Library, EMBASE, PsycINFO and PubMed to identify PST guidelines published before 03/2013. Search terms were “palliative sedation” or “sedation” and “guideline” or “policy” or “framework”. Inclusion criteria were dealing specifically with PST, fulfilment of the criteria of the “Practice Guideline” definition in MEDLINE and publication in English or German. The guideline quality was assessed independently by two authors using the Appraisal of Guidelines for Research and Evaluation II Instrument (AGREE II). Selected findings on medication are presented as narrative review.

**Results:** Nine guidelines which fulfilled the inclusion criteria were identified. In the quality assessment most guidelines received rather high AGREE II scores for the domain “scope and purpose” (median = 69%, range = 28-83%) whereas the domain “Applicability” received the lowest domain scores (median = 15%, range = 025%). The median values for the other four domains were 28% (Stakeholder Involvement), 23% (Rigour of Development), 42% (Clarity of Presentation) and 25% (Editorial Independence). The majority of guidelines suggest midazolam as drug of first choice. However, recommendations on dosage and alternatives vary.

**Conclusion:** The quality of the nine PST guidelines is medium or low for the majority of domains and recommendations on medication differ considerably. This can partly be explained by the lack of evidence concerning PST. However, higher domain scores have been achieved by some guidelines, e.g. by using systematic methods to reach consensus, and these can serve as benchmarks for the development of future guidance on PST.

**Abstract number:** FC24
**Abstract type:** Oral

A Randomised Controlled Trial of an Holistic Needs Assessment Questionnaire in a Supportive and Palliative Care Service Using the Sheffield Profile for Assessment and Referral for Care (SPARC): A Mixed Methods Study

**Ahmed N.¹, Hughes P.¹, Winslow M.¹, Bath P.², Collins K.³, Noble B.¹**

¹University of Sheffield, Academic Unit of Supportive Care, Sheffield, United Kingdom, ²University of Sheffield, Centre for Health Information Management Research, Information School, Sheffield, United Kingdom, ³Sheffield Hallam University, Centre for Health and Social Care Research, Faculty of Health and Wellbeing, Sheffield, United Kingdom

**Background:** At present, there is no widely used systematic, evidence-based holistic approach to screening patients for supportive and palliative care needs.

**Aims:** To determine whether the use of SPARC (a multidimensional holistic needs assessment tool) will lead to improved recognition of supportive and palliative care needs and improved health care outcomes for patients.

**Methodology:** Patients (in-patients, out-patients, day care and in community settings) were randomised to receive SPARC at baseline or after a period of two weeks (waiting list control). Care continued as normal; SPARC responses were communicated to the care team to ensure identified needs were addressed. Participants were asked to complete three short research questionnaires (MYCAW, EQ5D and PEI) as part of the study, repeated after two, four and six weeks. A small group of participants and health care professionals were invited to take part in semi-structured interviews.

**Findings:** There were no significant differences between the control and intervention groups in the scores for MYCAW, EQ5D and PEI at 2, 4 or 6 weeks, suggesting that the intervention did not have a detectable effect. When the MYCAW score was coded for improvement, no change or deterioration, there was a significant association between change in MYCAW score and whether the patients were in the intervention or control group ($\chi^2 = 5.51; df = 1; p = 0.019$). A higher proportion of patients in the control group had an improvement in the MYCAW score from baseline to Week 2: Control: 34/70 (48.6%) vs. Intervention: 19/66 (28.8%).

**Conclusions:** This negative trial result calls into question the utility of SPARC, leading to concerns about the methodology and raising questions about the concept of holistic needs assessment, in specialised supportive and palliative care settings. Findings from both the outcome and process evaluation will be presented.

**End-of-life care II**

**Abstract number:** FC25
**Abstract type:** Oral

Safety of Discontinuing Statins among Patients with Life limiting Illness

**Kutner J.S.¹, Abernethy A.P.², Blatchford P.J.³, Ritchie C.³, Fairclough D.³, Aziz N.³, Hanson L.³, Bull J.³, PCRC Investigators**
Aims: We hypothesized that, among people with life limiting illness, those discontinuing statins would not have a higher rate of death within 60 days.

Methods: This was a pragmatic trial conducted among 15 U.S. sites in the Palliative Care Research Cooperative Group. Eligible patients (adults with life-limiting illness on statin for primary or secondary prevention for ≥ 3 months, life expectancy > 1 month, declining functional status) were randomized to discontinuing (DS) vs continuing statins (CS). Assessments were weekly for 1 month then monthly until death or 1 year. Outcomes were: rate of death (margin = 0.05) within 60 days of enrollment (primary outcome), survival, cardiovascular events, quality of life (McGill QOL), symptoms (Edmonton Symptom Assessment Scale) and polypharmacy. Intent-to-Treat analyses assessed the primary endpoint with a non-inferiority hypothesis (using a 1-sided α = 0.05 level test) and used non-parametric log-rank tests to compare time-to-event secondary endpoints.

Results: 381 patients were enrolled (189 DS, 192 CS). Mean age=74.1 years (SD 11.6); 49% had a primary diagnosis of cancer. Rate of death within 60 days was 0.238 in the DS group and 0.203 in the CS group (difference=0.035 [90% CI -0.035 to 0.105]). Overall survival was not significantly different (p = 0.60); the DS group had longer median time-to-death (229 vs. 190 days). Total QOL was higher among the DS group (McGill QOL: 7.11 vs. 6.85, p=0.037) and there were fewer symptoms (Edmonton Symptom Assessment Scale: 25.2 vs. 27.4, p=0.128) and less polypharmacy (10.1 vs. 10.8 medications, p = 0.034) in this group. Few participants experienced cardiovascular events in either group (13 vs. 11).

Conclusions: Evidence suggests that statins prescribed for primary or secondary prevention should be considered for discontinuation in the setting of life limiting illness. 

Supported by: The U.S. National Institute of Nursing Research (Grant # 1UC4NR012584).

Abstract number: FC26
Abstract type: Oral

Making SPC Beds Centrally Available Round the Clock: A Safeguard to Patient Choice

García-Baquero Merino M.T.¹, Martínez Cruz M.B.¹, Santos Puebla D.¹, Pinedo F.², Molina C.²

¹Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, ²Subdirección General de Servicios de Sistemas de Información, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain

Background: Continuity of Specialist Palliative Care (SPC) is a challenge for patients and professionals alike. Often, patients in SPC programs end up in crowded A&E services while PC beds remain unoccupied. Many opt for early admissions to prevent emergency situations with nowhere to go.

Aim: To offer all our regions 300 SPC beds as a “Just in time” resource to both save lives and unnecessary suffering, and coordinate all stakeholders well coordinated.

Methodology: The regional 24hour SPC service allocated and managed SPC beds existent in the 6.3 m population region, without a formalized process for 2 years. Professionals from 5 teams across different settings (24 hour platform, Hospital support and Home Care Teams which more often asked for beds for patients, and the two bedded units, most frequently accepting the patients) established the relevant issues to help timely bed allocation avoiding time-consuming unnecessary activity.

Results: 19 questions were designed, including relevant issues to each settings (Main Diagnosis, Referring team, Patient location, Urgent? Updated Plan in Multidisciplinary Document (MDTD) etc). All teams saw it as a priority.

Discussion: Busy professionals are ready to take time to work on getting the necessary means ready to streamline patient care and their own work. The plan of action was underway within a week. The result became “SPC Bed Regional Procedure” Over the months, bed allocation increased by over 300 bed allocations/month. Three months after the Procedure was in place, all of the regional SPC beds were centrally managed and available to the 6.3 m population round the clock based on needs.

Conclusion: Team working is easier when centered around clear, meaningful, patient centered needs. Resource allocation is a challenge for policy-makers, frontline professionals are well placed to advice on resource management. This group were happy to do so. The number of home care deaths increased by over 7% in the first few 12 weeks.

Abstract number: FC27
Abstract type: Oral

Increasing Inpatient Hospice Use vs. Patient Preferences: Are Patients Able to Die in the Setting of their Choice?

Hurley S.¹, Teno J.², Casarett D.³

¹North Shore Medical Center, Boston, MA, United States, ²Brown University, Providence, RI, United States, ³University of Pennsylvania, Philadelphia, PA, United States
Background: Growth in hospice utilization has been accompanied by an increase in the proportion of hospice patients who die in an inpatient hospice setting rather than at home.

Objective: To determine whether this increase in inpatient utilization is consistent with patient preferences.

Design: Retrospective cohort study.

Setting: Seven hospices in the CHOICE network (Coalition of Hospices Organized to Investigate Comparative Effectiveness).


Measurements: We measured changes during the study period in patients' stated preferences at the time of admission regarding site of death, including weights to adjust for nonresponse bias. We also assessed patients' actual site of death, and concordance with patients' preferences.

Results: More patients died receiving inpatient care in 2012 compared to 2008 (1,920 (32.7%), 2,537 (18.5%); OR 1.21; 95% CI 1.19–1.22; p < 0.001). However, patients also expressed an increasing preference for dying in inpatient settings (weighted preferences 27.5% in 2012 vs. 7.9% in 2008; p < 0.001). The overall proportion of patients who died in the setting of their choice (weighted preferences) increased from 74% in 2008 to 78% in 2012 (p < 0.001).

Limitations: This study included only 7 hospices, and the results reported here may not be representative of the larger hospice population.

Conclusions: Although more patients are dying while receiving inpatient care, these changes in site of death seem to reflect changing patient preferences. The net effect is that patients in this sample were more likely to die in the setting of their choice in 2012 than they were in 2008.
to describe the provision of palliative care within their department and to define the training of the medical staff regarding palliative care. All questionnaires were strictly anonymous.

**Results:** 294 units participated in this survey (response rate: 70%), representative of all facilities in the country. Respondents reported an average of 62 deaths (2.4 deaths per bed) in 2012. On the day of the study, almost one fifth (17%) of the patients (n=6,568) had a serious, life-threatening and incurable disease at an advanced or terminal stage. 28.9% of the acute geriatric units are located in a facility with a Palliative Care Unit, and 76% are based in a hospital with a Palliative Care Support Team. 55% of them declare having frequent relations with these support teams, mainly to help the staff during a complex decision-making process (55%), to adjust specific pain treatments (34%) or to support the relatives (31%). In 117 units, physicians reported the existence of “palliative care beds”, along with specific resources in 32% of the cases. In 29% of all units, no member of the medical staff have ever received palliative care training.

**Conclusion:** This survey highlights the needs in terms of end-of-life care in acute geriatric units, and the discrepancies in the provision of palliative care in these facilities in France.

**Abstract number:** FC30

**Abstract type:** Oral

**Transferring Critically Ill Patients Home to Die: Scoping the Potential Population**

_Darlington A.1, Long-Sutehall T.1, Richardson A.1, Coombs M.1,2_

1University of Southampton, Faculty of Health Sciences, Southampton, United Kingdom, 2Victoria University, Wellington, New Zealand

**Aims:** Transfer home to die from critical care is rare, despite policy supporting the implementation of patient choice regarding preferred place of care at end of life. A retrospective 12-month audit of patients, who died in critical care, was undertaken to determine the size and profile of the population who could potentially, if they wished, be transferred home to die.

**Methods:** A cohort of patients from ten critical care areas (Intensive Care Units (ICU) and High Dependency Units (HDU)) from 2 hospitals in England who died in 2011 was investigated. A proforma was developed, collecting data on physiological (e.g. sudden death, clinical stability) and care variables (e.g. intense manual handling, high gastrointestinal losses).

**Results:** From an original sample of patients (n=7844) 422 were decedents. The majority of the deceased were judged as being unsuitable for transfer home due to: sudden death (14.7%), clinical instability (53.3%) or requiring complex care (8.3%). 100 (23.7%) patients were identified as potentially eligible for transfer: 53% of patients were conscious, and 20% were ventilated via an endotracheal tube. The majority of patients had been diagnosed with respiratory (41%), neurological (19%) or cardiac disease (19%). The mean time between discussion about withdrawal of treatment with family and time of death was 36.4 hours. Patients judged eligible for transfer were statistically significantly more likely to be treated in HDU than ITU compared to patients who were excluded (Chi²=19.80, p=0.00) and had less intensive nursing care needs.

**Conclusions:** This is the first study to establish the potential size and profile of patients who might possibly be suitable for transfer home to die from critical care. Although patient and family wishes were not ascertained, the data gives an indication of the potential population for transfer. For those patients who express a wish to be transferred home mechanisms need to be in place to facilitate this practice.

**Symptoms other than pain I**

**Abstract number:** FC31

**Abstract type:** Oral

**Randomised Control Trial of Oral Risperidone, Oral Haloperidol, and Oral Placebo with Rescue Subcutaneous Midazolam in the Management of Delirium in Palliative Care Inpatients**

_Agar M.R.1,2,3, Lawlor P.4, Draper B.3, Caplan G.3, Hill M.7, Rowett D.8, Sanderson C.7, Quinn S.6, Eckermann S.9, McCaffrey N.8, Devilee L.8, Fazekas B.8, Currow D.8, Palliative Care Clinical Studies Collaborative_

1Flinders University, Palliative and Supportive Services, Adelaide, Australia, 2University of New South Wales, South West Sydney Clinical Schools, Sydney, Australia, 3HammondCare, Palliative Care, Sydney, Australia, 4University of Ottawa, Ottawa, ON, Canada, 5University of New South Wales, Sydney, Australia, 6Southern Adelaide Palliative Services, Adelaide, Australia, 7Calvary Health Care Sydney, Sydney, Australia, 8Flinders University, Adelaide, Australia, 9University of Wollongong, Wollongong, Australia

**Background:** Antipsychotics are often used to treat delirium despite limited level placebo controlled trial evidence, and that delirium resolution may already occur as precipitants are treated. There is no registered medication internationally for delirium treatment. The few studies that exist have not specifically explored management of individual symptoms.

**Aim:** To compare the efficacy of oral risperidone solution relative to placebo in control of targeted delirium
symptoms (Sum of scores on Nursing Delirium screening scale items 2 (inappropriate behaviour), 3 (inappropriate communication), and 4 (illusions/hallucinations)) at 72 hours from treatment commencement. Secondary aims were to compare oral haloperidol solution relative to placebo; and oral risperidone solution relative to oral haloperidol solution.

**Study design:** A randomised double blind placebo controlled phase III study to compare the effectiveness and toxicity of oral risperidone, haloperidol, and placebo in the management of adult palliative care patients with delirium and the target symptoms of interest, where proxy consent was obtained. All arms received individualized management of delirium precipitants, attention to non-pharmacological measures, and had subcutaneous midazolam rescue available. Doses were titrated every 12 hours to maximum of 2mg in participants > 65, and 4mg in those ≤ 65. A total sample size of 165 completed participants will provide 80% power, at a 2-tailed type I error of 0.05, to detect a difference of 0.55 SD unit between any two treatment means.

**Results:** The study is currently open for recruitment at 10 sites around Australia. Recruitment is expected to be completed in late 2013. Final results will be available by May 2014.

**Conclusion:** This multi-centre, double-blind, controlled study will be an adequately powered study to evaluate the role of antipsychotics in the management of delirium in the palliative setting.

**Abstract number:** FC32

**Abstract type:** Oral

**International Comparison of Content and Quality of Clinical Practice Guidelines on Palliative Sedation**

*Abarshi E.1, Rietjens J.2,3, Caraceni A.4,5, Payne S.1, Deliens L.1,6, Van den Block L.1, EURO IMPACT*

1International Observatory on End of Life Care, Lancaster University, Division of Health Research, Lancaster, United Kingdom, 2ERASMUS MC, University Medical Center Rotterdam, Rotterdam, Netherlands, 3Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 4Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano, Italy, 5European Palliative Care Research Center, EAPC Research Network, Trondheim, Norway, 6VU University Medical Center, EMGO Institute for Health and Care Research, Amsterdam, Netherlands

**Background:** Palliative sedation is a last resort treatment option in case of refractory symptoms and endless terminal suffering. Recent studies suggest large variations in the prevalence of this end-of-life care practice. Worldwide, different guidelines on palliative sedation have been developed, aiming at ensuring prudent practice and standardising care.

**Aim:** To evaluate clinical practice guidelines (short: guideline) on palliative sedation, by examining their content and quality based on items on a checklist which includes the European Association for Palliative Care (EAPC) Framework on palliative sedation and the Appraisal Guideline Research and Evaluation (AGREE II) tool.

**Method:** We searched multiple databases (PubMed, CancerLit, CNAHL, Cochrane Library, NHS Evidence) and internet sources (Google/Google Scholar), for published and unpublished guidelines on palliative sedation. Then we selected guidelines developed between January 2000 and May 2011, authorised by a governing body, and available in five pre-selected languages. A guideline was defined as “a systematically developed statement used to facilitate decision making in clinical settings”.

**Results:** Eleven guidelines of 4-78 page-lengths emerged from Europe (Belgium, France, Ireland, Italy, Netherlands, Norway, Spain, Sweden), Canada, and Japan. Two had been revised. Nine contained elements from ≥9/11 EAPC recommendations, while two had < 50%. Pre-emptive planning, artificial hydration/nutrition, and clinician care were issues least mentioned in guidelines. AGREE scores were highest for ‘scope and purpose’, and lowest for ‘editorial independence’ domains.

**Conclusions:** Recommendations were generally comparable with the EAPC’s, although they varied in depth and detail. For many, “methodological rigour” was undermined by non-declaration of stakeholder involvement and editorial independence. However, eight guidelines scored moderate to highly; of which three were recommended for use with little modification.

**Abstract number:** FC33

**Abstract type:** Oral

**Association between Parenteral Fluids and Symptoms in Hospital End-of-Life Care An Observational Study of 280 Patients**

*Fritzson A., Tavelin B., Axelsson B.*

Umeå University, Department of Radiation Sciences, Umeå, Sweden

**Objectives:** To investigate whether dying patients receiving parenteral fluids (PF) suffer from more or less symptoms than patients who do not receive PF. Today’s evidence on how PF affects palliative patients’ symptoms is very scarce. Nevertheless, 40% of the patients who died expectedly in Swedish hospitals receive PF during their last 24 hours of life. A secondary aim was to analyse what volumes and kinds of fluids the patients had received.

**Methods:** A historical cohort study of medical records was performed. Of the 530 patients who were reported to have died expectedly at hospital in Västerbotten county (Sweden) between 1/1/2011 and 30/6/2012, 140 cases who had
received PF and 140 controls who had not, were identified by stratified randomization and matched by age, sex, and main disease. The groups were compared regarding documented presence of dyspnoea, respiratory secretions, anxiety, nausea, and confusion during the last 24 hours and the last week of life.

**Results:** The prevalence of documented dyspnoea in the PF groups was higher than in the non-PF groups (51% vs. 22% last 24 hours, p< 0.0001; 70% vs. 45% last week, p< 0.001). The proportions of patients suffering from dyspnoea increased with larger administered volume. Analogous trends were seen regarding proportion of patients with documented low oxygen saturation, and the proportion of patients needing oxygen therapy. Although our main hypothesis that the prevalence of respiratory secretions would be higher in the PF group was not confirmed, we found a tendency in that direction (63% vs. 50% last week, p=0.072). No clinically significant differences in anxiety, nausea, or confusion were found. In the PF group representing the last week of life, parenteral nutrition was provided to 24% whereas blood products was given to 25% of the patients.

**Conclusions:** There is an association between PF administration and increased frequency of documented dyspnoea for terminally ill patients in their last week of life.

**Abstract number:** FC34
**Abstract type:** Oral

**Screening for Body Image Dissatisfaction in Advanced Cancer Patients**

Rhondali W.1,2, Chisholm G.3, Filbet M.2, Kang D.-H.4, Hu D.1, Cororve Fingeret M.3, Bruera E.4

1MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 2Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 3MD Anderson Cancer Center, Biostatistics, Houston, TX, United States, 4The University of Texas Health Science Center, School of Nursing, Houston, TX, United States

**Background:** Cancer and its treatments can significantly affect appearance and body integrity. A number of studies have explored the impact of cancer and its treatment on body image, primarily in head and neck and breast cancer. Our aim was to examine the utility of a single question for measuring body image dissatisfaction in patients with advanced cancer by evaluating its screening accuracy compared to the Body Image Scale (BIS). We also examined associations between body image dissatisfaction, investment in appearance and symptom distress.

**Methods:** Outpatients with advanced cancer were recruited (N=81). Assessments included BIS, Appearance Schema Inventory (ASI-R), Edmonton Symptom Assessment System (ESAS) with a total symptom distress score (TSDS) and two subscale scores (physical distress, PHS and psychological distress, PSS), Hospital Anxiety Depression Scale (HADS) and one question assessing the overall appearance satisfaction from the Multidimensional Body-Self Relations Questionnaire (MBSRQ). We also asked patients to rate the body image changes importance compared with 5 symptoms (pain, fatigue, depression, insomnia, lack of appetite).

**Results:** Forty-seven (58%) patients had a BIS score >10 (body image dissatisfaction) with a median of 11 (Q1-Q3, 5-16) and the median ASI-R was 3.1(2.8-3.5). Sensitivity and specificity of ≤ 3 for body image dissatisfaction in the single overall appearance question using the BIS as a standard was 0.70 and 0.71, respectively. BIS score was significantly correlated with ASI-R (r=0.248; p=0.025), age (r=-0.225; p=0.043), HADS-A (r=0.522, p<0.001), HADS-D (r=0.422, p<0.001), PSS score (r=0.371, p<0.001), PHS score (r=0.356, p<0.001), TSDS score (r=0.416,p<0.001), and the overall appearance question (MBSRQ; r=-0.449, p<0.001).

**Conclusion:** Body image dissatisfaction was frequent and associated with symptom burden. A single item ≥3 has a sensitivity of 70% for body image satisfaction screening.

**Abstract number:** FC35
**Abstract type:** Oral

**Adrenal Insufficiency in Palliative Care Patients. Is a Routine Screening Reasonable?**

Schmidmayr B., Stepan V., Brunner C., Schmidt E., Amschl-Strablegg D.

Krankenhaus der Elisabethinen, Palliative Care Unit, Department of Internal Medicine, Graz, Austria

**Aims:** Adrenal insufficiency (AI) is a rare disorder and is associated with high morbidity and mortality, but if diagnosed it can easily be treated, and Quality of life can be improved immediately.

In 2012 two cases of AI were diagnosed at our palliative care unit (PCU). The aim of this prospective, observational cohort study was to evaluate the prevalence of AI in this specific population by a routine screening.

**Methods:** Inpatients without current cortisol treatment between January and June 2013 (n=56) were included. The morning serum cortisol concentration was measured. A morning serum cortisol of less than 3 µg/dl was thought to be strongly suggestive for AI. In patients with a serum cortisol between 3 and 10 µg/dl an additional ACTH stimulation test was performed.

**Results:** None of the patients showed a morning cortisol level below 3 µg/dl. Only two patient showed a cortisol level between 3 and 10 µg/dl, the ACTH stimulation test
in those patients showed an adequate response. Elevated basal cortisol levels were observed in 35 out of 56 patients (63%). 19 patients died during their hospital stay, 16 of those patients showed abnormally high levels. All patients with cortisol levels above 50 μg/dl (n=6) died during their hospital stay.

Conclusion: The data from this study does not support a routine screening for AI in palliative care patients. Patients with known metastatic cancer should be screened for adrenal metastases and eventually AI, because diagnosis is relatively easy and treatment can be of great symptomatic improvement for these patients.

Notably about 63% of the tested patients had abnormally high levels of serum cortisol, and this was related to increased mortality during the hospital stay. Surprisingly, patients with cortisol level above 50 μg/dl showed a mortality rate of 100%. To evaluate serum cortisol as a possible mortality marker in palliative care patients further prospective studies seem warranted.

Abstract number: FC36
Abstract type: Oral
Prospective Study of Sleep Disturbance: Frequency, Predictors and Validation of Edmonton Symptom Assessment Scale (ESAS) Sleep Item as a Screening Tool for Sleep Disturbance in Patients with Advanced Cancer

Yennu S.1, Balachandran D.2, Pedraza Cardozo S.L.1, Berg E.1, Chisholm G.B.1, Reddy A.1, DeLaCruz V.1, Marin A.M.1, Williams J.L.1, Bruera E.1

1MD Anderson Cancer Center, Palliative Care and Rehabilitation Medicine, Houston, TX, United States, 2MD Anderson Cancer Center, Pulmonary Medicine, Houston, TX, United States, 3MD Anderson Cancer Center, Biostatistics, Houston, TX, United States

Aims: Sleep Disturbance (SD) is a severe debilitating symptom in advanced cancer patients (ACP). Unfortunately, most instruments for SD assessment include multiple questions. ESAS includes a sleep quality question. The aim was to determine the optimal cutoff score for SD screening for ESAS sleep item using Pittsburgh Sleep Quality Index (PSQI) as a gold standard. We also determined the frequency of obstructive sleep apnea and restless leg syndrome (RLS) using STOP-Bang Scoring Model (SBS), Screening for RLS, and the association of SD, as measured by the PSQI and ESAS Sleep item with other symptoms on ESAS, SBS, RLS, Epworth sleep scale and HADS.

Methods: We prospectively assessed 180 consecutive ACP at a tertiary cancer hospital. After obtaining signed consent, the patients completed previously mentioned tools. The PSQI was also assessed in the last 24hrs. Data was analyzed as training(2/3rds) and validation sets (1/3rd).

We determined epidemiological performance, Receiver Operated Characteristics, and spearman correlations of SD.

Results: Of the 180 patients assessed, 51% were female, SD was found in 62% ACP, median ESAS Sleep was 5; and PSQI 30 days was 8. ESAS sleep item ≥ 4 had a sensitivity of 74% & 80% and specificity of 71% and 64% in the training and validation samples, respectively. The frequency of Sleep apnea was 61%; and RLS was 38%. SD was associated (ESAS Sleep[r, p-value] with pain(0.4, < 0.0001); fatigue(0.35, < 0.0001); depression(0.20, 0.006); anxiety(0.385, < 0.0001); drowsiness(0.385, < 0.0001), shortness of breath(0.24, < 0.0014); anorexia(0.32, < 0.0001), Feeling of well-being(0.36, < 0.0001). Multivariate analysis found no independent predictors except ESAS feeling of well-being(OR 1.237, p=0.021), PSQI 24hrs(OR 1.52, p=0.0001), Sleep apnea(OR 0.24, P=0.002). There was no association between SD and overall survival.

Conclusion: SD is frequent, SA and RLL are frequently underdiagnosed and ESAS SD item ≥ 4 is valid for SD screening.

Epidemiology and public health

Abstract number: FC37
Abstract type: Oral
The Changing Demographics of Inpatient Hospice Deaths. Population Based Study in England 1993-2010

Sleeman K.E.1, Ho Y.K.1, Verne J.2, Gao W.1, Higginson I.J.1, GUIDE_Care Project

1King’s College London, Dept of Palliative Care Policy and Rehabilitation, London, United Kingdom, 2Public Health England, Knowledge and Intelligence Team (South West), Bristol, United Kingdom

Background: For decades, policy makers have emphasised the need for equality in end of life care. Studies in the UK and abroad have repeatedly, though somewhat inconsistently, demonstrated inequality of hospice provision with respect to age, diagnosis and socio-economic status.

Aim: To describe the demographic factors associated with inpatient hospice death, and how these have changed over time.


Participants: Adults aged over 16 who died in an inpatient hospice unit in England, 1993-2010.

Results: There were 393,758 deaths in inpatient hospice units from 1993-2010. The mean age was 69.7 (SD 12.6), and 50.5% were men. The majority of deaths were from cancer (95.2%). The annual number of hospice deaths increased from 17,279 in 1993 to 24,071 in 2010. Compared with 1993-1995, hospice decedents in 2006-2010 were 1.16 (95% CI 1.14 to 1.17) times more likely to have non-cancer diagnoses, and 1.15 (95% CI 1.13 to 1.17) times more likely to be in the oldest age group (over 80 years). The likelihood of hospice decedents residing in the least deprived areas increased over time (PR 1.13, 95% CI 1.12-1.15).

Conclusion: Although there has been a modest increase in the likelihood of hospice decedents having non-cancer diagnoses and being over 80 years, these groups remain underrepresented. The increasing association between hospice death and living in areas of least deprivation requires further exploration.

Funding: NIHR HS&DR programme (project number 09/2000/58).

Abstract number: FC38
Abstract type: Oral

Cost Analysis of Hospital Inpatient Palliative Care Consultation for Patients with Advanced Cancer

May P.1,2, Garrido M.1,3, Kelley A.1, Stefanis L.1, Meier D.1, Morrison R.S.1

1Icahn School of Medicine at Mount Sinai, Brookdale Dept of Geriatrics and Palliative Medicine, New York, NY, United States, 2Trinity College Dublin, Centre for Health Policy and Management, Dublin, Ireland, 3James J Peters VA Medical Center, GRECC, Bronx, NY, United States

Aims: To evaluate the impact of inpatient palliative care consultation (PCC) on hospital costs for patients with advanced cancer.

Methods: A prospective, observational, multi-site study collected financial and clinical data on patients with advanced cancer admitted to four hospitals in the United States from 2007 to 2011. Propensity scores were calculated on the basis of observed co-variates to match patients who received a PCC with those who received usual care (UC) only. Following data cleaning and matching, the sample size was 1,023 patients (n=288 for PCC; n=735 for UC). Generalized linear models were estimated using demographic, social and clinical covariates as independent variables, and cost during hospital admission as the dependent variable. These models were applied for the whole sample, and re-run for sub-populations stratified by survival/death, hospital site, primary diagnosis and length of stay.

Results: Preliminary results suggest that costs were lower for the intervention group (p< 0.01) and this effect is consistently statistically significant across all four sites. It is also significant for specific diagnostic sub-populations.

Conclusion: Preliminary results suggest that PCC reduces costs for hospital treatment for patients with advanced cancer, and this effect is consistent across key sub-populations.

Abstract number: FC39
Abstract type: Oral

Child and Adolescent (0-17y) Deaths in Portugal (1987-2011): Epidemiology, Complex Chronic Conditions and Place of Death

Lacerda A.1,2, Gomes B.2

1Portuguese Institute of Oncology, Pediatrics, Lisboa, Portugal, 2King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

Background: Portugal (PT) is one of 14 European countries without recognised provision of pediatric palliative care. To inform service planning it is urgent to evaluate needs.

Aims: To examine the epidemiology of dying for children and adolescents in PT, focusing on deaths due to complex chronic conditions (CCC), to understand trends in place of death and determine factors associated with home death (HD).

Methods: Death certificate data of all deaths ages 0-17y in 1987-2011 in PT (n=38,870). Cause of death was recorded into CCC (cancer, neuromuscular, cardiovascular, respiratory, renal, gastrointestinal, metabolic, hematology & immunodeficiency, other congenital & genetic), other medical causes and trauma. Multivariate logistic regression identified factors associated with HD.

Results: Annual deaths decreased from 3,268 in 1987 to 572 in 2011 (crude mortality rate from 118 to 30:100,000). 48.8% were under 1y (31.5% neonates). 27.2% (n=10,571) were due to CCC (increasing from 23.7 to 33.4%), the most frequent being cancer (26.6%) Of these, 19.4% occurred at home (decreasing from 35.6% to 11.5%, with yearly fluctuations), 79.3% in hospital/clinic, 1.3% elsewhere. In multivariate analysis only year of death, age band, semester of death and area of residence by NUTS 3 retained significance for association with place of death. HD odds decreased by year of death (AOR 0.90, 95%CI 0.89-0.91), and were higher for age 6-10y (24.50, 19.19-31.26), death in Autumn-Winter (1.18, 1.06-1.32) and Serra da Estrela (22.14, 11.09-44.21).

Conclusions: While pediatric deaths are increasingly rare in PT, those due to CCC have increased from 1/4 to 1/3 of all deaths in the last 25y. The HD proportion for those dying from CCC remains low (1 in 9 in 2011), with a long-term trend of death away from home.
Alongsie regional and seasonal differences, age needs to be considered in the development of policy and services to facilitate HD for families who wish so.

Funding: Gulbenkian Foundation

Abstract number: FC40
Abstract type: Oral

Could Selected Patients with Advancing Chronic Obstructive Pulmonary Disease Benefit from Early Palliative Care

Snow R.J., Vogel K.L., Ferris F.D., Harrold B., Vanderhoff B.

OhioHealth, Clinical Transformation, Columbus, OH, United States, OhioHealth, Pulmonology, Grant Medical Center, Columbus, OH, United States, OhioHealth, Administration, Columbus, OH, United States

Background and aim of the study: Healthcare inefficiencies are under focus through value-based delivery systems. To examine the potential role for early palliative care in patients with chronic obstructive pulmonary disease (COPD), the associations between utilization and comorbid factors, and readmission risk were studied.

Methods: In a retrospective cohort study, the associations between a readmission after an index hospitalization and comorbid and utilization factors were evaluated for all patients with COPD admitted to four hospitals in central Ohio during 1 year. Episodes of care were constructed using an index hospitalization. Patient’s utilization patterns and comorbid disease prior to the index were used as risk factors. Comorbid diseases were quantified using the Agency for Healthcare Research & Quality (AHRQ) clinical classifications. Prior resource utilization was classified as the number and frequency of emergency visits, admissions and observation bed use. Associations between previous utilization patterns and comorbidities were investigated using a multivariate model.

Results: During this year, there were 1121 COPD discharges. Patients with no prior history of hospitalization had a 17.9% readmission rate and a density of 22 per 100 discharges. Those with a prior history of hospitalization had a readmission rate of 49% and density of 82 per 100 discharges. A multivariate analysis provided independent odds ratios ranging from 5.9 for readmission of patients with an active cancer diagnosis (~600% increase risk), to 1.5 for patients with anxiety disorders (50% increased risk). Previous hospitalization alone was associated with 12% increased risk of readmission. The model is associated with an ROC of 0.72.

Conclusions: Various comorbidity and utilization factors can predict risk of readmission and identify patients who may benefit from early referral to palliative care. These models warrant further study to improve patient experiences and healthcare delivery.

Abstract number: FC41
Abstract type: Oral

International Study of Place of Death (IPoD) on COPD and Lung Cancer Patients


Vrije Universiteit Brussel(VUB) and Ghent University, End-of-Life Care Research Group, Brussels, Belgium, National Observatory of End of Life Care, Paris, France, University of Southampton, Health Sciences, Southampton, United Kingdom, Cancer Prevention and Research Institute, ISPO, Clinical and Descriptive Epidemiology Unit, Florence, Italy, The University of Texas MD Anderson Cancer Center, Houston, TX, United States, EMGO Institute for Health and Care Research, Public and Occupational Health, and Palliative Care Expertise Centre, VU Medical Centre, Amsterdam, Netherlands, Hospice Waikato, Waikato, New Zealand, Ministry of Health, Government of Andalusia, Seville, Spain, University of Alberta, Faculty of Nursing, Edmonton, AB, Canada, International Observatory on End of Life Care, Lancaster University, Faculty of Health and Medicine, Lancaster, United Kingdom, University of Pécs Medical School, Hungary, Pécs, Hungary, Dongduk Women’s University, Health Sciences, Seoul, Korea, Republic of, Brown University, Community Health, Providence, RI, United States, Vrije Universiteit Brussel(VUB), Department of Family Medicine, Brussels, Belgium

Aims: To examine differences in place of death between patients with chronic obstructive pulmonary disease (COPD) and lung cancer in 14 countries, controlling for confounding factors.

Methods: Full population death certificate data for 2008 were collected from 14 countries (France, Italy, Spain, Belgium, the Netherlands, Czech Republic, Hungary, England, Wales, New Zealand, Canada, United States, Mexico and South Korea) and pooled into a common database containing place of death, underlying cause of death and socio-demographic information. Patients dying from lung cancer (ICD-10: C33-C34) or COPD (J40-44,J47) were selected. Descriptive statistics and multivariate binary logistic regressions were performed.

Results: Of all deaths (N=5,568,827), 5.8% were from lung cancer and 4.4% from COPD. Among lung cancer patients, the proportion dying at home ranged from 12.5% in South Korea to 57.1% in Mexico; in hospital from 27.5% in New Zealand to 77.4% in France. In COPD...
patients, the proportion dying at home ranged from 10.4% in Canada to 55.4% in Mexico; in hospital from 44.7% in New Zealand to 78.9% in South Korea. When controlling for age, sex and marital status, patients with COPD were significantly less likely than lung cancer patients to die at home (vs in hospital) in 9 countries [odds ratios from 0.3 in the Netherlands and New Zealand to 0.9 in Spain]. In England, Wales and New Zealand, lung cancer patients were considerably more likely than COPD patients to die in palliative care institutions; in the US both groups had a comparable chance.

**Conclusion:** While COPD and lung cancer have similar palliative care needs, in most countries COPD patients were less likely to die at home, possibly due to both a historical focus of palliative care on cancer as well as differences in disease trajectory and prognostication.

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**Abstract number:** FC42
**Abstract type:** Oral

**Place of Death in the Czech Republic and Slovakia: A Population Based Comparative Study Using Death Certificates Data**

Loucka M., Payne S.A., Brearley S.G.

Lancaster University, International Observatory on End-of-Life Care, Lancaster, United Kingdom

**Background:** Place of death represents an important indicator for end-of-life care policy making and is related to the quality of life of patients and their families. The aim of the paper is to analyse the place of death in the Czech Republic and Slovakia in 2011. Research questions were focused on factors influencing the place of death and specifically the likelihood of dying at home in subpopulation of patients with chronic diseases.

**Methods:** Whole population data from death certificates for all deaths in the Czech Republic and Slovakia in 2011 (N=154288) were used for bivariate and multivariate analyses. Separate analysis using binary logistic regression was conducted for subpopulation of patients who died from chronic conditions.

**Results:** The majority of the population in both countries died in hospitals (58.4% the Czech Republic, 54.8% Slovakia), less than one-third died at home. For those with chronic conditions, the chance of dying at home was significantly associated with underlying cause of death/cancer (odds ratio 1.255 in the Czech Republic and 1.304 in Slovakia), heart failure (OR 1.249 in CZ, 1.535 in SK), and Parkinson’s disease (OR 2.201 in Slovakia only), being male (OR 0.879, Slovakia only), age (“71-84 years”, OR 0.849 in CZ only, and “older than 85”, OR 1.572, in Slovakia only) and education (contradictory results between countries”higher education” OR 1.223 in CZ, and OR 0.793 in Slovakia).

**Conclusions:** Most people in the Czech Republic and Slovakia die in hospitals, although they wish to die at home. Moreover, Czech and Slovak patients with chronic conditions are more likely to die in hospitals than in some other European Union member countries. These findings should be addressed by policy makers in promoting home hospice care services and education in palliative care for staff in nursing homes and other end-of-life settings.

This study was funded by EURO IMPACT project (FP7/2007-2013, grant agreement number 264697).

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**Education research**

**Abstract number:** FC43
**Abstract type:** Oral

‘I Beg your Pardon?’Nurses’ Experiences in Facilitating Doctors’ Learning Process

Pype P.F., Mertens F., Deveugele M.

Ghent University, Ghent, Belgium

**Aims:** In Belgium, general practitioners (GPs) are assisted by nurses from specialized palliative home care teams (PHCTs) in caring for their palliative patients. Previous research indicates GPs’ learning from these nurses during collaboration (workplace learning: WPL). We trained PHCT nurses in communication techniques to facilitate GPs’ WPL behavior and process. It is not known how the nurses experience this new task and how they manage during everyday collaboration with GPs.

**Methods:** Semi-structured interviews were taken from 28 nurses one month after the training. Topics discussed: what goes well and what doesn’t; how do you feel in this new role; how does the training affect your work?

Grounded Theory analysis was done by two researchers.

**Results:** Shared themes by all nurses: Patient care as core business and Respect for other team members from whatever discipline.

Two axes were defined: from expert role to facilitator role and from patient care focused to GP relationship focused.

Crossing the axes resulted in 4 typologies of nurses: Consultant, Buddy, Supporter and Team Manager. Each had their own way of handling their tasks, roles and responsibilities.

**Conclusions:** Training of PHCT nurses added the role of ‘teacher/trainer’ to the previous role of ‘consulted expert’. This induced a tendency towards reflective practice with GPs. Some nurses mentioned a loss of spontaneity when applying certain communication techniques. Peer discussions within the nursing team helped to overcome this. The shared focus on quality of patient
care initiated collaborative discussions between nurses and GPs, resulting in mutual respect for each other’s views and responsibilities. Nurses felt more comfortable in discussing medical policy with GPs. Attention should be paid to the match of a nurse’s identity with one of the typologies.

Training PHCT nurses can foster conditions for WPL for GPs. Further research is needed to evaluate the effect on the learning outcomes of GPs.

Abstract number: FC44
Abstract type: Oral

Bus Rounds: Measuring Outcomes of a Community Model for Palliative Care Education
Zhang Y.1, Azhar A.1, Reddy S.1, Bruera E.2
1University of Texas, M.D. Anderson Cancer Center, Palliative Care & Rehabilitation Medicine, Houston, TX, United States, 2University of Texas, M.D. Anderson Cancer Center, Palliative Care & Rehabilitation, Houston, TX, United States

Aim: Bus Rounds (BR) is unique education model in Palliative Care (PC) where all the participants listen to case presentations by earphones and discuss PC issues while traveling between home visits. The purpose of our research is to report the evaluation by participants in BR.

Methods: Retrospective review of anonymous surveys completed by participants of BR from 2005-13. All the participants completed evaluation questionnaires at the end of BR. Assessment forms were different for 2005-10 and 2011-13.

Results: During 2005-13, there were a total of 33 BR with 106 patients and 690 participants with a mean of 21 participants per BR (including faculty). Participants were physicians 106/417(25%) and other professionals 311/417(75%). Overall satisfaction (Strongly agree + Agree) results: “Time well spent” 250/255(98%), “Help better manage patients” 233/252(92%) and “BR effective teaching tool” 250/253(99%). Satisfactions (Strongly agree + Agree) during 2011-13: “the organization and quality of BR met my expectations” 176/180(98%). And “Manage the complex symptoms” 191/196(97%), “Increased understanding & sharing of best practices in PC” 191/197(97%) and “How to discuss issues with interdisciplinary team” 185/190(97%).

Conclusion: BR is a very effective interactive community educational tool used to teach participants on issues of PC both at bedside followed by discussion on the bus. Our nine-year results show that BR was evaluated as an effective teaching method of PC. A broad range of themes were addressed and the participants reports high levels of leaning and satisfaction.

Abstract number: FC45
Abstract type: Oral

The Importance of Advance Care Planning for Seriously Ill Patients. A Qualitative Study of Doctors’ Experiences about Admission to Intensive Care
Cullati S., Hudelson P., Ricou B., Nendaz M., Perneger T.V., Dayer P., Escher M.
University Hospitals of Geneva, Geneva, Switzerland

Introduction: Triage of patients at high risk of death within 12 months to intensive care (ICU) is a difficult task. Doctors have to assess and balance medical and non-medical factors. This multifaceted process involves both the referring doctor and the ICU doctor.

Aim: To describe the experiences of ICU and internal medicine doctors about patient admission to ICU, and to determine what facilitates and what hinders the decision-making process.

Methods: Individual, in-depth interviews with 12 ICU and 12 internal medicine doctors working in the University Hospitals of Geneva. Doctors were asked to reflect on their experiences of ICU admission decision-making, and to specifically recall two clinical situations in which they were involved, and comment on them. Interviews were analyzed using a thematic approach.

Results: Both ICU and internal medicine doctors mention that the decision-making is usually a smooth process. Clinical situations are described as difficult when the admission decision is not straightforward due to medical or contextual factors. Doctors then speak of “a grey zone”. Identified factors that influence the perceived difficulty of decision-making are associated with the clinical situation (e.g. clarity of the objectives of medical treatment, family opinion), with the work environment (e.g. ICU bed availability, management of patient risk), and the doctors’ respective experience. The quality of interaction between the doctors, described in terms of mutual expectations, empathy and collaboration, was considered important by both ICU and internal medicine doctors.

Conclusion: Some factors associated with perceived difficult ICU admission decisions are amenable to change but others are not. Our findings suggest that promoting advance care planning in order to define clear goals of care and teaching communication skills could be target areas to improve the decision-making process of intensive care admission for seriously ill patients.

Abstract number: FC46
Abstract type: Oral

Impact of Palliative Care Rotation in Core Skills of Medical Students and Residents
Carneiro R.M.P.1, Costa I.1, Monteiro C.1, Andreia T.2, Silva P.1, Ferraz Gonçalves J.1
Institute of Public Health, Cambridge, United Kingdom

Barclay S., Gardner A.C.

Thiemann P., Quince T., Parker R., Benson J., Wood D.,

Students

Abstract type:

Abstract number:

Oral

FC47

Attitudes towards End of Life Care among Medical Students

Thiemann P., Quince T., Parker R., Benson J., Wood D.,

Barclay S., Gardner A.C.

University of Cambridge, The Primary Care Unit,

Institute of Public Health, Cambridge, United Kingdom

Background: Medical student End of Life Care (EOLC) education is increasingly recognised as important. Knowledge concerning drugs and services and communication skills are addressed. Although influencing behaviour in clinical practice attitudes are rarely considered. Little is known about medical students’ attitudes towards EOLC, how these change over time and what determines them. This study examined medical students’ attitudes towards EOLC and the impact on these of gender, age, spirituality, personal loss, death anxiety (DA) and empathy.

Methods: Four cohorts of core science and clinical students at the University of Cambridge Medical School (N=1027) took part in a longitudinal questionnaire survey that included Sullivan’s attitudes towards EOLC, Collet Lester Fear of Death Scale, Empathic Concern Scale of Davis’s Interpersonal Reactivity Index, Spirituality and Experience of Personal Loss items. Logistic and ordinal mixed effects regression analyses were undertaken.

Results: At the start of their course students’ attitudes towards EOLC in different domains (doctor’s responsibility, psychological aspects for patients, personal impact) were largely positive. No marked change was observed by the final year. Gender did not influence attitudes or their change. DA was found to be a significant predictor of negative attitudes towards the personal impact of EOLC in the first year (p<.001; NagelkerkerR²=.06–.20) as well in the final year. Higher DA resulted in greater concerns. Results for the other domains of EOLC were inconclusive.

Conclusion: Medical students’ attitudes towards EOLC were broadly positive at the start and the end of their course. But teaching faculty still need to foster positive attitudes towards EOLC and counter negative attitudes during medical school. Seeking to reduce DA would diminish concerns about the future personal impact of providing EOLC. Nevertheless more research needs to be done to better understand students’ attitudes towards EOLC.

Abstract number: FC48

Abstract type: Oral

Does an Online ‘Qstream’ Education Module Impact on Palliative Care Nurses’ Pain Assessment Competencies and Patients’ Reports of Pain? Results from a Quasi-experimental Pilot Study

Phillips J.L.¹, Heneka N.², Shaw T.³

¹The University of Notre Dame Australia and The Cunningham Centre for Palliative Care, School of Nursing, Sydney, Australia, ²Cunningham Centre for Palliative Care, Sydney, Australia, ³Sydney University, Sydney, Australia

Background: Pain is a complex phenomenon moderated by consumer, provider and health system factors. Despite pain management being core business for palliative care clinicians there is poor compliance with recommended routine pain screening and assessment practices in this setting.
Aim: To test the impact of an online ‘Qstream’ pain assessment learning module on specialist palliative care nurses’ pain assessment competencies, and on palliative care patients’ reported pain ratings.

Methodology:
Study design: Quasi-experimental pilot study.
Intervention: Eleven case based pain assessment scenarios developed by an expert multidisciplinary panel, delivered to participants via ‘Qstream’, over 28 days.
Methods: ‘Self-PAC’ survey and chart audit data (n=60) collected pre (T1) and post (T2) intervention.
Statistics: Descriptive statistics, independent and paired sample t-tests and Pearson chi-square test.
Results: Participants (n=34) who completed the study were predominantly female (94%), registered nurses (88%), with a median age of 43. A significant difference was found between participants’ mean pain assessment competencies scores including knowledge: T1 (M=7.18), T2 (M=8.37), t(33) = -4.6, p< 0.001; tool awareness: T1 (M=3.14), T2 (M=6.19), t(31) = -2.9, p< 0.007; and confidence T1 (M=7.47), T2 (M=9.34), t(31) = -2.9, p< 0.007. There was a significant reduction in the mean patient reported pain ratings between admission and audit date at T2 (M=2.4) compared to T1 (M=3.9) (t=1.51,df= 82, p< .0010), representing a reduction of 1.5 (95% C.I.=0.7-2.3) units in pain score.
Conclusion: This study has demonstrated ‘Qstream’s’ capacity as a learning format that is capable of increasing nurses’ pain assessment capabilities and impacting positively on patient reported pain outcomes. An adequately powered larger pragmatic trial is required to confirm these results with a larger sample.

Funding: The Curran Foundation; St Vincent’s Clinic Multi-disciplinary Research Grant.

Bereavement and family care givers
Abstract number: FC49
Abstract type: Oral

Challenges to Implementing Comprehensive Carer Assessment in Palliative Home Care: Findings from a Cluster Trial
Ewing G.1, Austin L.2, Grande G.2
1University of Cambridge, Centre for Family Research, Cambridge, United Kingdom, 2University of Manchester, School of Nursing, Midwifery and Social Work, Manchester, United Kingdom

Background: The Carer Support Needs Assessment Tool (CSNAT) is evidence based and comprehensive. It structures an assessment process that enables carers to consider, express and prioritise support needs, then together with a practitioner develop a shared action plan of support for needs identified. Previously reported research shows added benefits from CSNAT use for carers and practitioners.

Aim: To identify factors hindering implementation of CSNAT in routine palliative home care practice to inform CSNAT trial results.

Method: CSNAT was implemented in six palliative home care services as part of a stepped wedge cluster trial to test if it led to improved carer outcomes. CSNAT use was monitored. Qualitative data were collected from all trial sites on practitioners’ experiences of using the tool in practice (ongoing) using field notes (from CSNAT training sessions, post training feedback sessions, monthly contacts with CSNAT ‘champions’), focus groups and interviews with practitioners and service managers.

Results: Use of the CSNAT was low. Despite a palliative care remit that includes carers, practitioners’ main focus and time was on patients’ needs. A paradox existed between a policy of ‘being there for the family’ not just the patient, and concerns about doubling workload if carers’ needs were also assessed. Seeing carers’ needs as distinct from patients’ was problematic during joint assessment visits, particularly relating to carers support needs around patient care eg with managing medicines, areas also discussed with patients. CSNAT was used as an ‘add on’ to usual practitioner-led practice: a form to be completed at the end of a visit rather than an integrated carer-led approach. Finally, service structures, procedures and the trial itself presented additional barriers.

Conclusion: Barriers to CSNAT uncovered in the trial provide key insights into challenges for implementing comprehensive assessment of carer needs in palliative home care.

Funder: NIHR RfPB

Abstract number: FC50
Abstract type: Oral

‘We’re All Kind of Carrying a Burden that we’re Not Sharing among Each Other’- A Qualitative Study of the Impact of Cutaneous T-Cell Lymphoma on the Family
Selman L.1, Harding R.1, Beynon T.1, Radcliffe E.1, Whittaker S.2, Orłowska D.2, Child F.2
1King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, London, United Kingdom, 2St. John’s Institute of Dermatology, St. Thomas’ Hospital, London, United Kingdom

Background: Cutaneous T-cell lymphoma (CTCL) is an aggressive, often disfiguring cancer with profound negative impact on patients’ quality of life. While CTCL is known to affect interpersonal relationships, little is known...
regarding the needs and experiences of patients’ families.

**Aim:** To describe the impact of CTCL on the family and how it copes with and adjusts to this impact, to inform support services for this neglected group.

**Methods:** Semi-structured qualitative interviews were conducted with current carers of patients with CTCL. Interviews covering patient’s illness history, experiences of care giving and impact on the family/ everyday life were recorded, transcribed and imported into NVivo. Thematic analysis was in two stages:

1. inductive coding of the data;
2. appraisal of the coding frame using Patterson’s Family Adjustment and Adaptation Response (FAAR) model and analysis using the model.

On the FAAR model, adjustment and adaptation depends on how a family uses its capabilities (resources/coping) to meets demands (stressors/strains).

**Results:** 15 caregivers participated: 12 spouses, 1 friend and 2 daughters; 4 men; age 39-85. Key themes:

1. Demands of CTCL (the disease, demands of caregiving, financial impact, physical/emotional intimacy);
2. Family capabilities (family support, information, healthcare providers’ support);
3. Adjustment and adaptation (acceptance, changes in patient-caregiver relationship/family dynamics).

Carers described the difficulty of witnessing their loved one struggle with illness. CTCL played a central role in carers’ lives, particularly in relationships, communication and intimacy. Expert patient care and psychological support for carers was not locally available but urgently needed.

**Conclusions:** Findings demonstrate how CTCL affects the family, provide evidence to guide support, and highlight factors related to resiliency in families coping with illness. Psychological care and peer support for families are needed locally.

**Abstract number:** FC51
**Abstract type:** Oral

**Potential Impact of Health-care and Family-related Factors on Self-injury in Youths who Lost a Parent to Cancer: A Nation-wide Study**

**Brylund Grenklo T.** 1, 2, Kreichbergs U. 1, 2, Valdimarsdóttir U.A. 5, Nyberg T. 1, Steineck G. 1, 6, Fürst C.J. 1, 5

1Karolinska Institutet, Clinical Cancer Epidemiology, Stockholm, Sweden, 2Stockholms sjukhem Foundation, Stockholm, Sweden, 3Sopiahemmet University College, Stockholm, Sweden, 4Karolinska Institutet, Dept of Women’s and Children’s Health, Stockholm, Sweden, 5University of Iceland, Centre of Public Health Sciences, Rejkjavik, Iceland, 6Sahlgrenska Academy, Division of Clinical Cancer Epidemiology, Gothenburg, Sweden, 7Lund University, Dept of Oncology, Lund, Sweden, 8Karolinska Institutet, Dept Oncology Pathology, Stockholm, Sweden

**Aim:** Self-injury, a manifestation of severe psychological distress, is increased in youths who lost a parent to cancer during teenage. The aim of this study was to explore the impact of potentially modifiable factors related to parental disease, health-care and death (here referred to as health-care related factors) and the family around the time of loss (here referred to as family-related factors), on the risk of self-injury in parentally cancer-bereaved youths.

**Method:** In a Swedish nationwide population-based anonymous survey, 622 out of 851 (73%) cancer-bereaved youths aged 18 to 25 who six to nine years earlier, as teenagers aged 13 to 16, had lost a parent to cancer, answered questions about self-injury, parental disease, health-care, death and the family.

**Result:** In univariable analysis the risk of self-injury was statistically significantly increased (i.e. 95% Confidence Interval [CI] excluding 1.0) among cancer-bereaved youths who reported poor family cohesion before (Relative Risk [RR], 3.4, CI, 2.5-4.6) and after the loss (RR, 3.3, CI, 2.4-4.4), respectively; who had no or little trust (distrust) in the care provided to the dying parent (RR, 1.7, CI, 1.2-2.4); who perceived poor health-care efforts to cure (RR, 1.5, CI, 1.1-2.1) and poor efforts to prevent suffering (RR, 1.6, CI, 1.1-2.4); who reported that at least one of their parents had been depressed or had other troubles in life (RR, 1.5, CI, 1.1-2.1); and in those who three days before the loss still thought the disease was curable (RR, 1.6, CI, 1.1-2.3). Poor family cohesion before and after the loss, respectively, remained statistically significantly associated with self-injury while the associations for health-care related factors were attenuated in multivariable models including family cohesion.

**Conclusion:** Poor family cohesion before and after the death of a parent to cancer is associated with an increased risk of self-injury in teenage children.

**Abstract number:** FC52
**Abstract type:** Oral

**A Retrospective UK National Cohort Study of Cohabitees Living with Terminally Ill Patients with Cancer, Chronic Obstructive Pulmonary Disease, and Dementia**

**Sampson E.L.** 1, Lodwick R.K. 1, Low J. 1, Candy B. 1, Rait G. 2, King M. 3, Petersen I. 2

1University College London, Marie Curie Palliative Care Research Unit, London, United Kingdom, 2University
Abstracts

College London, Research Department of Primary Care and Population Health, London, United Kingdom, 1University College London, Mental Health Sciences Unit, London, United Kingdom

**Aims:** There have been few epidemiological studies of informal carers of people who are dying in the UK. We aimed to describe the characteristics of cohabitees of people dying with cancer, chronic obstructive pulmonary disease (COPD), and dementia.

**Methods:** Routinely-collected primary care data from The Health Improvement Network (THIN) database was used, which covers approximately 6% of the UK population. Patients were initially identified who had diagnoses of lung or colorectal cancer, COPD, or dementia, and who died between 2003-2012 aged 40 or over. The cohabitee cohort was constructed by identifying those recorded as being in two-adult households on the date of death, with a maximum age difference between patient and cohabitee of 15 years. Analysis was restricted to cohabitees aged 60 or over.

**Results:** In total, 15,540 individuals were included in the cohabitee cohort (Table), two thirds of whom were female. Relatively few (964, 6.2%) were identified as carers by their primary care physicians, with this proportion highest among cohabitees of people who died with dementia (13.3%). After bereavement, a small number had been identified as no longer being a carer (171, 1.1%), again with a higher proportion among cohabitees of people who died with dementia (2.1%). We are conducting further analyses comparing health outcomes in the three groups of cohabitees.

<table>
<thead>
<tr>
<th>COPD</th>
<th>Cancer</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>6907</td>
<td>4632</td>
</tr>
<tr>
<td>Sex</td>
<td>Number (%) female</td>
<td>4771 (69.1%)</td>
</tr>
<tr>
<td>Age at bereavement</td>
<td>Median (IQR) years</td>
<td>77 (72–83)</td>
</tr>
<tr>
<td>Area-level deprivation</td>
<td>Number (%) in most deprived Townsend quintile</td>
<td>980 (14.2%)</td>
</tr>
<tr>
<td>Recorded as being a carer (before bereavement)</td>
<td>Number (%)</td>
<td>294 (4.3%)</td>
</tr>
<tr>
<td>Recorded as no longer being a carer (after bereavement)</td>
<td>Number (%)</td>
<td>63 (0.9%)</td>
</tr>
</tbody>
</table>

**Conclusions:** Recording of people who care for a cohabitee at the end of life is low. This may indicate missed opportunities for support in primary care and may underestimate the contribution that informal family carers make to end of life care in the UK.

**Abstract number:** FC53

**Abstract type:** Oral

**Findings of a Community Survey of Bereavement Experience: Support for a Public Health Approach**

_Aoun S._¹, Breen L.², Rumbold B._³, McNamara B._², Hegney D._²_

¹Curtin University, School of Nursing and Midwifery, Perth, Australia, ²Curtin University, Perth, Australia, ³La Trobe University, Melbourne, Australia

**Aim:** This presentation describes the profiles of bereavement risk and support needs of a community sample in Australia and tests the fit of the data with the three-tiered public health model for bereavement support.

**Population:** People who were bereaved 6-24 months prior to the survey and who were clients of funeral providers in metropolitan and rural Western Australia and Victoria.

**Methods:** A postal survey was used to collect information on the deceased and the family carer or the closest person to the deceased, the experience of caring and satisfaction with bereavement support. The questionnaire included a validated risk assessment screening measure for Prolonged Grief Disorder, the PG-13.

**Results:** 678 bereaved people responded. Sixty percent of deaths were expected and of these about sixty percent had used palliative care services. The analysis of the demographic characteristics, experience and impact of caring and bereavement, and satisfaction with support received from a variety of services (within and outside palliative care) revealed differential experiences and needs that align with the expectation of low, moderate,
and high bereavement support need, as articulated in the public health model.

**Conclusions:** This is the first empirical test of this model nationally and internationally. As there is a lack of clear evidence to guide development and allocation of bereavement programs, findings have the potential to inform the ability of services, community organisations and informal networks to prioritise care according to each level of bereavement need. This is of utmost importance for cost-effective and equitable resource allocation.

**Abstract number:** FC54

**Abstract type:** Oral

**Measuring Family Carer Satisfaction with Palliative Care Using Famcare-2**

Aoun S.1, Kristjanson L.2

1Curtin University, Perth, Australia, 2Swinburne University, Melbourne, Australia

Measuring carers' perceived satisfaction with services is crucial if services are going to continually improve their responsiveness to the needs of those they serve.

**Aim:** The aim of this study was to assess the reliability of the next generation FAMCARE tool which was adapted to reflect inpatient and team-based care in palliative care services.

**Method:** FAMCARE-2 was distributed to a consecutive cohort of carers whilst in the caregiving role nationally in Australia. Analyses of internal consistency, generated structure and relationships of satisfaction with service provision by three demographic variables were undertaken.

**Results:** Four-hundred and ninety-seven carers were recruited from 29 palliative care services across Australia, a mix of inpatient and community services. The scale achieved a high level of internal consistency and item-to-total correlation coefficient. Factor analysis of FAMCARE-2 revealed a 4-factor structure (management of physical symptoms and comfort, provision of information, family support and patient psychological care). Results indicated satisfaction with service provision across the FAMCARE-2 subscales. However, responses revealed unmet needs relating to the provision of adequate information about the patient’s illness and emotional support provided to family carers. Females were more satisfied than males, older carers were more satisfied than younger ones and carers identifying with a particular cultural background were less satisfied than others.

**Conclusion:** FAMCARE-2 is a psychometrically sound instrument useful for measuring family carer satisfaction with service provision in a variety of palliative care settings. It has so far been translated into four European languages. To be effective, measurement of satisfaction must focus on aspects that are important to patients and carers and be responsive to improvements in service provision.

**Palliative care in specific groups I**

**Abstract number:** FC55

**Abstract type:** Oral

**Quality of End-of-Life Care in Patients with Hematologic Malignancies: A Retrospective Cohort Study**

Hui D.1, Didwaniya N.2, Vidal M.1, Shin S.H.2, Chisholm G.1, Roquemore J.1

1MD Anderson Cancer Center, Houston, TX, United States, 2The University of Texas MD Anderson Cancer Center, Houston, TX, United States, 3Kosin University, Busan, Korea, Republic of

**Aims:** Limited data is available on the quality of end-of-life care for patients with hematologic malignancies. In this retrospective cohort study, we compared the quality of end-of-life care between patients with hematologic malignancies and those with solid tumors.

**Methods:** All adult patients who died of advanced cancer between 9/1/2009 and 2/28/2010 while under the care of our institution were included. We collected baseline demographics and end-of-life care indicators, including emergency room visits, hospitalization, intensive care unit admissions, and systemic cancer therapy use within the last 30 days of life. We analyzed the data using descriptive statistics, Chi-square tests, Mann-Whitney tests, and multivariate logistic regression.

**Results:** 113/816 (14%) decedents had hematologic malignancies. In the last 30 days of life, hematologic patients were more likely to have emergency room visits (54% vs. 43%, P=0.03), hospital admissions (81% vs. 47%, P<0.001), >=2 admissions (23% vs. 10%, P<0.001), >14 days of hospitalization (38% vs. 8%, P<0.001), intensive care unit admissions (39% vs. 8%, P<0.001) and death (33% vs. 4%, P<0.001), chemotherapy use (43% vs. 14%, P<0.001), and targeted therapy use (34% vs. 11%, P<0.001) compared to patients with solid tumors. Patients with hematologic malignancies were also less likely to have palliative care unit stays (8% vs. 17%, P=0.02). The composite score for aggressiveness of care (0=best, 6=worst) was significantly higher among patients with hematologic malignancies than those with solid tumors (median 2 vs. 0, P<0.001). In multivariate analysis, hematologic malignancy was significantly associated with aggressive end-of-life care (Table).

**Conclusion:** Patients with hematologic malignancies received more aggressive care at the end-of-life.

**Funding:** Institutional grant
Table. Factors associated with aggressive EOL care.

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Odds ratio (95% confidence interval)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hematologic malignancy</td>
<td>6.63 (4.11–10.72)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age (per year increase)</td>
<td>0.97 (0.96–0.99)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Conclusions: Decisions to forgo treatment are made in a substantial proportion of older people in the Netherlands and more often than in younger age groups. Decisions could often not be discussed, which emphasises the relevance of advance care planning.

Acknowledgments: EURO-IMPACT (FP7/2007-2013, under grant agreement n° [264697]); ZonMw, the Netherlands Organization for Health Research and Development.

Abstract number: FC56
Abstract type: Oral

A Nationwide Study on Forgoing Treatment in the Netherlands: Do Incidence and Decision-making Differ for Different Age Groups?

Pereira S.M.,1 Pasman H.R.W.,1 van der Heide A.2, van Delden J.J.M.3, Onwuteaka-Philipsen B.D.4, on behalf of EURO-IMPACT

1VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, 2ERASMSU MC, University Medical Center Rotterdam, Rotterdam, Netherlands, 3University Medical Center Utrecht, Julius Center, Utrecht, Netherlands

Introduction: The ageing of the population raises the need to study end-of-life decision making for older people.

Aims: To describe the in2cidence and decision-making on forgoing potentially life-prolonging treatment and whether it differs for different age groups.

Methods: A nationwide study of a stratified sample from the death registry of Statistics Netherlands to which all deaths were reported in 2010. All attending physicians of those deaths received a questionnaire about end-of-life decisions (including withholding/withdrawing treatment and decision-making process). All cases were weighted to adjust for stratification and differences in response rates, reflecting all deaths in the Netherlands. We studied a total of 6600 cases and looked at three age groups: 80 years and over; 65-79 years; 17-64 years.

Results: A higher incidence of forgoing treatment was found among the oldest patients (42% vs. 36% and 25%). The type of treatment most frequently withheld was artificial hydration/nutrition (41% vs. 36% and 21%). Medication was the most frequently withdrawn treatment among the oldest patients (65% vs. 49% and 41%). The most common reason to make the decision of forgoing treatment was “no chance of improvement” for all age groups (72%, 69% and 77%). The decision was not discussed with the patients in respectively 57%, 58% and 59% of the cases, mostly because the patient had dementia (41% of the oldest patients vs. 21% and 8%) or was unconscious (57% vs. 74% and 86%).

Conclusions: Decisions to forgo treatment are made in a substantial proportion of older people in the Netherlands and more often than in younger age groups. Decisions could often not be discussed, which emphasises the relevance of advance care planning.

Acknowledgments: EURO-IMPACT (FP7/2007-2013, under grant agreement n° [264697]); ZonMw, the Netherlands Organization for Health Research and Development.

Abstract number: FC57
Abstract type: Oral

Palliative Care and Phase I Cancer Trials: Irrelevance, Antagonism, or Synergy?

Cassel B., Del Fabbro E.

Virginia Commonwealth University, Massey Cancer Center, Richmond, VA, United States

Aims: To explore ways of making the case for palliative care involvement in phase I cancer trials.

Methods:

1) A systematic review was conducted of studies that were retrospective re-analyses of data from multiple (pooled) phase I trials, focused on survival and prognostic factors.
2) The menu of phase I trials at our cancer center was analyzed from the past 4 years regarding likelihood of symptom incidence from agents used.

Results: Systematic review: 337 potential articles identified through PubMed using MeSH terms; another 46 identified through other means; 360 without duplicates. 322 excluded; 37 met criteria for evaluation of survival; and 23 met criteria for evaluation of prognostic factors. Patients had median survival 5.010.6 months; 90 day mortality 9.7%27%. Most patients have good performance status at the time of enrollment (ECOG PS 0 or 1, Karnofsky >70%); 0%-27% of patients in phase 1 trials had worse PS. 10 / 37 articles have discussion of ethical issues (risks, benefits, consent). Only 2 studies discussed palliative / supportive care; 0 discussed hospice; 2 mentioned pain or fatigue; 0 discussed distress; and 0 discussed end-of-life issues.

Trial & agent analysis: The agents used in 28 solid tumor drug trials that were relevant to patients with advanced disease were reviewed using an online repository of side effect and symptom incidence. All 28 (100%) had >10% risk of causing at least one symptom. Over 4-year period, 155 patients were enrolled in those 28 trials. More than half of subjects would be exposed to >10% risk of specific symptoms such as nausea, vomiting, diarrhea, pain, fatigue, and skin.

Conclusions: The relevance of palliative care for phase I patients is driven by two factors: advanced disease state, and symptom risk from agents used. Further research could
lead to ways to improve patient reported outcomes as well as to help ensure the efficiency of the phase I process.

Abstract number: FC58
Abstract type: Oral
Variation in Care and Support Needs of Patients with Advanced COPD Baseline Data from an Ongoing Longitudinal Study of Trajectories of Need
Farquhar M.C., Moore C., Gardener C., Holt Butcher H., Ewing G., White P., Burge P., Living with Breathlessness Study Team

1 University of Cambridge, Public Health & Primary Care, Cambridge, United Kingdom, 2 University of Cambridge, Cambridge, United Kingdom, 3 King’s College London, London, United Kingdom, 4 RAND Europe, Cambridge, United Kingdom

Background: Chronic obstructive pulmonary disease (COPD) is a chronic progressive condition with high symptom-burden, accounting for one death every 20 minutes (England and Wales). UK strategy documents state that quality end-of-life care should be available to patients with any condition, yet we rely for this on planning tools developed for cancer with its differing trajectory. We lack fundamental research on the non-malignant disease trajectory.

Aims: To describe variation in the care needs and service use of patients with advanced COPD, sampled from a population base.

Methods: Mixed method baseline interviews with a cohort of over 200 patients recruited from primary care and their informal carers in the East of England. The cohort forms part of the Living with Breathlessness study and, as such, is being followed over time in a mixed-method 18-month longitudinal interview study involving 3-monthly semi-structured interviews with flexible methodology to capture changing function, need and service-access. Quantitative measures include: validated patient measures of function and need; lung function (spirometry); and service access. Quantitative data are analysed using descriptive statistics. Purposively sampled qualitative data are analysed using a framework approach and multiple perspective case study methodology.

Results: At the time of abstract submission baseline data collection is ongoing but due for completion by the end of November 2013. The results will highlight variation in need and in the experience and outcome of care in advanced COPD by describing symptoms and perceived needs, disease-specific health-related quality of life, service access and informal care.

Conclusions: The Living with Breathlessness study aims to provide new evidence on the trajectories of health and social care need and service access of patients with advanced COPD and their informal carers to inform a new framework for care and support in advanced non-malignant disease.

Abstract number: FC59
Abstract type: Oral
Clinical and Cost Impact of Early Palliative Care Screening and Consultation in the ICU
Zalenski R.J.1,2, Jones S.2, Courage C.1, Waselewsky D.3, Welch R.4, Kaufman D.5, ICU-PAL Project
1 Wayne State University School of Medicine, Emergency Medicine/Palliative Care, Detroit, MI, United States, 2 Tenet Healthcare, Dallas, TX, United States, 3 Wayne State University School of Medicine, Emergency Medicine, Detroit, MI, United States

There are currently no reports of clinical and cost outcomes of early systematic screening triggering formal palliative care consultation for MICU patients in a multihospital setting. A 7-item palliative care screen was used at two university affiliated and five community teaching hospitals in 3 cities. Palliative care consultation was ordered on a subset of high risk patients, with a score of 1 or more positive screen items. Using a propensity model and a regression analysis, high risk patients with and without palliative consultation were compared for DNR conversion, hospice referrals, readmissions within 30 days, length of stay, and total direct costs.

A total of 1923 patients were admitted, of which 58.9% were screened; 38% of patients screened scored positive. Patients who were high risk and received a PC consult had much higher rates of DNR, hospice referral, and lower readmissions at 30 days. Median daily costs decreased significantly soon after the start of PC consultation, regardless of the day consult began. On multivariate regression and propensity analysis, early consultation, begun at 4 or fewer days from admission, was associated with a reduction of 2.5 days (95% CI: -3.7, -1.1) LOS and $2706 less (95% CI: -4518,-464 US dollars) per admission.

Early PC consultations in patients with positive screens were associated with significant clinical and cost impact. Early PC consultation is recommended for high risk MICU patients.

Abstract number: FC60
Abstract type: Oral
Mental and Physical Health and Multidimensional Problems among HIV Outpatients in East Africa: A Multicentre Observational Study
1 King’s College London, Cicely Saunders Institute, Dept of Palliative Care, Policy & Rehabilitation, London, United Kingdom, 2 London School of Hygiene and Tropical Medicine, London, United Kingdom, 3 Makerere University, Kampala, Uganda, 4 African Palliative Medicine
Global health investment has reduced HIV mortality and transmission. However, little is known of patient-reported outcomes. This study aimed to measure multidimensional wellbeing using PROMS among outpatients at PEPFAR-funded facilities, and to determine associations with patient-reported problems.


Results: Of 1,337 participants, the majority (68.3%) were female, mean age 34.8 years. Severe problems were more common in psychological, spiritual and social domains than physical. In multivariable analysis using GEE to adjust for facility effect, mental health was lower for people with limited functional status (\(B=-5.36, 95\% \text{ CI} 0.52, 1.34, p<0.001\)) and higher for wealthier people (\(B=0.93, 95\% \text{ CI} 0.52, 1.34, p<0.001\)). Physical health was lower for those with limited functional status (\(B=-8.56, 95\% \text{ CI} -9.44 \text{ to } -7.69, p<0.001\)) and for those who had a caregiver present (\(B=-2.12, 95\% \text{ CI} -3.87 \text{ to } -0.37, p=0.017\)), higher for wealthier people (\(B=1.16, 95\% \text{ CI} 0.68, 1.64, p<0.001\)), and positively associated with CD4 count (\(B=1.60, 95\% \text{ CI} 1.08-2.13, p<0.001\)). Multidimensional problems were more burdensome for people with limited functional status (\(B=-2.07, 95\% \text{ CI} -2.47 \text{ to } -1.68, p<0.001\)), less burdensome for those with more education (\(B=0.70, 95\% \text{ CI} 0.34-1.07, p<0.001\)) or those using ART (\(B=0.94, 95\% \text{ CI} 0.34-1.53, p=0.002\)).

Conclusions: Multidimensional problems are highly prevalent, and worse with declining function. Importantly, ART use does not appear to be protective for self-reported physical and mental health. Assessment and management of self-reported wellbeing must form part of HIV care and treatment services to ensure maximum benefit from ART investment.

Ethics

Abstract number: FC61
Abstract type: Oral

Stopping Oral Palliative Anticancer Treatment: International Reflections upon Difficult Decision-making at the End of Life. A Systematic Literature Review and Narrative Synthesis

Clarke G.1, Johnston S.2, Corrie P.2, Kuhn I.3, Barclay S.4

1University of Cambridge, Institute of Public Health, Cambridge, United Kingdom, 2Addenbrooke’s Hospital, Department of Oncology, Cambridge, United Kingdom, 3University of Cambridge, Medical Library, School of Clinical Medicine, Cambridge, United Kingdom, 4University of Cambridge, Institute of Public Health, Department of Public Health and Primary Care, Cambridge, United Kingdom

Background: Current guidelines set out when to start anticancer treatments, but not when to stop as disease progresses and death approaches. Older cytotoxic agents are administered intravenously. Newer drugs, such as Tyrosine-Kinase Inhibitors (TKIs), are oral and widely used to palliate incurable disease with evidence of survival benefit of a few months. These new generation agents are considerably more expensive, around £5K per month in the UK. They are widely perceived as easier to start than to stop.

Aim: Stopping oral and parenteral palliative anticancer agents in clinical practice:

a) How are decisions made?
b) When are they made?
c) Why are they made?
d) Who makes them?


Results: 42 papers included. No studies were found concerning stopping TKIs in practice. 37 papers (88%) examined palliative chemotherapy generally, a further 2 papers (5%) contained some discussion of new agents. Key findings: Decisions are an on-going process, often involving changing drugs and breaks before stopping. In some studies, stopping was perceived as ‘biological fact’ rather than a choice, treatment was stopped when the patient became too ill. Clinical factors for stopping: disease progression, worsening functional status, side-effects and burdens. Non-clinical factors were also influential: physicians’ personal experience and emotions. Oncologists found conversations about withdrawal difficult, often experiencing ‘professional role dissonance’ between their self-perception as ‘treaters’ and talking about dying.

Conclusion: Evidence to inform decision-making is variable and absent for new generation oral agents such as TKIs. Further research is needed to inform optimal patient care in resource constrained countries. Implications for healthcare systems internationally are discussed.

Abstract number: FC62
Abstract type: Oral

Exploring Informed Consent in Patients Considering Participation in a Cancer Clinical Trial that Has Palliative Intent

Murphy M.1, Mc Caughan E.2, Wilson R.3, Fitzsimons D.1
Aim: This study seeks to understand the issues that patients with incurable cancer consider when making decisions regarding consent for a drug trial with palliative intent only.

Method: In-depth interviews were conducted with a purposive sample of 16 patients using a grounded theory approach. They were taped and transcribed before analysis using the constant comparative method.

Results: “What have I got to lose?” was identified as the main concern for patients who considered participation in a palliative clinical trial and a variety of important contextual and decision-making issues were also highlighted. These were apparent for both groupsthose who consented to a clinical trial and those who did not. Consenting patients made their decision almost instantly and were influenced by a variety of factors including, desire for increased longevity, an expectation that they would receive better attention, desire to avoid passivity and the persuasive language used by doctors and nurses during the consent process. They gave almost no consideration to the side-effects of the trial drug. Patients who declined did so after much more deliberation. They reported being unhappy about extra hospital visits and unknown side-effects of the trial drug particularly as their life span was limited. Data will be presented using patients’ verbatim comments to elucidate meaning.

Conclusion: These findings demonstrate that patients’ motivation for trial consent is complex and that they perceive themselves in a paternalistic relationship with their doctor and thus are influenced by the emotional context and language used. Consenting patients and decliners both evaluated the “risk” of trial participation in the context of a limited lifespan thinking “what have I got to lose?” Consenting patients put significant value on the trial as a vehicle of hope and personalised care from research team, whereas decliners decided they had more to lose by trial participation and opted for standard treatment.

Abstract number: FC63
Abstract type: Oral

End of Life Decisions and Advance Directives: Differences across Regions in Switzerland

Pautex S.1,2, Gamondi C.3,4, Philippin Y.5, Gremaud G.6, Herrmann F.7, Camartin C.8, Vayne P.2

1Division of Primary Care, Primary Care and Emergency, Carouge, Switzerland, 2Division of Palliative Medicine, Rehabilitation and Palliative Care, Collonge-Bellerive, Switzerland, 3Centre de soins Palliatifs, La Chrysalide, Chaux de Fond, Switzerland, 4Division of Geriatricas, Geneva, Switzerland, 5Palliativ Station, Kantonsspital, Chur, Switzerland

Introduction and objectives: The potential influence of cultures, religious and health care factors on end-of-life decisions have been suggested, but little is known about this topic in Switzerland. Aims of this study (part of a larger study) were to better understand which patient’s features impact on their decision to complete advance directives (AD) or not, to better understand their preferences about decision-making, as well as the preferences of a designated relative in different regions of Switzerland.

Method: Prospective study conducted in 4 palliative care units within three different linguistic regions. Included were patients with an advanced cancer and a MMSE>20.A structured questionnaire was completed by patients and their relative. Health care professionals (HP) of the PCU completed also a questionnaire.

Results: 143 patients have been included (mean age 68.3, 62 male, 102 Geneva-Neuchâtel, 28 Graubünden, and 13 Ticino). At the end of the study respectively 26, 15 and 0 patients had completed their ADs in Geneva, Graubünden and Ticino (P< 0.05). No other particular features were associated with the completion of ADs. One third of the patients were not worrying about their future, especially those living in the German part of Switzerland (20%; P:0.086). A fifth of patients preferred that physician takes the medical decisions alone. However, the analysis by each region shows that 75 % of the Italian speaking patients thought that physicians alone should take the medical decisions; P< 0.05. Only 29% (compared to 75% all HP) of the Italian speaking HP thought that we should always anticipate the future with patients with the fear of increasing the anxiety of the patients by talking about their disease and their future.

Conclusions: These results indicate that the recommendations for the management of patients with severe life-limiting disease and decisions-making at the end of life must be adapted according to the regions of Switzerland.

Abstract number: FC64
Abstract type: Oral

Does Knowing Patients’ Wishes Influence Nurses’ and Physicians’ Intention to Perform Euthanasia?

Lavoie M.1,2, Godin G.1, Vézina-Im L.-A.1, Blondeau D.1, Martineau I.3, Roy L.4

1Université Laval, Faculté des Sciences Infirmières, Québec, QC, Canada, 2Centre de Recherche du CHU de...
Respecting patients’ autonomy is often mentioned as one of the main reasons why certain health professionals are favorable to euthanasia. Few studies have compared whether nurses and physicians hold different beliefs towards euthanasia. The objective of our study was to experimentally test whether knowing patients’ wishes and health profession can affect intentions and beliefs regarding performing euthanasia. This was a 2 × 2 random factorial study. A clinical vignette describing the case of a person near death was used to manipulate knowledge of patient’s wishes. In one version, the patient made several explicit and documented requests for euthanasia while this information was not known in the other version. Data were collected by means of an anonymous questionnaire based on an extended version of the Theory of Planned Behavior. Random samples of nurses and physicians from the province of Québec, Canada, were obtained using random digit tables. The main outcome was nurses’ and physicians’ intention to practice euthanasia in palliative care. Other variables measured were: perceived behavioral control, cognitive and affective attitudes, subjective norm, moral norm and professional norm. The overall response rate was 41.3%. Results show that there is a significant “known wishes × profession” interaction for intention, F (3, 266) = 7.38, p = .0070, and only a known wishes effect for the other beliefs, F (6, 256) = 2.86, p = .0102. Knowing patients’ wishes regarding euthanasia appears to influence physicians, but not nurses. When patients’ wishes are unknown, physicians express a lower intention and hold less favorable beliefs towards euthanasia. This is the first study to test whether knowledge of patient’s wishes and profession influence health professionals’ intentions and beliefs regarding euthanasia. This work was supported by the Ethics Office of the Canadian Institutes of Health Research.

Abstract number: FC65
Abstract type: Oral

How Technologized Care Can Lead to Compassionate Professional Involvement: A Longitudinal, Qualitative Multiple Case Study about Teleconsultation in Palliative Home Care

van Gurp J.L.P.1, Hasselaar J.1, Vissers K.1, van Leeuwen E.2, van Selm M.3

1Radboud University Nijmegen Medical Centre (RUNMC), Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands, 2Radboud University Nijmegen Medical Centre (RUNMC), IQ Healthcare, Section Medical Ethics, Nijmegen, Netherlands, 3University of Amsterdam, Amsterdam School of Communication Research, Amsterdam, Netherlands

Research aim: To provide insight into the nature of a palliative home teleconsultation (TC) service between a specialized palliative care team and patients residing at home. Secondary objectives: to investigate

a) different uses of TC technology by patients and professionals and
b) TC technology-mediated communication between patients and professionals.

Study population, design, and methods: An embedded multiple-case study in palliative home care in the service area of RadboudUMC (Netherlands). During the courses of 18 terminal care trajectories, the experiences with teleconsultation (TC) of home-based palliative patients (18), informal carers (15), specialist palliative care team members (SPCT; 12), and general practitioners (GP; 18) were recorded in serial interviews (56) and ethnographic conversations (40). In addition, consecutive observations (129) of actual TC delivery were conducted.

Method of analysis, results and interpretation: Analysis in line with a grounded theory approach resulted in three theoretical categories: transcendence referred to the findings that TCs neutralized physical distance between home and hospital. TC technology ‘demanded’ mutually focused, personal attention, but could also intrude into condensed, virtual encounters and jeopardize patients’ privacy. TC technology’s (lack of) transparency was salient when it poorly fitted the life-worlds of vulnerable patients by reminding them of an approaching death, when it extended but at the same time limited the professional’s clinical eye, and when it made professionals experience a lack of physical proximity. Finally, TC technology enriched contact as digital engagement lead to mutual trust, intimacy, and patients experiencing relief.

We conclude with a theoretical but practical model showing TC technology’s potential to build and maintain high quality palliative patient-caregiver relationships in complex care settings, but also its potential to medicalize homes and technologize care.

Abstract number: FC66
Abstract type: Oral

Clinical Research in Palliative Care: (Diverging) Perspectives of Ethics Commissions

Alt-Epping B.1, Stiel S.2, Ostgathe C.2, Nauck F.1

1University Medical Center Göttingen, Dept. of Palliative Medicine, Göttingen, Germany, 2University of Erlangen, Dept. of Palliative Medicine, Erlangen, Germany
Background: Clinical research faces numerous methodological and ethical obstacles, many of them recognizing patients in palliative care as particularly vulnerable. The Declaration of Helsinki requires clinical research projects to be reviewed by an independent ethics commission. Experiences of palliative care study groups and research networks show that there might be some major discrepancies in assessing ethical and juridical innocuousness by ethics commissions.

Methods: We therefore performed a brief, written survey on all 51 ethics commissions in Germany, giving two characteristic study scenario vignettes and asking for an informal, brief assessment if and where those hypothetical but realistic research projects would imply formal ethical objections.

Results: 16 of 51 ethics commissions replied, ranging from short-sentence emails to complete ethical report. The appraisal of a placebo-controlled RCT in final phase patients differed substantially, ranging from complete rejection to approval under certain legal and ethical constraints. The assessment of a retrospective study requiring data from already deceased persons differed in terms of the claimed consent standards. Most respondents appreciated the need for research in palliative care, despite its particular ethical obligations.

Discussion: This non-representative prospective survey supports the assumption that ethics commissions do not always share common appraisals on research projects in palliative care. This is particularly relevant for multicenter research projects. This survey has triggered an intense and constructive dialogue between the Research Working Group of the German Association of Palliative Medicine (AG Forschung der DGP) and the Working Group of the Medical Ethics Commissions in Germany, aiming at clarifying the ethical and legal fundament and thereby promoting palliative care research.

Assessment, measurement and research methodology II

Abstract number: FC67
Abstract type: Oral

Inner Curriculum in Palliative Care Professionals: An Explicative Model of Self-awareness In Coping with Death Process

Sansó N.1,2, Galiana L.3, Oliver A.3, Barreto P.3, Pascual A.4, Barbero J.5, Fombuena M.6, Benito E.5

1Ibsalut, Palliative Care Program of the Balearic Islands, Palma de Mallorca, Spain, 2University of Balearic Islands, Palma de Mallorca, Spain, 3University of Valencia, Valencia, Spain, 4Sant Pau Hospital, Barcelona, Spain, 5La Paz Hospital, Madrid, Spain, 6Dr. Moliner Hospital, Valencia, Spain

Aims: This study is an empirical test of an adaptation of the self-awareness model of self-care1 in the Spanish context. It is hypothesized that self-awareness, self-care and specific professional training will influence the degree of professional competence coping with death, and additionally, this competence would be related to compassion fatigue, burnout risk and compassion satisfaction.

Method: Data from 420 valid questionnaires were gathered all over Spain, by online cross-sectional survey during 2013. From those responses, 387 from palliative care professionals were considered in the present research. The survey included, among others, socio-demographic questions, coping with death, three modulator variables (specific training on spirituality, self-care and awareness) and three outcome variables (compassion satisfaction, compassion fatigue and burn-out). A path analysis was estimated using maximum likelihood and robust methods with EQS 6.1 program.

Results: A path analysis hypothesizing the model adaptation was tested. The estimated model adequately fitted the data: $\chi^2_{12} = 50.888 \ (p < .01); \ CFI = .913; \ GFI = .958; \ SRMR=.061; \ RMSEA = .112$. Specific training and physical self-care did not affect coping with death, whereas inner and social self-care and awareness positively affected it. Coping with death, in turn, positively predicted compassion satisfaction and negatively compassion fatigue and burnout. Awareness also predicted these variables in the same way.

Conclusion: Results of this research empirically supported Kearney’s and Weininger’s model, offering evidence of the importance of self-awareness in self-care and for Spanish palliative care professionals.

Funding: Partially funded by SECPAL

References

Research aims: Few studies have examined variations in vital signs in the last days of life. The purpose of our study was to describe the variations of vital signs in the final 14 days of life in advanced cancer patients and to examine whether these variations were associated with impending death in 3 days.

Methods: In this prospective longitudinal study, we enrolled consecutive patients admitted to two acute palliative care units and documented their vital signs (heart rate [HR], blood pressure [BP], respiratory rate [RR], oxygen saturation and temperature) twice a day serially from admission to death or discharge. We examined the association between vital signs changes and impending death with odds ratios (ORs), and their diagnostic performance with sensitivity, specificity, and likelihood ratios (LRs).

Results: 203/357 (55%) patients died in hospital. Systolic BP (P<0.001), diastolic BP (P<0.001) and oxygen saturation (P<0.001) decreased significantly in the final 3 days of life, and temperature increased slightly (P<0.04). HR (P=0.22) and RR (P=0.24) remained similar to admission values in the last 3 days of life. HR increase >10 (OR [95% CI]: 2 [1.1-3.2]), systolic BP decrease >20mmHg (2.5 [1.4-4.7]), diastolic BP decrease >10mmHg (2.3 [1.4-4.3]) and oxygen saturation decrease >8% (3.7 [2.1-10.8]) from admission values were associated with impending death in 3 days. These changes had high specificity (>79%), low sensitivity (<36%), and modest positive LRs (<5) for impending death within 3 days. 45%, 47%, 71%, 70%, 44% and 81% of patients had normal HR, systolic BP, diastolic BP, RR, oxygen saturation, and temperature in the last day of life, respectively.

Conclusions: BP and oxygen saturation decreased in the last days of life. Clinicians cannot rely on vital sign changes alone to rule in or rule out impending death. Our findings do not support routine vital signs monitoring in patients who are imminently dying.

Abstract number: FC69
Abstract type: Oral

Assessing the Validity and Intraobserver Agreement of the MIDAM-LTC; An Instrument Measuring Factors that Influence Personal Dignity in Long-term Care Facilities

Oosterveld-Vlug M.G.¹, Pasman H.R.W.¹, Van Gennip I.E.¹, De Vet H.C.W.², Onwuteaka-Philipsen B.D.¹
¹EMGO Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Department of Public and Occupational Health, Amsterdam, Netherlands, ²EMGO Institute for Health and Care Research, VU University Medical Center, Department of Epidemiology and Biostatistics, Amsterdam, Netherlands

Aims: An instrument measuring factors that influence dignity can be used to better target dignity-conserving care to an individual patient, but no such instrument is yet available for the long-term care setting. The aim of this study was to create the Measurement Instrument for Dignity AMsterdamfor Long-Term Care facilities (MIDAM-LTC) and to assess its content- and construct validity and intraobserver agreement.

Methods: 13 items specific for the LTC setting were added to the earlier developed, more general MIDAM. The MIDAM-LTC consisted of 39 symptoms or experiences for which presence as well as influence on dignity were assessed, and a single item score for overall dignity. Questionnaires were administered at two moments (with a 1-week interval) to 95 nursing home residents residing on general medical wards of six nursing homes in The Netherlands. Ten residents answered the questions while thinking aloud.

Results: None of the 39 items barely exerted influence on dignity. Eight of them could be omitted, because the thinking aloud method revealed sensible explanations for their small influence on dignity. Hypotheses to support construct validity, about the strength of correlations between on the one hand personal dignity and on the other hand well-being, quality of life or physical health status, were confirmed. On average, 83% of the scores given for each item’s influence on dignity were practically consistent over 1 week, and more than 80% of the residents gave consistent scores for the single item score for overall dignity.

Conclusion: The MIDAM-LTC has good validity and intraobserver agreement. By omitting 8 items from the instrument, a good balance between comprehensiveness and feasibility is realised. The MIDAM-LTC allows researchers to examine the concept of dignity more closely in the LTC setting, and can assist caregivers in providing dignity-conserving care.

Main source of funding: The Netherlands Organisation for Scientific Research (NWO).

Abstract number: FC70
Abstract type: Oral

Predicting the Unpredictable? Investigating Potential Markers of Adverse Outcome in a Group of Patients who Died Following an ‘Unpredictable’ Deterioration

Etkind S.N.¹, Kario J.², Edmonds P.M.², Murtagh F.E.M.¹
¹King’s College London, Cicely Saunders Institute, Dept. of Palliative Care, Policy and Rehabilitation, London, United Kingdom, ²Kings College Hospital NHS Foundation Trust, London, United Kingdom

Background: A previous study identified a group of patients who died on medical wards following unpredictable
deterioration. These patients are less well supported by current advance care planning tools.

**Aim:** To describe a sample of patients who deteriorate unpredictably at the end of life and assess the feasibility of recording features which are associated with poor outcome.

**Methods:** Electronic patient records of patients who died in 5 hospital wards over 1 year were reviewed. An 'unpredictable' trajectory was defined as deterioration over 1 to 7 days with a new diagnosis or unexpected illness progression in a patient not expected to die.

**Results:** 31 patients followed an unpredictable trajectory. Median length of stay was 82, interquartile range (IQR) 7089. Median length of stay was 15 days (IQR 1037) and patients were admitted for median 12 days (IQR 534) before terminal deterioration. 2 patients had cancer as their main admission problem, 10 patients had a non-cancer problem and 19 patients had multiple medical problems. Mean admissions in the past year was 1.16. At admission, 9 patients (29%) had Acute Kidney Injury (AKI), 11 (35%) had delirium and 12 (39%) had falls/collapse. Median Charlson comorbidity index was 3. Our sample had higher prevalence of the above indicators than reported in the literature (AKI 7.2%, delirium 20.7% and falls 3%) and all acute medical discharges from the same hospital (AKI 7.7%, delirium 2.4%, falls 1.9%). Differences in data collection method, population characteristics and small sample size limit this comparison.

**Conclusion:** Patients who die unpredictably are admitted for several days before deteriorating. It is feasible to collect data on delirium, falls, AKI and comorbidities scores from medical records and Initial data show high prevalence of these markers associated with poor outcome. Further research should investigate the usefulness of measuring these features prospectively to help identify the unpredictably deteriorating patient.

**Abstract number:** FC71

**Abstract type:** Oral

**Assessing the Processes of Specialist Palliative Care Provision for Patients with Newly Diagnosed Lung Cancer**

*Ryan S., Ryan K.*

Mater University Hospital, Palliative Medicine, Dublin, Ireland

**Background:** Lung cancer is the leading cause of cancer mortality in the Republic of Ireland. Early access to palliative-care services is recommended for patients who cannot be offered curative treatment, as well as those with significant symptom burden. Despite the importance of this topic, only two original research papers relating to palliative care provision to lung cancer patients in the Republic of Ireland have been published. Although a number of Key Performance Indicators (KPIs) relating to palliative care have been developed internationally, none are currently in use nationally and audit has not been reported.

**Aim:** To assess the quality of care provided by a regional specialist palliative care (SPC) service to patients with newly diagnosed lung cancer in a Cancer Centre by examining processes of care provided.

**Methods:** Retrospective review of the medical records of patients newly diagnosed at the Lung Cancer Multidisciplinary Team Meetings in 2012. Data was analysed using Microsoft Excel.

**Results:** 226 patients were diagnosed with lung cancer. Median age was 70 years. 81 patients (36%) received treatment with curative intent. 145 patients had advanced disease; 114 patients were within the catchment area of our palliative care service. 95 (83%) of these were referred to SPC. The median timing of referral to SPC was 16 days after diagnosis. Median survival from date of diagnosis was 96 days. Median number of community SPC visits was 8 and 45% of patients died at home.

**Discussion:** Audit and performance indicators are important components of processes to monitor, evaluate and continuously improve quality of care but little has been presented nationally on this topic. We present findings on our regional processes of SPC provision in order to stimulate debate and reflection, thus improving quality of care provision.

**Abstract number:** FC72

**Abstract type:** Oral

**Validation Study of a Palliative Care Screening Tool for Cancer Patients**

*Glare P.1,2, Chow K.1*

1Memorial Sloan-Kettering Cancer Center, New York, NY, United States, 2Weill Cornell Medical College, Medicine, New York, NY, United States

**Aims:** Most American hospitals now have a palliative care (PC) program, but barriers still exist to prevent the timely referral of patients. Screening for PC need is one strategy for improving access. The aim of this study was to validate a screening tool (ST) in patients hospitalized at a US comprehensive cancer center (CCC).

**Methods:** Patient population: patients hospitalized under one solid tumor service at the CCC during a 3 month period.

**Study Measure:** A generic ST (recommended by the Center to Advance Palliative Care) was modified for cancer patients, with 11 scored items: advanced disease: 2 points (pt); ECOG score: 0-4 pt; life limiting complications: 1 pt; serious comorbidities (2 items): 1 pt each; and 1 pt each for: poor symptom control; moderate-severe
distress; decision making problems (patient/family; team); prolonged admission; patient/family requests consult. Total score: 0-14 pt.

Study design: ST completed once on admission by floor nurse.

Validation: Content Validity: Content Validity Ratio (CVR, range -1 to +1) for each ST item; Construct Validity: ST score vs. survival category; Criterion Validity: ST score vs. PC referral criteria developed by National Comprehensive Cancer Network (NCCN).

Results: 228 ST were scored. Median score was 4 (range 0-11, interquartile range 3-6). The CVR ratio was positive for nine of 11 items. Average ST score was higher in patients with shorter survivals (F= 28.04, df 2, p< 0.0001, see Table), and in patients meeting the NCCN referral criteria (4.8 vs. 3.5, p=0.002).

Conclusion: This scored ST appears to have good content, construct and criterion validities for identifying patients with PC needs in an American CCC. The ST’s reliability, transferability and other psychometric properties need to be tested.

### Table. Mean ST scores for different survival categories (indicating Construct Validity).

<table>
<thead>
<tr>
<th>Survival time</th>
<th>N</th>
<th>score</th>
<th>SD</th>
</tr>
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<tbody>
<tr>
<td>&lt; 3 months</td>
<td>90</td>
<td>5.3</td>
<td>2.3</td>
</tr>
<tr>
<td>3–6 months</td>
<td>35</td>
<td>3.8</td>
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<td>&gt; 6 months</td>
<td>103</td>
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</table>

### Palliative care in specific groups II

**Abstract number:** FC73  
**Abstract type:** Oral

**Patients’ and Family Members’ Decision Making and Information Disclosure Preferences: A Single-center Survey in China**

Guo H.1,2, Wei S.1, Guo Y.1, Hui D.2, Kwon J.H.2,3, Gary C.2, Bruera E.2

1Xinqiao Hospital of Third Military Medical University, Chongqing, China, 2M D Anderson Cancer Center, University of Texas, Houston, TX, United States, 3Kangdong Sacred Heart Hospital of Hallym University, Seoul, Korea, Republic of

**Aims:** Factors that influence decision making among Chinese advanced cancer patients and family members have not been studied before. In this study, we identify whether the decision making preferences are related to various factors, including financial burden.

**Methods:** Two hundreds patients with advanced cancer (local recurrence or distant metastasis) and their family members were surveyed using questionnaires, after the treatment decision had been made. Patients’ demographic information and Karnofsky Performance Scale were collected. The factors examined include the Decision Making Preferences Questionnaire, the Disclosure of Information Preferences Questionnaire, the Satisfaction with Decisions and Care Questionnaire, and the Information of patient-Doctor Form.

**Results:** The patients’ median age was 56.5 years, 28.5% female. The median Karnofsky Performance Scale score was 80. The family members’ median age was 46.5 years, 58.5% female. The types of decision making include 3 parts: passive decision (decided by other people), shared decision (decided with other people), and active decision (decided by patient him/herself). Patients’ preferences for decision making were 61 (30.5%) for passive, 135 (67.5%) for shared, 4 (2%) for active; while the family members’ preferences were 73 (36.5%) for passive, 122 (61%) for shared, and 5 (2.5%) for active decision making. In univariate analysis, lower portion payments toward medical expense by patient (P<0.001) was positively correlated with passive decision making. In multivariate logistic regression, increased portion of payment by the patient was positively correlated with a lower preference for passive decision making (OR=0.97, 95% CI 0.96-0.99).

**Conclusions:** Chinese advanced cancer patients and family members prefer to make shared decisions. The least preferred option is to make active decision. Patient-responsible financial burden correlates with patients’ desire for active decision making.

**Abstract number:** FC74  
**Abstract type:** Oral

**Wellbeing among Sub-Saharan African Patients with Advanced HIV and/or Cancer: An International Multicentred Study Comparing Two Outcome Measures**

Harding R.1, Gikaara N.2, Gwyther L.1, Powell T.2, Mwangi-Powell F.2, Selman L.1, Siegert R.4

1King’s College London, Cicely Saunders Institute, Dept of Palliative Care, Policy & Rehabilitation, London, United Kingdom, 2African Palliative Care Association, Kampala, Uganda, 3Hospice Palliative Care Association of South Africa, Cape Town, South Africa, 4Auckland University of Technology, Person Centred Research Centre, Auckland, New Zealand

**Aim:** To measure multidimensional wellbeing among patients with advanced HIV and/or cancer in three African countries, and to determine the relationship between two validated outcome measures.

**Methods:** Cross-sectional self-reported data from palliative care populations in Kenya, Uganda and South Africa using FACIT-Pal and POS measures.
Results: Among 461 participants, a significant country effect showed lower (better) scores on FACIT core scale, Personal, Emotional and Family Well-Being subscales for Uganda. For all countries, FACIT subscale “social and family wellbeing” had the highest (worst) score. In multiple regression, country and functional status accounted for 21% of variance in FACIT-Pal scores. Worsening functional status was associated with poorer POS score. Compared to South Africa, Ugandan participants had a worse POS score, and Kenyans even worse. The matrix of correlational coefficients revealed moderate correlation between the POS and the FACIT-Pal core scale (0.60), the FACIT-G and the APCA African POS (0.64), and the FACIT-G+Pal with the POS (0.66).

Conclusion: The data reveal worst status for family and social wellbeing, which may reflect the sample being from less individualistic societies. The two measures appear to measure different constructs of wellbeing in palliative care, and reveal different levels of wellbeing between countries. Those with poorest physical function require greatest palliative and supportive care, and this does not appear to differ according to diagnosis.

Abstract number: FC75
Abstract type: Oral

Are we Addressing the Issues Raised by Families at Palliative Care Case Conferences (PCCC) in Long Term Care


1The University of Queensland, School of Nursing and Midwifery, Brisbane, Australia, 2University of Queensland, Brisbane, Australia, 3WA Cancer and Palliative Care Network, Perth, Australia, 4Brisbane South Palliative Care Collaborative, Brisbane, Australia, 5Resthaven, Adelaide, Australia, 6Southern Adelaide Palliative Services, Adelaide, Australia

Palliative care case conferences (PCCC) provide an opportunity for care planning and ensuring everyone is on the same page. The convening of a PCCC in long term care is not standard practice and limited research in this area has been conducted. The aim of this paper is to examine the needs of family members attending a PCCC in residential aged care and how well these needs were addressed during the conference.

Thirty two family members completed a questionnaire prior to attending a PCCC. Families were asked to list any concerns or issues as well as rate these on a 10 point Likert scale. They were also asked to identify what questions they wanted answered at the PCCC. The extent to which PCCC documentation addressed issues and concerns identified in the family questionnaire was reviewed by thematically coding responses to the family questionnaire and documentation in the case notes.

Main family concerns were the physical and medical needs of the resident (68.8%), specific mention about pain and comfort (56.3%), end of life care planning (53.1%), nutrition and hydration (40.6%), care processes (40.6%), psychological needs (37.5%), family role (25%), quality of life (21.9%) and pastoral care (6.3%). The level of concern was on average 7/10 (where 10 is ‘as worried as I possibly could be’). Audits of PCCC documentation indicate that pastoral care and end of life care planning was documented for all residents where this issue had been raised by the family. Physical and medical needs were documented in 86.4% of notes, pain and comfort 94.4%, nutrition and hydration 92.3%, quality of life 85.7%. Less likely to be documented were issues concerning psychological needs (66.7%), care processes (46.2%), and family role (37.5%).

It is important to understand the issues and concerns of the family who attend a PCCC so these needs can be incorporated into the residents palliative care plan.

Abstract number: FC76
Abstract type: Oral

Implementing Palliative Care in Non-cancer Settings: A Theory-led Investigation of Three UK Stroke Services

Burton C.R.1, Payne S.2, Turner M.2

1Bangor University, Healthcare Sciences, Bangor, United Kingdom, 2International Observatory on End of Life Care, Lancaster University, Lancaster, United Kingdom

Background: Although specific evidence is lacking, UK National Clinical Guidelines for stroke specify a generalist palliative care role for health professionals.

Aims: We report a theory-led investigation which aims to explore the implementation of palliative care within the UK acute stroke setting.

Methods: Focus groups were conducted in three services, including a total of 30 healthcare professionals across seven professional disciplines. Focus groups were co-facilitated, exploring perceptions of patient needs, professional practice and service organisation. Data analysis was driven by May’s (2009) Normalisation Process Theory (NPT) which provides a sociological account of the work of implementation.

Results: Professional understanding of palliative care was missing, with competition between palliative and rehabilitation clinical paradigms. A discourse around ‘supportive care’ may provide an acceptable middle-ground where staff could see the value of palliative care in promoting ‘quality of life’ rather than ‘a good death’. Changing cancer policy contexts appeared instrumental in refocusing attention on palliative care. Leadership around palliative care at a clinical level was diffuse and
sometimes conflicted. Clinical facilities were a barrier to the provision of palliative care, but gave opportunities for creativity to meet patients’ expectations. Skills development was dependent on previous experience rather than deliberate education and training strategies. Uncertainties around the disease trajectory and a service model which increasingly focuses on active treatment appeared to hamper implementation.

Conclusions: Palliative care presents a competing clinical paradigm which staff may struggle to embed in generalist stroke services. The NPT proved useful in understanding implementation issues, highlighting a need to develop conceptual coherence at the interface of palliative and generalist healthcare, education and training, and collective action on implementation.

Abstract number: FC77
Abstract type: Oral

The Prognostic Role of Circulating Tumor Cells in Heavily Pre-treated Individuals with A Low Life Expectancy

Schofield G., Stebbing J., Shaw J., Coombes R.C., Krell J., Urch C.E.

Imperial College London, Departments of Medical Oncology and Palliative Care, London, United Kingdom

Aims: Studies of circulating tumor cells (CTCs) have generally recruited individuals with newly diagnosed metastatic cancer, with recent data also indicating their prognostic value in the adjuvant setting. Their role in dying patients has not been established.

Methods: CTCs were measured in individuals with metastatic breast cancer estimated to have less than 6 months to live who had exhausted standard therapeutic options.

Results: Those with a CTC count of \( \leq 100 \) had a median of 182 days to live, compared to those with a CTC count of \( > 100 \) who had a median of 17 days until death \( (p = 0.009, \text{ Log Rank, HR 3.1, 95\% CI 1.47.3}) \).

Conclusion: A CTC count of \( > 100 \) is associated with imminent death. Provided external validity is demonstrated, such information would be useful for patients and their families who often request specific prognostic clarity. Measurement of CTCs can be considered in dying individuals, to improve the quality of end-of-life care.

Abstract number: FC78
Abstract type: Oral

Towards an Evidence-based Model of Palliative Care for People with Malignant Glioma and their Carers

Philip J.¹, Collins A.², Gold M.³, Brand C.⁴, Lethborg C.⁵, Murphy M.⁴, Moore G.⁴, Sundararajan V.⁶

¹University of Melbourne, Centre for Palliative Care Education & Research, Fitzroy, Australia, ²St Vincent’s Hospital Melbourne, Centre for Palliative Care, Fitzroy, Australia, ³Alfred Hospital, Palliative Care Service, Melbourne, Australia, ⁴University of Melbourne, Melbourne EpCentre, Melbourne, Australia, ⁵St Vincent’s Hospital Melbourne, Melbourne, Australia, ⁶University of Melbourne, Department of Medicine, Melbourne, Australia

Aims: To assist clinicians caring for patients with Primary Malignant Glioma (PMG) and their carers, we aimed to develop and describe an evidence-based model of palliative care which integrates quantitative and qualitative findings.

Methods: A mixed-methods sequential approach was adopted to accrue data informing the model, including:

1. Oversight by an Expert Advisory Group,
2. A detailed systematic review and evaluation of studies reporting patient and carer needs,
3. Cohort epidemiological study of health service use,
4. Qualitative study exploring needs according to patients, carers (current and bereaved) and health professionals.

These data were integrated to develop a model of care.

Results: Data supports a new model responsive to this unique cancer trajectory involving rapid, unpredictable deteriorations; uncertain, but limited prognosis; and marked, often early, behavioural and cognitive changes. Four overlapping components were critical to optimal patient care.

1. Coordination, continuity and support; proactively offered through a consistent contact that provides regular screening during tele-medicine reviews.
2. Staged information; routinely delivered to patients and carers at key points including diagnosis, following first-line treatment, and at first recurrence.
3. Routinely staged palliative care services; including routine referral to palliative care at first recurrence (if not already occurred), access to step-down longer term palliative care inpatient facilities with respite capacity, and outpatient allied health.
4. Education for HCPs; including awareness and advocacy for a more collaborative role of palliative care alongside acute providers.

Conclusions: An improved understanding of needs using a mixed-methods approach enabled the development of...
this evolving model of care. We believe multiple and different forms of data provide the most robust and informed base for model development and improved patient care.

Symptoms other than pain II

Abstract number: FC79
Abstract type: Oral

Symptom Clusters Differentially Affect Quality of Life: Outcomes: Preliminary Evidence in HIV/AIDS

Namisango E.1, Harding R.2, Powell R.A.3

1African Palliative Care Association, Learning and Research, Kampala, Uganda, 2King’s College London, Cicely Saunders Institute, Palliative Care, London, United Kingdom, 3African Palliative Care Association, Learning and Research, Nairobi, Kenya

Background: This study aimed to establish if sub-groups of patients with particular symptom clusters differed on quality of life and functional status.

Methods: Measures: Data on symptom 7-day period prevalence and distress were self reported by 302 participants using the Memorial Symptom Assessment Schedule (MSAS-SF). Quality of life was measured using the Medical Outcome Scale HIV (MOS-HIV).

Cluster analysis was used to identify patient sub-groups based on their symptom experience. The subgroups were defined depending on how many symptoms are greater than the cut off score for the different categories of symptom severity. I.e mild, moderate and severe.

Consequently ALL LOW is one or no symptom greater than the cut score, MILD is two symptoms greater than the cut score MODERATE is three or more symptoms greater than the cut scores and ALL HIGH is all symptoms above the cut scores.

Analysis of variance was used to compare symptom cluster groups on mental health, physical health and functional performance.

Results: Two patient subgroups were identified patient group one (n=35) reported high distress on symptoms of difficulty moving, difficulty walking, muscle aches, and moderate distress on other symptoms and was labelled MODERATE. The second subgroup (n=267) reported low distress for all the physical symptoms was labelled ALL LOW. Subgroup one was; symptom occurs frequently for three of the four psychological symptoms of worry, feeling sad, feeling irritable and feeling nervous (n=112), symptom occurs occasionally for feeling sad and worry then symptom occurs rarely for feeling nervous and irritable (n=145). Low distress on all psychological symptoms had significantly higher mental health and functional performance scores. Mental health (F=148.09, P< 0.001), functional performance (F=133.55 P< 0.001).

Findings provide preliminary support for symptom clusters that correlate with reduced function and quality of life in persons with HIV/AIDS.

Abstract number: FC80
Abstract type: Oral

Characterizing Episodic Breathlessness in Patients with Advanced COPD or LC: Results of a Cohort Study

Weingärtner V.1,2, Scheve C.2, Gerdes V.2, Schwarz-Eywill M.1, Prenzel R.4, Bausewein C.2,3, Higginson I.J.6, Voltz R.1, Herich L.7, Simon S.T.1,2, on behalf of PAALiativ

1University Hospital of Cologne, Department of Palliative Medicine, Clinical Trials Unit (BMBF 01KN1106), and Centre for Integrated Oncology (CIO) Cologne/Bonn, Cologne, Germany, 2Institute of Palliative Care (ipac) (BMBF 16KT0951), Oldenburg, Germany, 3Protestant Hospital Oldenburg, Department of Palliative Medicine, Oldenburg, Germany, 4Pius-Hospital Oldenburg, Clinic for Internal Medicine, Oldenburg, Germany, 5University Hospital Munich, Department for Palliative Medicine, Munich, Germany, 6King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and RehabilitationWHO Collaborating Centre for Palliative Care and Older People, London, Germany, 7University of Cologne, Institute of Medical Statistics, Informatics and Epidemiology (IMSIE), Cologne, Germany

Aims: Episodic breathlessness is a distressing symptom in advanced disease. Understanding its patterns over time is important to improve management and patients’ quality of life. The aim of this study was to describe the characteristics of episodic breathlessness in patients with advanced diseases over time.

Methods: This cohort study included patients with COPD (GOLD stage III/IV) or lung cancer (LC, any stage). Data were assessed monthly by up to 12 telephone interviews. Outcomes were peak severity (mod. Borg Scale, 0-10), duration and frequency of breathlessness episodes. Descriptive analysis compared all outcomes between COPD and LC exploring characteristics in two different ways: forward over time and pooling the data of all episodes described.

Results: Eighty-two patients (50 COPD, 32 LC), mean (SD) age 67 (8) years, 36% female, were included and reported 592 breathlessness episodes in total (COPD 403, LC 189). Over the study period, mean peak severity of episodes was constantly up to three units (Borg) higher in COPD patients than in LC patients. This observation remained significant for the pooled data (COPD mean (SD) 7 (2); LC 4(2); p< 0.001). Median duration fluctuated between 5-7min or 2-5min over time in COPD or LC,
respectively, and showed significant differences for the pooled data (COPD 7min (range 1s-10h); LC 5min (15s-2h); p=0.002). Median frequency was 1-3/day over almost all time points and for the pooled data, respectively, in both groups (n.s.).

**Conclusion:** Episodic breathlessness manifests with higher peak severity in COPD patients compared to LC patients but with similar frequency. Although median duration was short in both groups, COPD patients suffered about 2 min longer and there was high fluctuation in individual patients of both groups. Effective treatment options that adjust with the short duration of the symptom are urgently warranted. The study was funded by the German Federal Ministry of Education and Research (BMBF 16KT0951).

**Abstract number:** FC81  
**Abstract type:** Oral

### Does Erythropoietin Improve Cognitive Symptoms in Patients with Cancer? A Systematic Review

de Wolf-Linder S., Koffman J., Ramsenthaler C.

King’s College London, Cicely Saunders Institute, Palliative Care, Policy & Rehabilitation, London, United Kingdom

**Background:** Cognitive functional impairment is a frequently reported symptom in cancer patients after finishing systemic anti-cancer treatment. Some evidence supports erythropoietin as a preventive intervention to maintain normal cognitive function during and after chemotherapy.

**Aim:** To review the effectiveness of erythropoietin to improve cognitive symptoms such as memory or attention problem and related symptoms in patients with cancer.

**Methods:** A systematic search was conducted in Embase, Medline, PsycInfo, Cochrane, and CINAHL on 28.3.2013. All study designs, cancer patients with symptoms of cognitive impairment (memory or attention problem and related symptoms) receiving erythropoietin were included. Results were summarized using narrative data synthesis.

**Results:** Of 1350 retrieved references, 5 studies were included. Prevalence of cognitive impairment before receiving erythropoietin was within the normal range for cognition, bar one study including elderly patients with cancer. Significant improvements in cognitive function were seen in elderly patients receiving high doses of erythropoietin and cognitive domains, particularly memory, in women with breast cancer. Participants with solid malignancy reported improved quality of life.

**Conclusion:** Erythropoietin may improve cognitive function in cancer patients receiving erythropoietin but further evidence is required. This review adds detailed baseline data to existing evidence, highlighting important factors to be taken into account when choosing a cognitive function tool in practice, e.g. age. Population-based studies to redefine the norm of specific cognitive function tools, particularly for the elderly cancer survivors, are needed.

**Abstract number:** FC82  
**Abstract type:** Oral

### Dietary Treatment of Weight Loss in Patients with Advanced Cancer and Cachexia: A Systematic Literature Review

Balstad T.R.1, Solheim T.S.1, Strasser F.2, Kaasa S.1, Bye A.3

1European Palliative Care Research Centre (PRC), Department of Cancer Research and Molecular Medicine, Norwegian University of Science and Technology (NTNU), Trondheim, Norway, 2Department of Internal Medicine and Palliative Care Center, Cantonal Hospital, St. Gallen, Switzerland, 3Department of Health, Nutrition and Management, Faculty of Health Sciences, Oslo and Akershus University College of Applied Sciences, Oslo, Norway

**Background:** Patients with progressive cancer often suffer from weight loss. This might be caused by inadequate energy intake alone or be a consequence of inadequate intake and in combination of metabolic and endocrine abnormalities. Guidelines for dietary treatment of weight loss in patients with incurable cancer are lacking. The aim in this review is to assess the effect of dietary counselling on weight loss and energy intake in patients with advanced incurable cancer and investigate whether it is more effective to give dietary counselling in pre-cachexia or cachexia than in late cachexia.

**Methods:** A systematic literature review of PubMed, EMBASE and Cochrane Central register of controlled trials database was performed using both text words and MeSH/EMTREE terms.

**Results:** Five trials were retrieved, of which three were randomized. Two out of five studies showed less weight loss in patients treated with dietary counselling (0.6 kg vs -2.1 kg, ns and 1.4 kg vs. -2 kg, p< 0.05), two studies presented positive effect on energy balance (92% of total caloric need vs. 73%, p< 0.01 and 1865±317 kcal vs. 1556±497 kcal, ns). Two out of five studies were small (N< 50) and population and effect sizes poorly described in most of the trials.

**Conclusion:** Based on this systematic literature review it is not possible to conclude that dietary advice given to advanced cancer patients is of benefit in improving weight or energy balance. This finding underlines the correctness of the international cachexia definition that states that cachexia cannot be treated with nutrition alone. Additionally, it was not possible to describe a difference in the effectiveness between the interventions considering the different cachexia stages. Nevertheless, nutrition is an essential part of a multimodal cachexia treatment as it is not possible to increase or stabilise weight if nutritional needs are not met.
A Prospective Evaluation of Octreotide in the Palliation of Gastrointestinal Symptoms

Kilonzo I., Waldron D., Mannion E., Kromer D.
Galway University Hospitals, Palliative Medicine, Galway, Ireland

Background: Symptoms of gut dysmotility are common and can be distressing and debilitating. There are numerous causes of dysmotility and they include malignant bowel obstruction (MBO), treatment related diarrhoea, excessive secretions from gastrointestinal (GI) tumours and dysmotility not related to malignancy.

Objectives: The aim of this study is to examine the use, tolerability and effectiveness of octreotide in the management of gastrointestinal symptoms of patients referred to the palliative care service of a large tertiary referral hospital.

Methods: All patients referred to the palliative care team requiring treatment with octreotide were included in this prospective, single-centre study. Data collected included diagnosis, indication, symptoms, response to treatment and adverse effects. Symptom assessment was undertaken using the Edmonton Symptom Assessment System (ESAS). This was completed on day 1, day 3 and 1 week after commencing subcutaneous octreotide treatment.

Results: Twenty-four patients treated with octreotide between October 2012 and June 2013 were included in the study. The most common indication for octreotide was MBO (66%) and the dose used ranged from 500 to 3000 mcg. Three patients had upper GI dysmotility as a result of previous surgical treatment. The combination of octreotide and metoclopramide was used in 54%. The mean ESAS scores were 49 on day 1, 32 on day 3 and 21 on day 7. The average reduction in ESAS scores by day 7 were: Pain = 3.9, Nausea = 5.0, Anorexia = 3.3 and General ill feeling = 3.7. Adverse effects reported were dry mouth (n=4) patients and constipation (n=2).

Conclusion: Our results show that in this cohort of patients, octreotide improved GI symptoms in both malignant and non-malignant patients. It was well tolerated at doses higher than those recommended in current literature. We would recommend that further studies examine the effectiveness of octreotide use in higher doses and in combination with metoclopramide.

Abstract number: FC84
Abstract type: Oral

Public Preferences and Priorities for End of Life Care in Germany

Lehner M.1, Fegg M.J.1, Simon S.T.2, Harding R.3, Gomes B.3, Bausewein C.1, on behalf of PRISMA

1Munich University Hospital, Department of Palliative Medicine, Munich, Germany, 2University of Cologne, Centre for Palliative Medicine, Cologne, Germany, 3King’s College London, Cicely Saunders Institute, London, United Kingdom

Background: Knowledge of the perception of the general public of dying and death is essential for planning of adequate end of life care (EOLC).

Aim: To identify public preferences and priorities for EOLC in Germany; to examine factors associated with a preference for self-involvement in decision making in EOLC and to identify factors associated with hospital death being the least preferred place of death.

Methods: A telephone survey with randomly selected individuals aged 16+ was carried out in Germany. Questions were framed in a scenario of serious illness such as advanced cancer and < 1 year to live. Binary logistic regression determined factors associated with wanting to be involved in making decisions about care and with naming hospital as the least preferred place to die.

Results: 1363 persons were interviewed. 1237 (90.8%) preferred self-involvement in decisions when capable. This preference was associated with higher educational level (Exp(B)=0.71, p=0.005). 1135 (83.3%) wanted to be involved in decisions even if they had lost the ability to do so (e.g. through living will). This preference was associated with higher age (Exp(B)=0.78, p< 0.001), higher educational level (Exp(B)=0.79, p=0.02) and not being partnered (Exp(B)=1.50, p=0.02). Hospital was the least preferred place of death (48.2%), particularly among women (Exp(B)=1.42, p=0.003) and those with higher educational level (Exp(B)=0.84, p=0.02).

Conclusion: In a scenario of a serious time-limiting illness, more than 8 in 10 people in Germany want to be involved in decisions about their care, regardless of whether they are able to do so or not. The least preferred place of death is the hospital.

Funding: This work was supported by the European Commission’s Seventh Framework Programme as part of the project PRISMA (contract number: Health-F2-2008-201655).

Psychosocial care and spirituality

Abstract number: FC85
Abstract type: Oral

Physical Impairment, Meaning in Life and the Wish to Hasten Death in Advanced Cancer Patients

Monforte-Royo C.1,2, Lichtendfeld S.3, Villavicencio-Chávez C.4,5, Tomás-Sábado J.6, Porta Sales J.2,4,5, Maier M.3, Balagué A.2,5

1Universitat Internacional de Catalunya, Nursing Department, Faculty of Medicine and Health Sciences, Sant Cugat del Vallés, Spain, 2Universitat Internacional...
Aims: The goal of our study was to assess the relationship between physical impairment, meaning in life (MiL) and the wish to hasten death (WTHD) in advanced cancer patients.

Methods: Cross-sectional study on 101 advanced cancer patients admitted to an acute palliative care unit. The mean age was 61.7 (SD=11.0) [range 33-84 years]. Physical status was assessed using the ECOG Performance Status (ECOG-PS), the Barthel Index (BI) and the Karnofsky Index (KI). MiL was assessed using the subscale of MiL in the Palliative Outcomes Score. To assess the WTHD, the Spanish version of the Schedule of Attitudes to Hastened Death (SAHD) was used. Direct and indirect relationships among the variables were analyzed using parametric (Logistic regression and structural model analysis) and nonparametric tests (Spearman’s rho and Mann-Whitney U tests).

Results: Significant correlations ($p<0.01$) were found between the three indicators of physical impairment and SAHD (SAHD with ECOG-PS $r = 0.276$; SAHD with BI $r = -0.324$ and SAHD with KI $r = -0.356$) indicating increased WTHD when physical impairment was also increased. Also significant correlations ($p<0.01$) were obtained between SAHD and indicator of psychological functioning, SAHD with MiL $r = 0.601$, indicating decreased ratings of WTHD with better psychological status. Moreover, structural equation modeling was used in analyzing the results of the present study. A regression analysis on SAHD revealed a significant direct effect of KI ($\beta = .40$; see Figure 1). Furthermore, a model including MiL was calculated to examine whether MiL mediated the predictive effect of KI on SAHD. Analysis revealed a significant influence of MiL on SAHD ($\beta = -.72$). Inclusion of MiL into the equation reduced the coefficient for the direct effect from .40 to .05, indicating full mediation.

Conclusion: Physical impairment and WTHD are the most closely related factors in population studied. The MiL acts as a full mediator variable between these two factors.
The Power of Dreams, a Grounded Theory Study into Dream Fulfilment in Children and Young People with Life Limiting and Long Term Conditions and their Families

Galinsky J., France E., Forbat L.
University of Stirling, Stirling, United Kingdom

Anecdotal evidence suggests that the experience of having a personal ‘dream’ realised can empower a sick child and their family and bring hope and new perspectives that can help them cope with the burdens of chronic illness. Such experiences may have a substantial contribution to make to different stages of care provision for life-limiting illness. However, little research has been done in this field. This study looks at the impact of dream fulfilment on children with life-limiting and life-threatening conditions, and their families. The study’s aim is to understand the impact of dream fulfilment on the quality of life and psychosocial well-being of seriously ill children and their families. The research questions are: what is the experience of having a dream fulfilled for the child and their family? What are the short and long term impacts of having a dream fulfilled? The sample consists of children and young people who had had a dream fulfilled by a dream fulfilment charity, and their families. We used theoretical sampling to select participants, and initially sought variation in the type of health condition, the age of the child, and the time since the dream experience. Using a qualitative grounded theory (GT) methodology, we interviewed children aged 5 upwards and their families across the UK. GT seeks to construct theory about issues of importance in people’s lives and consists of simultaneous data collection and analysis, with each informing the other. This results in an analytic interpretation of participants’ worlds. The findings indicate that dream fulfilment has a wide range of impacts on the child and family members beyond the standard health outcomes which are usually measured in palliative care research and that the effects start prior to the actual experience and last well beyond it. We discuss how the emerging theory fits with concepts from the field of positive psychology and how dream fulfilment can fit into existing palliative care pathways.

Use of Psychosocial Activities as a Non Pharmacological Management among Orphaned Children Living with HIV/AIDS

Kavange A.A.1,2, Iriya J.N.1, Mwalongo M.1

1PASADA, Pediatric HIV Care and Treatment Department, Dar es Salaam, Tanzania, United Republic of. 2University of Oslo, SAMFMED, Department of Community Medicine, Oslo, Norway

There are currently 12.1 million AIDS orphans in Sub-Saharan Africa alone. Since the emergency of HIV pandemic, Tanzania has experienced an increasing number of orphan children the majority who have had parents that have died from HIV/AIDS. In Tanzania 42% of Orphans and Vulnerable Children are due to HIV/AIDS and some of them live with HIV/AIDS.

PASADA is a community-based health and social services agency providing holistic care to people infected and affected by HIV and AIDS. It has about 5000 children living with HIV/AIDS. Out of these children, there are those who live with a single parent (mother or father) where as others are full orphans living with grandmothers, uncles, aunties and Good Samaritan.

After enrollment in care and treatment, it was found these children needed something beyond antiretroviral drugs and opportunistic infections drugs. Some of them had developed abnormal behavior such as reduced self esteem, not talking to other family members, absconding from school, not taking medication, running away from home, stealing home items, irregular attendance to the clinic etc.

The children were triaged during their clinics, consent was made from their caretaker to allow their children to be involved in the psychosocial activities such as choir, fine art/painting, clay art, rap music, football, dancing, drama, adolescent sexual and reproductive health education and Outreach visits. Assessments were done after one year from the children themselves and their caretakers showing an improved school attendance, improved health well-being, self determination, improved self esteem and drug adherence, increased hope of living, and raised family awareness on issues pertaining to HIV/AIDS as well as development of good behavior among children.

Psychosocial activities play a key role as a non pharmacological way of managing orphaned children living with HIV/AIDS to improve their health wellbeing among.

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Psychosocial activities play a key role as a non pharmacological way of managing orphaned children living with HIV/AIDS to improve their health wellbeing among.
Abstract number: FC89

Abstract type: Oral

The Heart of the Matter: Understanding Spiritual Care Provision in South Africa and Uganda

Selman L.1, Harding R.1, Higginson I.J.1, Speck P.1, Gysels M.2, Gwyther L.3, Dinat N.4, McDaniel B.5, Encompass Collaborative

1King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, London, United Kingdom, 2Centre for Social Science and Global Health, University of Amsterdam, Amsterdam, Netherlands, 3Hospice Palliative Care Association South Africa, Cape Town, South Africa, 4Formerly of Division of Palliative Care, University of the Witwatersrand, Johannesburg, South Africa, 5South Coast Hospice, Port Shepstone, South Africa

Background: Palliative care patients usually experience psychological distress as disturbing symptoms undermine their quality of life. Identifying the distressing psychological beliefs (DPBs) ensuing from coping with a terminal disease is important for understanding the nature of the suffering experience and for administering specific psychological interventions.

Aim: To develop a tool-kit for assessing the main DPBs of palliative care patients at the end of life.

Methods: After reviewing and analyzing relevant databases (Medline, Cochrane, PsychInfo and EMDR database), we identified a list of 30 DPBs related to psychological distress in palliative care, as well as their positive. The tool-kit thus elaborated was reviewed at two focus group meetings of 4 palliative care psychologists and 4 EMDR clinicians, and revised by means of a Delphi process by 5 external psychologists.

Results: The tool-kit was part of a larger study and consisted of 3 instruments: the “BASIPC guide”, a list of DPBs and their positive opposites related to a more adaptive self-assessment; the “BASIPC-(-)”, a questionnaire including negative beliefs; and the “BASIPC(+)?”, including positive beliefs. Five main domains of psychological distress in palliative care were identified: Autonomy, Self-esteem, Meaning, Control, Communication, and Reconciliation, composed of a total of 30 negative and 30 positive beliefs. The answer format had 4 categories and ranged from “not at all” to “very much”. A pilot study employing this tool kit was conducted with 20 palliative care patients to analyze its adequacy. Final analyses will be conducted with 100 patients.

Conclusions: The BASIPC toolkit may provide a clinical profile of the distressing beliefs that underlie psychological distress while facing the end of life. It would facilitate addressing specific psychological interventions for more adaptive self-assessments improving quality of life. The toolkit remains to be evaluated in a larger sample.

Abstract number: FC90

Abstract type: Oral

Religiosity and Code Status Preference among Patients with Advanced Cancer

Delgado Guay M.O.1, Rhondali W.2, Chisholm G.1, Williams J.1, Brueru E.1

1The University of Texas MD Anderson Cancer Center, Palliative Care and Rehabilitation Medicine, Houston, TX, United States, 2Centre de Soins Palliatifs, Lyon, France

Background: Policy guidelines mandate spiritual care (SC) in advanced disease, yet SC is often neglected in clinical practice. SC development is hindered by a lack of evidence, particularly in sub-Saharan Africa. Improved understanding of SC and its implementation in palliative care (PC) is needed to determine best practice, a key research priority identified in the EAPC survey on SC.

Aim: To describe the work of SC providers (SCPs) supporting patients with incurable illness in South Africa and Uganda, the challenges they face in their work and their recommendations to inform SC development.

Methods: Qualitative in-depth interviews with a purposive sample of SCPs identified through 3 PC services in South Africa and one in Uganda. Interviews covered personal background, experiences of providing care, services provided and recommendations. Interviews were recorded, transcribed verbatim and imported into NVivo for thematic analysis.

Results: 21 SCPs were interviewed: 12 women; mean age 54; 6 pastors, 5 volunteers, 4 social workers, 3 nurses, 2 SC co-ordinators, 1 hospice counsellor. One SCP was Buddhist, the rest Christian. Key themes: challenges of providing SC (population diversity, funding, marginalisation within PC service, staff misperceptions); patients’ spiritual problems (accepting diagnosis, guilt, regret, prejudice from the church community, meaninglessness); types of intervention (e.g. counselling, ‘companioning’, praying, complementary therapies, peer support); recommendations (designated SC managers, training staff and faith leaders, routine assessment).

Conclusions: This is the first study to explore the views of SCPs in African PC. SCPs described patients' profound spiritual distress and the approaches/ interventions they use to support patients. Many reported barriers in meeting SC needs are organisation/education-related. Findings regarding the nature of SC and its implementation are relevant beyond Africa to PC services and researchers globally.
beliefs on approaches to end-of-life care and code status preferences is not well understood.

Methods: This is a secondary analysis of a randomized controlled trial evaluating patient-physician communication about code status preferences. We analyzed the relationship between the intensity of religiosity using The Santa Clara Strength of Religious Faith Questionnaire—Short Form (>13/20= Highly religious) and code status preferences.

Results: 78 patients completed the study. 46 (57%) were female. 59 (74%) were Caucasian, 15 (19%) African-American, and 5 (6%) were Hispanic. Type of cancer: Gynecologic: 18(23%), Genito-urinary 11(14%), Gastro-intestinal 9 (11%), Head and Neck 8(10%), Breast 6(8%). 46(44%) were Protestant, and 13(16%) were Catholic. 45(56%) had some degree of college education.

After watching both videos, 53/60 patients who chose DNR (88%) and 16/18 patients who refused DNR (89%) for the video-patient, were highly religious (p=0.64). 43/48 patients who refused DNR (90%) and the 26/30 patients who chose DNR (87%) for themselves were highly religious (p=0.08). Spearman correlation between choosing DNR for themselves and intensity of religiosity was r=-0.16, p=0.16. 30/78 patients who chose DNR for the video-patient but refused DNR for themselves (38%) and 42/78 patients who chose DNR for both (54%) were highly religious (p=NS).

Conclusion: This population of American advanced cancer patients was highly religious. There was no significant association between intensity of religiosity and DNR preferences for the video patient and for themselves. Culture and religious beliefs might impact end-of-life discussions and code status preferences. More research is needed this issue.
Identifying In- and Outpatients in a Comprehensive Cancer Centre for Specialised Palliative Care at Home


1Copenhagen University Hospital, Copenhagen, Denmark, 2Copenhagen University, Department of Clinical Medicine, Faculty of Health and Medical Sciences, Copenhagen, Denmark, 3The Danish Knowledge Centre for Palliative Care, Copenhagen, Denmark, 4The Danish Cancer Society, Copenhagen, Denmark

Introduction: Proving a timely referral to Specialised Palliative Care (SPC) at home is a persisting challenge during oncological treatment. The identification of patients is a key point and we developed a screening procedure for an RCT (registered at clinicaltrials.gov) to identify in- and outpatients treated in a comprehensive cancer centre for SPC at home.

Aim: The aim of this study is to identify oncological patients who may benefit from accelerated transition from oncological treatment to SPC at home.

Design and method: The study is a descriptive study with multiple patient selections. Consecutive patients treated in a comprehensive cancer centre were assessed in September 2013. The inclusion criteria comprised incurable patients with limited or no antineoplastic treatment options. Limited treatment options were defined for each cancer disease, e.g. breast cancer refractory to 3rd line treatment, lung cancer refractory to 1st line treatment etc. Incurable patients with a European Cooperative Oncology Group Performance Scale of 2–4 were considered eligible for SPC at home. Inpatients were screened daily and outpatients were screened with a sequential alternation procedure that secured equal screening of all visits in the six outpatient clinics. The screening used clinical data which are routinely documented during oncological treatment.

Results: During the study 1157 patients were assessed for eligibility from whom 149 (12.8%) were considered incurable and had limited treatment options. Forty-five (3.9%) also demonstrated an ECOG PS of 2–4 and were therefore eligible for SPC at home. Half of the eligible patients were already referred to SPC at screening.

Conclusion: The prevalence of oncological patients eligible for SPC at home was 3.9%. Our selection criteria may be applied in healthcare planning for routine clinical identification of patients that should be considered for SPC at home.

Funded by: The Danish Cancer Society and The Tryg Foundation

Abstract number: P2
Abstract type: Poster Discussion

Supporting Family Carers: National Evidence Based Recommendations for Hospices in the UK

Morvey H., Payne S.

Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom

Background: Within Europe approximately 100 million people have caring roles, and increasing calls are made for family carer health and care support. In 2012 Help the Hospices UK, launched a Commission into the Future of Hospice Care, with the aim to improve the experience of people who are approaching the end of their life, and that of their families and carers.

Aims: The study informed the Commission through enhancing understanding of the role of family carers and identified interventions to meet their needs. It aimed to promote the integration of family carer’s assessment and support services within clinical hospice care and organisational practice.


Results: The dual experience for carers as providers and receivers of care is marked by competing demands on their own health while at the same time supporting their family member. An ageing carer population have significant health needs that are at the forefront of requiring carer services and support. With the exception of a limited number of systematic research reviews, little priority has been placed on substantiating robust and effective carer support interventions. There is an overarching need to address research evidence in this area.

Conclusions: Substantial research evidence exists on the demands upon carers and their needs. However, despite policy changes the experiences of family carers of those approaching the end of life continues to be unnecessarily challenging. Developments in hospice care that truly include family carers as central in their relationship with
patients, will position them as worthy beneficiaries of support both during and after the death of the patient. **Funded by:** Help the Hospices UK.

**Abstract number:** P3  
**Abstract type:** Poster Discussion  
**Relational Model of Nursing Students’ Experiences of Death and Dying during their Clinical Training**  
*Édouard, M.*, *Aradilla-Herrero, A.*, *Bardallo-Porrás, D.*  
*1Gimbernat School of Nursing, Autonomous University of Barcelona, Nursing, Sant Cugat del Vallès, Spain,*  
*2Universitat Internacional de Catalunya, Department of Nursing, Sant Cugat del Vallès, Spain,*  
*3WeCare Chair, End-of-Life Care, Faculty of Medicine and Health Sciences, Universitat Internacional de Catalunya, Sant Cugat del Vallès, Spain*

**Aims:** One of the experiences that nursing students report as having the greatest impact during their clinical training concerns the death of a patient. The way in which a student experiences death and dying may affect not only the end-of-life care that he or she is able to offer patients and their relatives, but also the nurse as a person in the future. It is therefore important to understand the factors that may influence and modulate the impact of such experiences so that they can be addressed during nurse training. The aim of this study was to explore the relationships between emergent themes identified in students’ own accounts of their experiences of death and dying during clinical training.

**Methods:** **Design.** Interpretative phenomenological study. **Sample.** Twelve nursing students with a mean age of 23.5 years (±5.2). **Procedure.** Data were gathered by means of semi-structured interviews. The first stage involved recording, transcribing and analysing the interviews in order to identify the emergent themes, using ATLAS-ti 7 software. These transcripts were then analysed a second time, comparing the overall results and exploring the relationships between the different emergent themes.

**Results:** On the basis of the connections between the emergent themes a relational model was developed in order to explain the phenomenon. The central theme concerned the enormous impact that the first experiences of death and dying during clinical training had on the nursing students. The other emergent themes were related to ethical issues, the need for specific training in providing end-of-life care, coping and learning. In the model, these latter four themes appeared as a response, need or modulator in relation to the central theme.

**Conclusion:** The relational model described here could be a useful tool as it is based on the needs reported by nursing students themselves. As such, it could serve for the design of nurse training programmes in relation to end-of-life care.
opportunity for reflection which facilitated articulation of experience and understanding that ‘coping’ is a dynamic, evolving response. Participants suggested innovative ways to develop effective coping strategies, which should cost-effectively promote wellbeing and improve quality of life.

**Funding:** Dimbleby Cancer Care charity.

### Abstract number: P5
### Abstract type: Poster Discussion

**Out-of-Hours Palliative Care Provision by General Practitioners: What Factors Challenge Good Care?**

Magee C.L. 1,2, Koffman J. 2

1Marie Curie Hospice West Midlands, Solihull, United Kingdom, 2King’s College London, London, United Kingdom

**Background:** Most people express a wish to be cared for and to die at home. To achieve this patients and carers need access to support 24-hours a day, seven days a week. Concerns have been raised about continuity of care, availability of information and access to support services out-of-hours. General practitioners (GPs) provide the majority of care in this setting, but overall see few palliative patients.

**Aims:** To examine GPs’ attitudes towards palliative care out-of-hours, and to explore whether service organisation or a lack of clinical knowledge/skills has the greatest impact on the provision of good care.

**Methods:** A structured postal survey was designed and sent to 1005 GPs employed by an independent provider of out-of-hours services across England. Quantitative data was analysed using descriptive and non-parametric statistics; free-text responses were analysed for themes.

**Results:** 203 GPs (20.3%) completed the survey questionnaire. 76.8% (n=155) found palliative care rewarding, but 18.1% (n=36) wished to hand over care to specialists. Organisational factors were felt to have significantly greater impact on good care delivery than clinical factors (p<0.0005). Lack of familiarity with patients/carers was felt to have the greatest impact (39% ranked first of twelve factors, n=57), followed by time pressures (21.3%, n=30) and lack of information from in-hours services (12.9%, n=18). The highest ranked clinical factor was lack of confidence in syringe drivers (5.4%, n=7). Additional themes identified were lack of anticipatory planning by in-hours GPs, difficulty maintaining skills and high family expectations.

**Conclusions:** GPs recognise their important role, but have concerns about their ability to deliver adequate care. Service organisation factors continue to hinder care delivery and GPs rank these above a lack of clinical knowledge and skills. Future service development and training must address the concerns expressed by out-of-hours practitioners.

### Abstract number: P6
### Abstract type: Poster Discussion

**When Do Patients with Dementia Receive Spiritual Care at the End of Life? A Prospective Study on Predictors of the Receipt of Spiritual End-of-Life Care as Perceived by Physicians**

van der Steen J.T. 1, Gijsberts M.-J.H.E. 2, Hertogh C.M.P.M. 3, Deliens L. 3

1VU University Medical Center, EMGO Institute for Health and Care Research, Dept. of General Practice & Elderly Care Medicine, Amsterdam, Netherlands, 2VU University Medical Center, EMGO Institute for Health and Care Research, Dept. of General Practice & Elderly Care Medicine, Public and Occupational Health, Amsterdam, Netherlands, 3VU University Medical Center, EMGO Institute for Health and Care Research, Dept. of Public and Occupational Health, Amsterdam, Netherlands

**Aim:** To examine predictors of the providing of spiritual end-of-life care in dementia as perceived by physicians.

**Methods:** The observational Dutch End of Life in Dementia study (DEOLD; 2007-2011) collected data prospectively in 28 long-term care facilities in the highly secularized western society of the Netherlands. Newly admitted nursing home residents with dementia were enrolled, and we selected 207 who died within the course of data collection and had complete outcome data. Outcome of Generalized Estimating Equations (GEE) regression analyses was whether spiritual care was provided shortly before death as perceived by the on-staff elderly care physician who was responsible for end-of-life care. Potential predictors were indicators of high-quality, person-centered, and palliative care, and demographics and some other factors supported by the literature. Resident-level potential predictors were measured 8 weeks after admission (baseline, by families and physicians), physician-level factors midway-study, and facility-level factors applied throughout data collection. We used multiple imputation techniques with multivariable analyses.

**Results:** Independent predictors of spiritual end-of-life care were: families’ satisfaction with physicians’ communication at baseline (OR 1.6, CI 1.0; 2.5 per point on 0-3 scale), and faith or spirituality very important to resident whether (OR 19, CI 5.6; 63) or not (OR 15, CI 5.1; 47) of importance to the physician. Further, female caregiving was an independent predictor (OR 2.7, CI 1.1; 6.6).

**Interpretation:** Palliative care indicators were not predictive of spiritual end-of-life care and palliative care in dementia may need better defining and implementation in practice. Physician-family communication upon admission may be important to optimize spiritual caregiving at the end of life.
Efficacy and Tolerability of Intranasal Fentanyl Spray in Cancer Patients with Breakthrough Pain

Thrones M.1,2, Popper L.3, Eeg M.K.4, Jaatun E.A.A.1,6, Kvitberg M.1, Pólya Z.5, Kaasa S.1,2
1Norwegian University of Science and Technology (NTNU), Faculty of Medicine, European Palliative Care Research Centre, Department of Cancer Research and Molecular Medicine, Trondheim, Norway, 2St. Olavs Hospital, Trondheim University Hospital, Cancer Clinic, Trondheim, Norway, 3Takeda Pharma A/S, Clinical Science, Roskilde, Denmark, 4Takeda Pharma A/S, Analytical Science, Roskilde, Denmark, 5Norwegian University of Science and Technology (NTNU), Faculty of Medicine, PRC/ IKM, Trondheim, Norway, 6St. Olavs Hospital, Trondheim University Hospital, Department of Oto-Rhino-Laryngology, Trondheim, Norway, 7Drammen Hospital, Vestre Viken HF, Palliative Unit, Oncology Department, Drammen, Norway, 8Jósa András Oktató Kórház Egészségügyi, Onkoradiológiai Osztály, Nyíregyháza, Hungary

The primary aim of this study was to explore the efficacy of Intranasal Fentanyl Spray (INFS) 400µg. The secondary aims were to evaluate 12 weeks tolerability of the nasal mucosa and to explore safety data for all dose strengths of INFS in cancer patients with breakthrough pain (BTP). The investigation of tolerability of INFS was a Sponsor commitment to the European Medicines Agency.

Methods: Patients were titrated to 50, 100, 200 or 400µg of INFS after a test dose of INFS 50 µg. Patients titrated to 200 and 400µg entered a randomized double blind cross-over efficacy phase where 8 episodes of BTP were randomly treated with INFS 400µg (6 episodes) and placebo (2 episodes), followed by a tolerability phase. Primary outcome was measured by pain Intensity decrease at 10 min. (PID 10), calculated using ANCOVA and presented as least square (LS) mean. Patients titrated to 50 or 100µg entered the tolerability phase directly. A rhinoscopy was conducted at inclusion and after 12 weeks of treatment.

Results: 46 patients, 67% females, mean age 61 years (38-79) were included. Thirty eight were titrated to an effective dose of INFS: 50µg (N=8), 100µg (N=9), 200µg (N=9), 400µg (N=12), 15 patients entered the efficacy phase, 31 entered the tolerability phase. In the efficacy phase, 88 and 29 episodes of BTP were treated with INFS 400µg and placebo respectively. LS mean (95% CI) at 10 min. was 2.5 (1.42, 3.49) (p= 0.001) and LS mean difference (95% CI) between INFS and placebo was 1.1 (0.41, 1.79) (p= 0.002). Runny nose (10%) and change of color of the mucosa (9 %) were the most frequent findings related to INFS in the nasal examination. Nausea and dizziness were the most frequent treatment related AE’s, reported by 10 (22%) and 9 (20%) patients respectively. One SAE (respiratory depression) was considered related to INFS.

Conclusion: This study shows that the 400µg of INFS is effective and that nasal tolerability and over all safety of INFS after 12 weeks of use is acceptable.

Under-diagnosis of Malnutrition in Palliative Medicine

Aktas A.1, Walsh D.1, Fischer M.2, Rybicki L.3
1Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Section of Palliative Medicine and Supportive Oncology, Cleveland, OH, United States, 2Cleveland Clinic Digestive Disease Institute, Section of Nutrition, Cleveland, OH, United States, 3Cleveland Clinic Lerner Research Institute, Department of Quantitative Health Sciences, Cleveland, OH, United States

Introduction: Malnutrition is common but likely under-diagnosed. Precise criteria or guidelines are lacking. Our objectives were to determine

1) prevalence and severity of malnutrition in cancer patients who received a nutrition therapy assessment (NTA)
2) if the registered dietitian (RD) and physician (MD) agree on malnutrition prevalence
3) if malnutrition is associated with survival.

Methods: N=182 consecutive NTA by a single RD. ≥2 of the 6 criteria were diagnostic of malnutrition:

1) any unintentional weight loss (WL)
2) BMI
3) visual muscle wasting
4) nutrient intake
5) wounds
6) laboratory values (pre-albumin, albumin, transferrin).

McNemar’s test determined congruence between RD and MD. Cox analysis assessed the association between malnutrition and survival.

Results: Median age 61 years (range 28-96); 51% female. The commonest primary cancer sites: lung (21%), GI (16%), GU (15%). NTA done by RD in 145 patients and malnutrition present in 70% (9% mild, 31% moderate, 30% severe). The commonest RD malnutrition criteria were: 1) unintentional WL (47%) 2) low oral intake (39%) 3) low serum albumin (29%). N=91 (50%) nutritional status recorded by MD; malnutrition was noted in 77% (24% mild, 22% moderate, 22% severe, 9% unspecified). N=77 had both MD and RD assessment; there was high
congruence between RD (77%) and MD (75%; P=0.78). Malnutrition was an indicator for poor prognosis (hazard ratio 1.88, 95% confidence interval 1.26-2.81, P=0.002).

Conclusions: Malnutrition was highly prevalent. Any WL, oral intake, and albumin were the commonest criteria used by RD to detect malnutrition. Physicians under-recorded nutritional status. Physician and RD agreed on the prevalence of malnutrition. Malnutrition was an indicator of poor prognosis in cancer.

Abstract number: P9
Abstract type: Poster Discussion

The DOMUS Study Protocol: A Randomized Clinical Trial of Accelerated Transition from Oncological Treatment to Palliative Care at Home

Nordly M.1,2, Benthien K.S.1,2, von der Maase H.1, Johansen C.1,2, Kruse M.1, Timm H.1, Vadstrup E.1, Kurita G.P.1,6, von Heymann-Horan A.B.1, Sjøgren P.2,6
1Department of Oncology, Rigshospitalet, Copenhagen University Hospital, Copenhagen, Denmark, 2Department of Clinical Medicine, Faculty of Health and Medical Sciences, Copenhagen University, Copenhagen, Denmark, 3Danish Cancer Society Research Center, Copenhagen, Denmark, 4The Danish Institute for Local and Regional Research, Copenhagen, Denmark, 5Knowledge Centre for Palliative Care, University of Southern Denmark, Danish, Copenhagen, Denmark, 6Section of Palliative Medicine, Department of Oncology, Rigshospitalet, Copenhagen University Hospital, Copenhagen, Denmark, 7Multidisciplinary Pain Centre, Rigshospitalet, Copenhagen University Hospital, Copenhagen, Denmark

Background: The focus of Specialized Palliative Care (SPC) is to improve 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: This study describes the methodology used in the DOMUS protocol. DOMUS investigate 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. The trial is registered at Clinicaltrials.gov.

Method: DOMUS is a controlled randomized clinical trial with an allocation ratio of 1:1. The planned sample size is 340 in- and outpatients at a comprehensive cancer centre. 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. Inclusion criteria are incurable cancer with no or limited antineoplastic treatment options and ECOG performance status (PS) 2-4. The primary analysis is conducted on the basis of “intention to treat principle”.

Discussion: This protocol defines a palliative patient population in a comprehensive cancer centre in need of SPC at home. By using ECOG PS and defining limited treatment options, a set of criteria that are already an integrated part of oncological treatment is established. With these criteria, we may in the future enable clinicians to proactively identify patients in the oncological treatment trajectory, who may benefit from SPC. It is essential to find out whether place of care and death, longer survival and healthcare benefits are associated with the intervention. As the organizational and financial consequences of the model will also be investigated, there is a direct basis on which decisions can be taken regarding the organization of SPC in the future. Funded by the Danish Cancer Society and the Tryg Foundation.

Abstract number: P10
Abstract type: Poster Discussion

Access to Opioid Medicines: Perception of Barriers among Different Stakeholder Groups in Four Countries

Linge-Dahl L.1, Jünger S.1, Vranken M.J.M.2, Mantel-Teeuwisse A.K.2, Schutjens M.-H.1, Payne S.A.3, Scholten W.K.4, Radbruch L.1,3
1University Hospital Bonn, Department of Palliative Medicine, Bonn, Germany, 2Utrecht University, Utrecht Institute for Pharmaceutical Sciences, Division of Pharmacoepidemiology & Clinical Pharmacology, Utrecht, Netherlands, 3Lancaster University, International Observatory on End of Life Care, Division of Health Research, Lancaster, United Kingdom, 4Consultant, Medicines and Controlled Substances, Lopik, Netherlands, 5Malteser Hospital Bonn/Rhein-Sieg, Centre for Palliative Medicine, Bonn, Germany

Aims: Access to opioid medicines can be hampered by barriers on different levels such as regulatory, knowledge, and attitudes and concerns. Discussions within the Access To Opioid Medication in Europe (ATOME) project indicated that healthcare professionals and decision makers may have a different perception of the nature and scope of barriers to opioid use. We therefore aimed at comparing the perception of barriers in different stakeholder groups in the field of pain management, palliative care and harm reduction.

Methods: Data were collected during ATOME national conferences in 4 countries (Estonia, Hungary, Latvia, Serbia) using a questionnaire on knowledge and attitudes regarding medical use of opioids (true/false items), and on the perception of different types of barriers (4-point Likert scales).

Results: Questionnaires were completed by 142 stakeholders, among which 59% healthcare professionals, 26% government officers / health-care decision makers, and 4% patient representatives. Inadequate knowledge, absence of specific national policies, concerns about opioid dependence, and lack of financial resources were most
often perceived as a major barrier. Considerable differences were identified between groups; overall, government officers perceived issues least often as a major barrier compared to the other stakeholders.

**Conclusion:** This survey provides empirical substantiation for the observation that government officers, healthcare professionals, and patients have a different perception of barriers to access to opioid medicines. These findings were also reflected during workshops within the ATOME project: for government officers it is often difficult to imagine the practical impact of certain regulations, while a lack of adequate knowledge on opioid medicines appears to discourage many healthcare professionals from trying to cope with potential obstacles. Intensified dialogue is necessary to facilitate a mutual understanding and develop effective solutions.

**Abstract number:** P11  
**Abstract type:** Poster Discussion  

**Key Criteria for Medical Decisions about Life-sustaining Treatment in Children: Focus Groups with Clinicians**  

**Lotz J.D.**, **Marhold C.**, **Jox R.J.**, **Borasio G.D.**, **Führer M.**

1University Children's Hospital, Ludwig-Maximilians University, Munich, Germany, 2Institute of Ethics, History and Theory of Medicine, Ludwig-Maximilians University, Munich, Germany, 3Centre Hospitalier Universitaire Vaudois, Service des Soins Palliatifs, Lausanne, Switzerland

**Background:** In children with life-limiting conditions, decisions regarding life-sustaining treatment (LST) are challenged by: prognostic uncertainty, high emotional burden, lacking ability to communicate of many pediatric patients. Clinicians' understanding of the child's best interest plays a key role in LST decision-making. Our aim was to investigate pediatricians' attitudes on key criteria for medical decisions about LST for children.

**Methods:** We conducted two focus groups with six pediatricians from different specialities involved in the care of children with life-limiting conditions. They discussed LST for two case scenarios that varied according to diagnosis, age and gender. The discussions were analyzed by content analysis to identify key criteria for LST decisions.

**Results:** Participants viewed empirical data and expert consultations as important information sources in LST decisions. They discussed medical and other criteria that would influence their decision: Medical criteria related to the current health status, medical history and prognosis (risk for complications, reversibility of neurological damage, future ability to participate in social life). Psychosocial factors related to the family's psychosocial situation and readiness for limiting LST as well as the child's (presumed) will. Economic factors (financial costs for the family/society, just distribution of limited resources) were also considered. Ethical considerations related to patient autonomy and the protection of human life. Clinicians were also influenced by personal factors such as their own intuition, discomfort with withdrawing treatments, hope for medical progress and fear of over-treatment.

**Conclusion:** When making medical decisions about LST, pediatricians consider medical, psychosocial, economic, ethical and personal factors. Medical decisions are also influenced by parent/patient preferences. There is a need for empirical data on treatment outcomes that may inform clinicians' decisions.

**Abstract number:** P12  
**Abstract type:** Poster Discussion  

**Implementing and Evaluating the Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care in Australia**  

**Aoun S.**, **Toye C.**, **Grande G.**, **Ewing G.**, **Stajduhar K.**

1Curtin University, Perth, Australia, 2Manchester University, Manchester, United Kingdom, 3Cambridge University, Cambridge, United Kingdom, 4University of Victoria, Victoria, BC, Canada

**Aim:** To investigate the extent to which a carer assessment tool of support needs in end of life home care improved perceived support, carers' psychological and physical wellbeing and carer strain and distress.

**Methods:** The target group consists of primary carers of terminally ill patients referred to Silver Chain Hospice Care in Western Australia, 2012-13. CSNAT consists of 14 items, with the first set covering support that enables the carer to care for the patient at home and the second set covering support for the carer in their caring role. An RCT was used to trial the CSNAT intervention (stepped wedge design) in 3 sites. The outcome measures at baseline and follow up were compared for the control and intervention groups. Feedback on using the CSNAT was sought from carers in the intervention group through telephone interviews.

**Results:** The most significant difference between the control (n=89) and intervention (n=163) groups was in carer strain increasing for the control group between baseline and follow-up, while this remained the same for the intervention group (p=0.017). The 3 most frequent needs for carer support related to (a) knowing what to expect in the future (52%), (b) having time to yourself in the day (43%) and (c) dealings with your feelings and worries (36%). The carers were positive about the CSNAT being easy to complete, helped acknowledge their support needs and they got the timely support they needed.

**Conclusions:** The CSNAT is a useful tool to elicit carer concerns in a systematic way. The tool represents a simple, yet potentially effective intervention to help palliative care providers better assess and address carer needs.
EAPC2014: Posters

Abstract number: P13
Abstract type: Poster

Efficacy of Speed Feedback Therapy against Cognitive Decline in Elderly Cancer Patients

Miki E., Kataoka T., Okamura H.
Hiroshima University, Graduate School of Biomedical & Health Sciences, Hiroshima, Japan

Aims: There have been no reports on the rehabilitation practices for cognitive decline in elderly cancer patients. We conducted this study with the aim of demonstrating the efficacy of speed feedback therapy against cognitive decline in elderly cancer patients.

Patients and methods: The subjects were patients with breast or prostate cancer who were 65 years of age or over. Among 146 patients, 78 who fulfilled the eligibility criteria for this study and provided consent for participation were randomly assigned to an intervention group (N = 38) or a control group (N = 40). The intervention group received intervention consisting of speed-feedback therapy with a bicycle ergometer for 4 successive weeks. Evaluations were carried out both before and immediately after the intervention using the Frontal Assessment Battery (FAB), the Barthel Index (BI), Lawton and Brody Instrumental Activities of Daily Living (IADL), and the Functional Assessment of Cancer Therapy-General ver.4 (FACT-G).

Data were analyzed by a two-way repeated-measures analysis of variance (ANOVA).

Results: Comparison of the scores on each of the evaluation scales by the two-way ANOVA showed significant differences between the two groups in interaction (p = 0.006) and main effect (time: p < 0.001 and group: p = 0.003) on the FAB, an evaluation scale used to determine frontal lobe function.

Conclusion: These results suggested that speed feedback therapy is effective for improving the cognitive function in elderly cancer patients.

Abstract number: P14
Abstract type: Poster

Inner Curriculum in Palliative Care Professionals: A New Instrument for Self-care Assessment

Galiana L.1, Sansó N.2,3, Oliver A.1, Barreto P.1, Jiménez E.4, Pascual A.5, Benito E.2
1University of Valencia, Valencia, Spain, 2Ibsalut, Palliative Care Program of the Balearic Islands, Palma de Mallorca, Spain, 3University of Balearic Islands, Palma de Mallorca, Spain, 4Institut Català de la Salut (ICS), Granollers, Spain, 5Sant Pau Hospital, Barcelona, Spain

Aims: Working in palliative care involves risks of burn-out and compassion fatigue among professionals. Although self-care is recognized as an important factor preventing these risks, we do not have self-care evaluation tools of easy clinical application. The evaluation of a new brief questionnaire of 9 items and 0 to 4 Likert type scale of response is presented.

Method: A cross-sectional design was implemented, and 387 Spanish palliative care professionals from all along Spain were surveyed by an on-line platform. Of those, 43.0% were doctors, 33.1% nurses, 14.2% psychologists, 4.0% social workers, 4.8% nursing assistants and 0.8% had more than one profession. Together with the new self-care scale, data from variables such as awareness, coping with death, or quality of life were collected. A confirmatory factor analysis was estimated, in which three factors of self-care were proposed: physical, social and inner self-care. Besides the structural equation model, correlations for criterion-related validity and estimates of reliability were obtained.

Results: Confirmatory factor analysis overall fit indices mainly supported the three factor structure of the scale: c2 (24) was 126.595 (p < .01), CFI was .908, GFI was .925, SRMR was .094, and RMSEA was .108. Altogether, the indexes showed the model as an adequate representation of the observed data. Cronbach’s alpha was .781 and the relations of self-care and the related variables were in the expected direction.

Conclusion: The new instrument shows good psychometric properties and could be easily used in clinical studies.

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Abstract number: P15
Abstract type: Poster

Trajectories of Depressive Symptoms for Bereaved Family Caregivers of Terminal Ill Cancer Patients

Kuo S.C., Tang S.T.
Chang Gung University, School of Nursing, College of Medicine, Kwei-Shan Tao-Yuan, Taiwan, Republic of China

Aims: Bereaved family caregivers’ grieving is a dynamic and individualized process. However, there are some limitations inherent in the few studies that treat grieving as heterogeneous, including insufficient follow-up, the intervals between assessments being too long, and inadequate sample sizes. In addition, trajectories of depressive symptoms have never been explored among bereaved caregivers of terminal ill cancer patients. Therefore, the purposes of this study were to identify distinct trajectories and to estimate the prevalence of each trajectory for bereaved caregivers of terminal ill cancer patients.
Methods: Caregiver depressive symptoms were measured by Center for Epidemiological Studies Depression Scale at 1, 6, 13, 18, and 24 months post-bereavement among a convenience sample of 352 bereaved caregivers. Distinct trajectories were identified by latent class analysis.

Results: Five trajectories were identified and named as endurance, resilience, grief reaction, chronic grief, and chronic depression, and contained 28.6%, 21.2%, 36.9%, 1.4% and 8% of the sample, respectively. Bereaved caregivers in the “endurance” group have consistently low levels of depressive symptoms over time. “Resilience” and “grief reaction” group’s distress return to their pre-bereavement level by 6 months post-bereavement. However, the “resilience” group suffered from higher depressive symptoms than the “grief reaction” group initially. “Chronic grief” and “chronic depression” groups were with high depressive symptoms which extended into 24 months post-bereavement, but “chronic grief” group’s depressive symptoms improved rapidly by 24 months post-bereavement, with the potential to fall below clinical threshold later.

Conclusion: Bereaved caregivers did not have uniform emotion responses to their relative’s death. By identifying trajectories of caregivers’ depressive symptoms, suitable interventions can be provided to facilitate rapid returning to healthy psychological function.

Abstract number: P16
Abstract type: Poster

Finding Meaning in Euthanasia and Physician Assisted Suicide: Accounts of Dutch Bereaved
Snijdewind M.1, van Tol D.2, Onwuteaka-Philipsen B.3, Willems D.1
1Academic Medical Center, University of Amsterdam, Department of General Practice, Section of Medical Ethics, Amsterdam, Netherlands, 2University Medical Center Groningen, Department of General Practice, Groningen, Netherlands, 3VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Expertise Center for Palliative Care, Amsterdam, Netherlands

Aims: In research about euthanasia and physician assisted suicide (EAS) the experiences of the bereaved have gained little attention. We tried to gain insight into how the bereaved evaluated the whole experience and what moments in the period of the (upcoming) EAS were of special significance to them.

Methods: We performed in-depth interviews with 21 bereaved of patients who had died by the performance of EAS. In the interviews the bereaved described their experience of the period of time from the moment of the request for EAS up to the death of the patient. Through open coding and inductive analysis, we identified different moments that were meaningful to them.

Results: It was remarkable that when the interviewees talked about the experience of the whole process towards EAS - although it had been a hard and sad time - positive remarks dominated their stories. The following moments were of particular meaning for the bereaved: sharing food, exchanging gifts, organizing the funeral, being there during the performance of EAS and looking back at the experience as beautiful and special.

Conclusion: Traditionally, transitional states like a death or funeral are surrounded by rituals, so-called rites de passage. The whole process of talking about EAS, anticipating and organizing the upcoming funeral, saying goodbye to their loved one, being there during the performance of EAS and afterwards returning to life as usual and looking back upon the experience as meaningful, follows the pattern of a ritual. Within this larger ritual, we can see smaller rituals, like the exchange of gifts. A notable aspect about EAS is that death is planned ahead carefully which leaves room for rituals to take place preceding the actual death in which the person waiting for EAS can participate. The presence of such rituals contributes to meaningful experiences which may help the bereaved cope with their loss.

Abstract number: P17
Abstract type: Poster

Predicting Psychological Distress among People who Care for Longterm Survivors of Primary Malignant Glioma
Russell B.J.1, Collins A.1, Dally M.2, Gold M.1, Dowling A.3, Murphy M.3, Philip J.1
1Centre for Palliative Care, St Vincent’s Hospital, Melbourne, Australia, 2The Alfred Hospital, William Buckland Radiation Oncology Service, Melbourne, Australia, 3The Alfred Hospital, Department of Palliative Care, Melbourne, Australia, 4St Vincent’s Hospital Melbourne, Department of Medical Oncology, Melbourne, Australia, 5St Vincent’s Hospital Melbourne, Department of Neurosurgery, Melbourne, Australia

Aim: Caregivers of longterm survivors of primary malignant glioma (PMG) have the unique and stressful challenge of caring for a person with cognitive impairment as well as cancer-related issues over a prolonged period. This study aims to identify factors that predict psychological distress in this population.

Method: Fifty-one caregivers (32%) of eligible patients with PMG surviving greater than two years were recruited from two Australian metropolitan tertiary hospitals. Caregivers completed cross-sectional measures of psychological distress (GHQ-12), strain and family wellbeing (FACQ-PC) and patient functional wellbeing (FACT-Br).
Correlational analyses were performed to identify factors related to caregiver psychological distress. Those of significance ($p \leq 0.01$) were further explored using a hierarchical multiple regression model to determine their predictive value.

**Result:** Caregivers were mostly male (62%), spouses (71%), living in the same residence (80%) and caring for a median of 6.0 years. Whilst caregivers overall reported minimal psychological distress, one in four were at increased risk warranting clinical attention. Caregiver psychological distress significantly correlated with patient functional wellbeing ($r(44) = -0.49$, $p = 0.001$), caregiver strain ($r(44) = 0.47$, $p = 0.002$) and family wellbeing ($r(44) = -0.49$, $p = 0.001$), but not other factors. Controlling for caregiver age, gender and relationship to the patient, only patient functional wellbeing significantly predicted caregiver psychological distress ($\beta = -0.52$, $t(35) = -3.56$, $p = 0.001$), accounting for 26% of variance.

**Conclusion:** Findings suggest patient functional well-being is the most important predictor of psychological distress among caregivers of longterm survivors of PMG. Duration of caregiving, performance status, symptom burden, and disease or demographic related factors were not predictive. Periodic screening of long-surviving patients is recommended to identify those caregivers at greatest risk.

**Abstract number:** P18
**Abstract type:** Poster

**Making Sense of Continuous Sedation in End of Life Care for Cancer Patients: An Interview Study with Bereaved Relatives in Three European Countries**


1Erasmus Medical Centre, Public Health, Rotterdam, Netherlands, 2De Montfort University, School of Nursing and Midwifery, Leicester, United Kingdom, 3Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 4Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 5University of Nottingham, Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, Nottingham, United Kingdom

**Aims:** To explore relatives’ experiences of continuous sedation in end-of-life care and to identify and explain differences between respondents from the Netherlands, Belgium and the UK.

**Study population:** 38 relatives of 32 cancer patients who received continuous sedation until death.

**Design and methods:** Qualitative case study design, based on face-to-face interviews.

**Methods of statistical analysis:** The interviews were transcribed verbatim and analyzed with the help of qualitative analysis software (NVIVO 9).

**Results:** Most relatives used the term ‘sedation’ or ‘palliative sedation’ while referring to the use of continuous sedation until death. Their descriptions of the practice referred to the outcome of the sedation, to practical aspects of using sedation and to the goals of sedation. Nevertheless, several relatives were left with questions about what sedation entails. Most relatives believed sedation had contributed to a ‘good death’ for the patient. Yet many relatives expressed concerns regarding the wellbeing of the patient or their own wellbeing, whether it may have shortened life (mostly UK), and whether an alternative approach (e.g. euthanasia or a deeper sedation) would have been more suitable. Such concerns were sometimes provoked by unexpected events such as the patient waking. In the Netherlands and in Belgium relatives tended to report that the (often planned) start of the sedation allowed for a planned moment of ‘saying goodbye’. In contrast, relatives from the UK described the use of sedation and therefore the process of saying goodbye as a more gradual and less explicit process.

**Conclusion:** Although most relatives believed the sedation contributed to the patient having a good death, they may also express concerns, which seemed to be related to unexpected events. Differences in the process of saying goodbye between the Netherlands/Belgium and the UK may affect the way relatives cope with the use of sedation for their loved one.

**Abstract number:** P19
**Abstract type:** Poster

**Investigating the Impact of a Carer Support Needs Assessment Tool (CSNAT) Intervention in Palliative Home Care: Stepped Wedge Cluster Trial**

Grande G.E., Austin L., Ewing G.

1University of Manchester, School of Nursing, Midwifery & Social Work, Manchester, United Kingdom, 2University of Cambridge, Centre for Family Research, Cambridge, United Kingdom

The CSNAT intervention facilitates comprehensive needs assessment, enabling family carers to indicate, prioritise and identify solutions to support needs aided by practitioners.

**Aim:** To test whether the CSNAT intervention improved carer perceptions of end of life support and outcomes post-bereavement.

**Method:** 15 month stepped wedge cluster trial with six palliative home care services: services changed from being a control cluster to an intervention cluster in a set sequence. Carers who experienced the control condition (standard end of life support) were compared with those who experienced...
the intervention. Outcome measures were collected through self-completed postal surveys with carers 4-5 months post bereavement, including perceived adequacy of end of life support, grief (Texas Revised Inventory of Grief) and distress (Distress Thermometer). Process data were collected on CSNAT assessments, and qualitative data on practitioners’ experiences of CSNAT. The trial is ongoing. To date data have been collected on 333 control and 114 intervention carers. Preliminary exploratory comparison of outcomes between control and intervention conditions used t-tests and Mann-Whitney U-tests.

Results: Preliminary results indicate no significant differences in outcome between carers in the control and intervention condition. Process data, however, suggest the intervention was not implemented at a sufficient level to have an impact: only a small proportion of eligible carers had effective CSNAT assessments with follow up. Often CSNAT was simply used as a form left with the carer or not introduced at all. Qualitative data suggest that several factors that operated at structural, procedural and inter-relational levels combined to hinder effective implementation of carer support needs assessment. Change management, addressing these different levels of factors, is required to embed comprehensive carer support needs assessment into palliative home care.

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Abstract number: P20
Abstract type: Poster
Defining Complicated Grief is Complicated - A Review

Ollars C.L.1, Guldin M.-B.1,2, Vedsted P.2,3, Bonde Jensen A.1

1Aarhus University Hospital, Department of Oncology, Aarhus, Denmark, 2Aarhus University Hospital, Research Unit for General Practice, Aarhus, Denmark, 3Aarhus University Hospital, Danish Research Centre for Cancer Diagnosis in Primary Care - CaP, Aarhus, Denmark

Background: Bereavement support is an important but challenging task within palliative care. In the bereavement literature a diagnosis of Complicated Grief (CG) has been proposed to classify individuals who suffer from painful and persistent grief reactions associated with comorbidity, functional impairment and mortality. However, researchers disagree on the specific diagnostic criteria, which are reflected in the many different names applied to the concept (e.g. Pathologic Grief, Traumatic Grief, Prolonged Grief and Prolonged Grief Disorder).

Aim: The aim of the study is to perform a literature review and synthesize different definitions and symptoms of the concept of CG.

Method: A literature search was performed in PubMed and PsychInfo based on the mesh terms: bereavement, grief and reproducibility of results; combined with the keywords: validity, pathological grief, traumatic grief, prolonged grief disorder, prolonged grief and complicated grief. Inclusion criteria were population age 19+, quantitative studies, published after 1995. Of the 33 studies found, 8 studies were excluded as they based on their abstracts did not investigate CG resulting in the inclusion of 25.

Results: Preliminary synthesis confirms that CG has been shown to be distinct from other mental disorders, but show considerable symptom overlap with depression, anxiety disorders and Post Traumatic Stress Disorder. Studies show a general agreement on the primary symptoms of CG, however the descriptions and importance of secondary symptoms lack uniformity.

Conclusion: Despite consensus of CG as a diagnostic entity there is a lack of uniformity in the understanding and concept of CG. Palliative care has the potential to provide early assessment of maladaptive grief reactions that could help secure early intervention. However, agreement on the definition of CG is essential to bereavement support reaching people in need.

Abstract number: P21
Abstract type: Poster
Screening for Depression in Advanced Disease: Psychometric Properties of Two Items of the Palliative Care Outcome Scale (POS)

Antunes B.1, Murtagh F.1, Bausewein C.2, Harding R.1, Higginson I.J.1, on behalf of EUROIMPACT

1King’s College London, Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Interdisziplinäres Zentrum für Palliativmedizin, Klinikum der Universität München, Munich, Germany

Context: Depression is common among patients with advanced disease but is often difficult to detect.

Aims: To explore the Palliative care Outcome Scale 10 items and determine what are the most appropriate items to screen for depression among people with advanced disease.

Methods: Secondary analysis of data from five studies. Four psychometric properties were assessed: data quality, scaling assumptions, acceptability and internal consistency (reliability). Receiver operating characteristic curves were used to determine the area under the curve. Sensitivity, specificity, positive and negative predictive values, false positive and negative rates and positive and negative likelihood ratios were computed for different cut-offs of the palliative care outcome scale items under study. The Geriatric Depression Scale-10 items total score and the Hospital and Anxiety Depression Sub-scale total score were used to assess presence or absence of depression.
Results: Overall sample of 416 patients from Germany and England: 144 had cancer, 60 had chronic obstructive pulmonary disease, 82 had Parkinson, 74 had advanced renal disease and 51 had heart failure. Floor and ceiling effects were rare. Overall median scores were slightly below the midpoint. Two items combined - feeling depressed and feeling good about self - consistently presented the highest area under the receiver operating characteristic curve, ranging from 0.76 (C.I.:0.60-0.93) (German lung cancer) to 0.97 (C.I.:0.91-1.0) (heart failure), highest negative predictive value and lowest false negative rate. For the overall sample, at cut-off 2/3: negative predictive value= 89.4% (C.I.:84.7-92.8); false negative rate=10.6 (C.I.:7.2-15.3).

Conclusion: Like other depression screening tools the Palliative care Outcome Scale is good for excluding true negative cases of depression. It can be used in patients with different advanced diseases. Items 7 and 8 combined are the most appropriate to screen for depression.

Abstract number: P22
Abstract type: Poster

Do Anticipatory Grief Symptoms and Preparedness Affect Distress in Bereaved Family Caregivers? A Nation-wide Cohort Study
Kjaergaard-Nielsen M.1, Bro F.2, Neergaard M.A.3, Jensen A.B.4, Guldin M.-B.2,3
1Aarhus University, Research Unit for General Practice, Aarhus, Denmark, 2Research Unit for General Practice, Aarhus University, Aarhus, Denmark, 3Aarhus University Hospital, Palliative Team, Department of Oncology, Aarhus, Denmark, 4Aarhus University Hospital, Department of Oncology, Aarhus, Denmark

Objective: Family caregivers of terminally ill patients are in a vulnerable position, and previous studies show that bereaved caregivers are at risk of psychological distress. Pre-loss grief symptoms seem to predict post-loss psychological distress, while preparedness for a looming loss tends to decrease distress.

The aim of this nation-wide study was to investigate the association of both anticipatory grief symptoms and pre-loss preparedness with psychological distress in bereaved family caregivers.

Methods: A list of all adult patients in Denmark receiving drug reimbursement for terminal illness was retrieved from the Danish Health and Medicines Authority on a weekly basis during 2012. All newly registered patients were requested by letter to pass on an enclosed baseline questionnaire to their closest relative. Responding caregivers bereaved within six months received a follow-up questionnaire six months after the loss. The baseline questionnaire included a pre-loss version of the Prolonged Grief-13 and one question regarding caregiver preparedness, while the follow-up questionnaire contained the Prolonged Grief-13 and Beck’s Depression Inventory II.

Results: Of the contacted 9,512 patients 3,636 caregivers completed the baseline questionnaire (response rate: 38%). At the end of October 2013, a total of 2,366 bereaved caregivers received a follow-up questionnaire and 2,010 completed it (response rate: 85%). By the end of 2013, the follow-up period will end and findings will be presented, including descriptive statistics and an analysis of the association of both anticipatory grief symptoms and pre-loss preparedness with post-loss grief symptoms and depression.

Conclusions: This study will provide valuable information on the associations of anticipatory grief and preparedness with psychological distress during bereavement. Early identification of caregiver’s needs is crucial to optimize support and reduce psychological distress during bereavement.

Abstract number: P23
Abstract type: Poster

The Financial Costs of Family and Whānau Caregiving within a Palliative Care Context
Gott M., Moeke Maxwell T., Allen R., Robinson J., Gardiner C.
University of Auckland, School of Nursing, Auckland, New Zealand

Research aims: To explore the financial costs of caring for family caregivers within a palliative care context and gain family caregivers’ perspectives on the importance of, and preferred methods to conduct, future research in this area.

Study population: Thirty current or recent family and whānau caregivers of people with a life limiting condition in Auckland, New Zealand.

Study design and methods: Phase one comprised a systematic review of the literature. Phase two involved interviews with family and whānau caregivers recruited from:

1) a hospital-based specialist palliative care service;
2) via community media targeted at recruiting Māori caregivers.

Analysis: A narrative gerontology framework informed analyses. A Kaupapa Māori methodology informed methods and analyses with Māori participants.

Results and interpretation: The systematic review identified a number of studies reporting data relevant to the costs and impact of family caregiving at the end of life; however, none had this issue as their central focus and no validated tools were identified for collecting financial data within a palliative care context. Interview participants
reported the financial costs of caregiving as an important topic for future research, although a number of challenges for designing future studies were identified. Face-to-face contact with the researcher was preferred by most; mixed views were expressed about collecting information via cost diaries. It was evident that participants had incurred financial hardship as a result of caregiving, with some amassing significant debt. Direct costs discussed included those related to telephone, food, parking, medications, and funeral/tangi costs. Indirect costs relating to employment, their own health, and their credit rating were also reported. This study confirms the financial costs of family caregiving as an important topic for future research and provides recommendations as to preferred research methods from the carer perspective.

Abstract number: P24
Abstract type: Poster
The Benelux Experience and Mainstream Palliative Care’s Objections to Legal Euthanasia
Bernheim J.L.1, Chambaere K.2, Deliens L.3,4
1 Vrije Universiteit Brussel (VUB), End-of-Life Care Research Group, Brussel, Belgium, 2 Vrije Universiteit Brussel (VUB) & Ghent University, End-of-Life Care Research Group, Brussel, Belgium, 3 Vrije Universiteit Brussel & Ghent University Brussel, End-of-Life Care Research Group, Brussel, Belgium, 4 VU University Medical Center, EMGO Institute, End-of-Life Care Research Group, Amsterdam, Netherlands

Aims: In 2003 the EAPC Ethics Taskforce’s intellectually legitimate objections to legal euthanasia were

1) possible stunting of the development of palliative care (PC),
2) risks of slippery-slope effects and
3) erosion of confidence in medicine.

Eleven years of legal euthanasia in Belgium and the Netherlands (BeNe), joined in 2009 by Luxembourg, now inform these concerns.

Methods:

1) Analysis of the trends in indicators of PC strength between 2005 and 2012 in the EAPC atlases,
2) systematic review of the peer-reviewed literature and
3) European Values Survey data on confidence.

Results:

1) Between 2005 and 2012 Luxembourg and the Netherlands strongly developed PC services, climbing in rank among the top seven of over 40 European countries. Belgium doubled its expenditure for PC and stays among the seven best European countries.
2) In BeNe indicators like increased impact of PC and more consultation before end-of-life decisions suggest that the overall quality of end-of-life care improved. Overall incidences of life-ending without explicit request decreased and did not increase among vulnerable patients, who are under-represented among euthanasia recipients. More transparency has improved societal control over end-of-life practices.
3) The confidence of Belgians in their health-care system increased from 87% in 1999 to 92% in 2008.

Conclusions: Concerns that legal euthanasia could stunt PC development are not verified in the Benelux countries, slippery-slope effects did not materialize and public confidence in health care has not suffered. The developments in Belgium and Luxembourg, where legal regulation of euthanasia was accompanied by a law mandating universal access to PC, suggest that the cause of PC may have been furthered. If only because some effects of legal euthanasia may manifest only later or in more subtle ways, developments in both permissive and non-permissive countries should be further monitored and indicators of patient outcomes should be included.

Abstract number: P25
Abstract type: Poster
Facilitating a Shift to Comprehensive Carer-led Assessment in Palliative Home Care: The CSNAT Approach
Austin L.1, Ewing G.2, Grande G.1
1 University of Manchester, School of Nursing, Midwifery and Social Work, Manchester, United Kingdom, 2 University of Cambridge, Centre for Family Research, Cambridge, United Kingdom

Background: The Carer Support Needs Assessment Tool (CSNAT) is an evidence based tool for comprehensive assessment of carers’ needs. Use of the tool in practice requires a shift from informal practitioner-led methods of identifying carers’ needs to a practitioner-facilitated, carer-led approach.

Aim: To identify training requirements to enable practitioners to move from practitioner-led to carer-led carer support needs assessment.

Method: CSNAT was implemented in six palliative home care services as part of a stepped wedge cluster trial to test if it led to improved carer outcomes. Training was delivered to staff at each site prior to implementation. Qualitative data
were collected on practitioners’ responses to the training, their experiences of using the tool (field notes from training and feedback sessions, monthly contacts with CSNAT ‘champions’), focus groups and interviews with practitioners. Ongoing analysis identified challenges in adopting carer-led assessment and was used to revise training materials for later sites in the trial sequence using an iterative approach.

**Results:** The CSNAT was often perceived as a form representing an ‘add on’ to usual practitioner-led practice. Use of the tool to promote carer-led assessment required training explicitly focusing on the use of the CSNAT as an assessment process with delineation of each stage: Introducing the CSNAT, Carer’s consideration of needs, The Assessment Conversation, Shared Action Plan and Shared Review. Each stage is facilitated by the practitioner but at all stages carers can say what is most important to them and what they feel would help support them.

**Conclusion:** Understanding of the CSNAT approach is fundamental to achieving carer led assessment and support in palliative home care. CSNAT approach resources are currently being tested as part of a CSNAT toolkit.

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**Abstract number:** P26

**Abstract type:** Poster

**Poor End-of-Life Care: What Are the Main Problems According to Patients, Proxies, Physicians, Nurses and Chaplains?**

Bolt E.E.1,2, Onwuteaka-Philipsen B.D.1,2, Pasman H.R.W.1,2

1VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, 2VU University Medical Center, Center of Expertise in Palliative Care, Amsterdam, Netherlands

**Background and aim:** Care at the end of life is often a balance between palliative care and curative or life prolonging care. While good end of life care can improve quality of life considerably, poor (or inappropriate) care has a negative impact on quality of life. Many mechanisms that could lead to poor end of life care are identified already, both in the field of palliative care and in the field of curative or life prolonging treatment. However, it is unknown which mechanisms are most relevant and which problems should be tackled first. The goal of this study is to identify and prioritize the main problems in end of life care, in order to direct policy makers and physician organizations.

**Methods:** An online survey is held amongst Dutch citizens and care providers with experience with end of life care. They were invited to participate through multiple channels. Using open ended questions, respondents were asked to describe their experience with end of life care, and to describe why this experience was positive or negative.

**Results:** Eighty-eight patients, 570 proxies, 349 physicians, 389 nurses, 100 chaplains, 88 paramedics and 63 others participated. In total, 987 positive cases and 803 negative cases were described. In most cases, patients suffered from cancer (62%). In the negative cases, physicians focused mostly on the problem of overtreatment (with a curative or life prolonging goal) (57%) and less on poor palliative care (23%), while patients and proxies mentioned poor palliative care (39%) more often than overtreatment (30%). Overtreatment was caused by problems in communication or in decision making in most cases, while causes for poor palliative care were more diverse and included insufficient collaboration between caregivers, a lack of support from caregivers and a lack of knowledge about palliative care.

**Conclusion:** Based on this research, we recommend focusing both on the prevention of overtreatment and the improvement of palliative care.

**Abstract number:** P27

**Abstract type:** Poster

**Feelings of Reward among Family Caregivers during Ongoing Palliative Care**

Henriksson A.1,2, Carlander I., Årestedt K.1

1Ersta Sköndal University College and Ersta Hospital, Palliative Research Centre, Stockholm, Sweden, 2Capio Geriatrics, Palliative Care Unit, Stockholm, Sweden

**Objectives:** Palliative family caregivers appear to experience rewards of caregiving concurrent with burdens and negative feelings. Relatively few studies have especially attended to the positive and rewarding aspects in palliative family caregiving. In addition, most studies on rewards are retrospective and examine the experiences of bereaved family caregivers. This study aimed to describe feelings of rewards among family caregivers during ongoing palliative care. A further aim was to compare experience of rewards in relation to sex and age.

**Methods:** The sample consisted of 125 family caregivers and the study took place in three specialist palliative care units and one hematology unit. Participants answered a questionnaire including demographic background questions and the Rewards of Caregiving Scale (RCS). Descriptive statistics were used to describe characteristics of the participants and the level of rewards. Mann-Whitney U test was used to compare differences between groups of different sex and age.

**Results:** Palliative family caregivers reported in general high levels of reward. The largest source of rewards was feelings of being helpful to the patient. This was closely followed by rewards as a consequence of giving something
Abstract number: P28
Abstract type: Poster

Are we Providing ‘a Good Death’ for those who Die at Home? The Views of Bereaved Relatives about Symptom Control and Unmet Communication Needs

Maryland C.R.1,2, Lees C.1, Mason S.3, West A.3, Cox T.4, Ellershaw J.5

1Marie Curie Palliative Care Institute, University of Liverpool, Liverpool, United Kingdom, 2Aintree University Hospital NHS Foundation Trust, Palliative Care, Liverpool, United Kingdom, 3Liverpool Community Health NHS Trust, Liverpool, United Kingdom, 4Marie Curie Palliative Care Institute Liverpool (MCPCIL), Liverpool, United Kingdom, 5Liverpool John Moore’s University, Liverpool, United Kingdom

Aims: To assess symptom control and communication, as perceived by bereaved relatives, using ‘Care Of the Dying Evaluation’ (CODE), a 40-item validated post-bereavement questionnaire. CODE is based on the key components of best practice for care of the dying.

Study population: Next-of-kin (NOK) to adult patients who died an ‘expected’ death at home in Northwest England, UK, from advanced incurable illness between July 2011 and December 2012 and had received care from the community healthcare team.

Study design and methods: A post-bereavement survey with 291 NOK invited to complete CODE at least two months following the bereavement. A reminder letter was sent 4 weeks later. Ethical approval was obtained.

Methods of statistical analysis: As a feasibility study, formal sample sizes were not calculated. Response rate and questionnaire responses were assessed using descriptive statistics (proportions and %).

Results and interpretation: 72 bereaved relatives (24.7% response rate) returned the CODE questionnaire. Participants were mainly female (n=47, 65.3%), a spouse or partner (n=40, 55.6%) and aged 50 years or above (n=57, 79.1%). Most deceased patients had advanced cancer (n=57, 79.2%). Participants reported inadequate control of symptoms with 23 (31.9%) perceiving pain present ‘all of the time’ and 20 (27.8%) reporting restlessness ‘all of the time’. Unmet information needs were highlighted with 24 (33.3%) participants reporting discussions about giving fluids would have been useful. Similarly, 24 (33.3%) reported being informed about what to expect when their family member was dying would have been helpful. Although focus on enabling more patients are able to die at home is important, evaluating the quality of this care is essential. Despite limitations due to small sample size and participant representativeness, more proactive means to improve symptom control and screen about pertinent end-of-life care issues is required within the community setting.

Abstract number: P29
Abstract type: Poster

Family Care for People with Dementia: Support through Training and Experience Exchange

Reitinger E.1, Heimerl K.1, Hoppe M.2, Fercher P.2

1Alpen-Adria University of Klagenfurt, IFF - Palliative Care and Organizational Ethics, Vienna, Austria, 2Austrian Institute of Validation, Klagenfurt, Austria

Aims: Family Care givers are the most important group in the care for people with dementia. Being aware that palliative care with people with dementia has to be supportive even in early stages of the disease a training course in validation ® has been offered for family care givers. The aims of the presented study are to describe the effects of the training course for the relatives and to find out supporting factors for a “dementia friendly society”.

Methods: Within a qualitative research design a small scale study encompassing 3 expert interviews, one focus group with care giving relatives and 3 narrative interviews with families living with a person with dementia were conducted. Additionally typical situations of the film taken during the training course are identified, transcribed and analysed. Data are analysed individually and within an interdisciplinary team.

Results: First results show that the training course in validation ® had very positive effects for the family care givers. Learning that the loved person suffers from dementia and changes in personality are one possible expression of the disease make accepting care giving easier. Understanding and cultivating communicative behaviour based on validation ® helps to deal with difficult situations in every day life. Exchanging experiences supports talking about taboos and gives emotional relief. Gender effects...
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can be observed in the need for emotional vs. practical assistance.
Conclusion: Based on the first results direct support for family care givers of people with dementia through training in validation® seems to be a core element of professional supply. Breaking the silence that often is associated with dementia and talking about difficult and challenging experiences strengthens coping strategies. Elements of a “dementia friendly society” are connected with public offers of professional support and relationships within the community.

Abstract number: P30
Abstract type: Poster

“It’s like I’ve Become a Piece of Furniture” - Decision-making to With-hold and Withdraw Dialysis Treatment: A Qualitative Synthesis

Hussain J.A. 1, Flemming K. 2, Johnson M. 3
1Hull York Medical School, York, United Kingdom, 2University of York, York, United Kingdom, 3University of Hull, Hull, United Kingdom

Background: Nephrology teams have made significant advances in incorporating advance care planning into their clinical practice. This is particularly true for the decision to commence dialysis, but less is known about how patients are supported to make decisions about withdrawal.
Aim: To explore the decision-making process for patients with end stage kidney disease and their healthcare team (HCT) regarding with-holding and withdrawing dialysis.
Method: A systematic review of qualitative studies. The search strategy was peer-reviewed and two independent researchers were involved in screening, data extraction, quality appraisal and synthesis. The Hawker et al (2002) appraisal checklist was used to provide an assessment of quality. The synthesis was conducted using thematic analysis.
Results: Eleven studies were eligible for inclusion, including 177 patients and 53 HCT members.
With-holding dialysis: Patients and their informal carers struggle with the decision-making process but decisions were made in the context of a formal and supportive education process. HCTs prioritised biomedical factors, which influenced the way in which the risks with dialysis or conservative management were presented and the subsequent choice made by the patient.
Dialysis withdrawal: An intimacy develops between the HCT and patients, but support and ‘care’ was provided mainly with reassurance and encouragement to continue dialysis. Patients are reluctant to burden busy nurses. In general, cues that the patient wanted to discuss withdrawal, were missed or managed insensitively. Even when dialysis seemed to be prolonging suffering, treatment was continued until no longer physically possible and patients no longer had mental capacity.
Conclusion: Education on withdrawal from dialysis needs to be developed similarly to pre-dialysis education. Regular support and supervision for HCTs may help to recognise the affect caring has on their interaction with patients.

Abstract number: P31
Abstract type: Poster

Residential Aged Care Staff: Palliative Care Experience, Education and Willingness to Undertake Formal Palliative Care Training

Boyd M., Frey R., Robinson J., Foster S., Gott M.
The University of Auckland, School of Nursing, Auckland, New Zealand

Introduction: Internationally, aging populations have resulted in increasing acuity and complexity of health needs as well as financial and organisational challenges placing the residential aged care (RAC) sector under strain. Moreover, RAC is the most likely place of death for people over 65 years in New Zealand. The objectives of the study were to examine the palliative care related: experience, education and willingness to engage formal in palliative care training of RAC staff.
Methods: Healthcare staff (n = 431) from 53 RAC facilities completed a survey which examined their palliative and end of life care experiences and education needs, as well as factors (both psychological and organisational) influencing engagement in formal palliative care training.
Results: Staff members (109 of 431) most frequently reported that 51-75% of their time was spent caring for residents who were at the end-of-life. However only 199 of 431 (47.2%) of staff reported having undertaken formal palliative care training. Logistic regression analysis of willingness to engage in formal palliative care training included five predictor variables:

a) palliative care experience,
b) support service accessibility,
c) quality of palliative care communications environment,
d) level of burnout, and
e) level of resilience.

Results indicated that the full model, which considered all the five independent variables together, was statistically significant. The strongest predictors were previous palliative care experience and the quality of the palliative care communications environment. Higher scores for burnout predicted a decreased likelihood of engaging in formal palliative care training.
Conclusion: Results indicate that the model variables are important correlates of willingness to engage in formal palliative care training. The results of the study can inform the design and delivery of future palliative care education programmes within RAC to successfully meet the needs of all healthcare staff.

Abstract number: P32
Abstract type: Poster

‘Hoping for the Best... but Preparing for the Worst’: Exploring the Experiences of Healthcare Professionals Caring for People with Uncertain Recovery

Bristowe K1, Carey I2, Hopper A3, Shouls S2, Prentice W4, Caulkin R5, Higginson IJ1, Koffman JS1

1King’s College London, Cicely Saunders Institute, Palliative Care, Policy & Rehabilitation, London, United Kingdom, 2Guy’s and St Thomas’ NHS Foundation Trust, Palliative Care, London, United Kingdom, 3Guy’s and St Thomas’ NHS Foundation Trust, General Medicine, London, United Kingdom, 4King’s College Hospital NHS Foundation Trust, Palliative Care, London, United Kingdom

Background: Recent reports have highlighted the need to improve hospital care for those where clinical uncertainty is present and who may be approaching the end of life. However, recognising clinical uncertainty and planning future care is challenging for healthcare professionals (HCPs). The AMBER care bundle is a systematic approach to managing the care of patients who are clinically unstable, deteriorating, with limited reversibility, and at risk of dying in the next 1-2 months.

Research aims: To explore HCPs’ experiences of providing care for people who are clinically unstable, deteriorating, with limited reversibility, and at risk of dying in the next 1-2 months; and providing care supported by the AMBER care bundle, to inform its future development.

Study design and methods: Semi-structured qualitative interview study of 20 HCPs, purposively sampled from two London hospitals, by; AMBER care bundle experience (+/-); specialty; profession; and seniority. Recruitment ceased once data saturation was achieved. Interviews were transcribed verbatim and analysed using thematic analysis.

Results: Participants described the challenges of recognising uncertainty and deterioration, and then establishing common goals of care across multiple hospital teams. HCPs conveyed the emotional impact of caring for deteriorating patients, often viewing death as failure, and the responsibility of ‘bearing bad news’. They identified the AMBER care bundle as a solution to succinctly communicating the clinical picture, and emotionally preparing HCPs for the worst. However, they raised concerns around the sustainability and consistency in its use.

Conclusions: Providing care to patients with uncertain recovery is associated with considerable clinical and emotional challenges. The AMBER care bundle may support HCPs in delivering this care, however further exploration of the consistency, quality and cost of care supported by the AMBER care bundle is needed.

Funding: Guy’s and St Thomas’ Charity.

Abstract number: P33
Abstract type: Poster

The Voice of Children with Incurable Cancer

Kars M.C.1, de Bock L.C.2, Grypdonck M.H.F.3, van Delden J.J.M.1

1UMC Utrecht, Medical Ethics, Utrecht, Netherlands, 2UMC Utrecht, STR 6.131, Utrecht, Netherlands, 3Ghent University, Nursing Science, Ghent, Belgium

Introduction: In paediatric oncology parents are expected to act and decide in the best interest of their child. To be able to do justice to the child’s interests, the child’s voice has to be heard. There are indications that in the face of their child’s death parents have difficulty doing so.

Aim: To explicate the parents’ expression and handling of ‘the voice of the child’ during the end of life (EOL) of children suffering from cancer.

Population: Parents (n=34) of 18 children with incurable cancer. 37 onetime or repeated individual interviews were held to explore the parents’ experiences in parenting and caring for children with incurable cancer at the EOL.

Design: A grounded theory approach. Two researchers analysed the transcripts, using constant comparison and initial and focused coding. The analysis was supported by NVivo7.

Results: The ‘voice of the child’ becomes manifest in the parents’ expression of the child’s perspective. This was articulated in three different ways: the child’s needs; the child’s perceptions and the child’s interests. The extent to which parents gave expression to the child’s voice varied largely among the parents, but was generally low.

Most parents expressed an intention to act in the child’s best interest. Some of their descriptions seemed to contradict this. Difficulty in coping with loss interfered with the parents’ ability to take the child’s perspective.

Besides actively initiating a conversation, passive strategies were identified, for instance to transfer previously expressed opinions to the current situation. Interestingly motivations for parents to initiate conversations and to avoid conversations with their child were partly identical.

Conclusions: To be able to do justice to the child’s perspective, parents actively have to give their child a voice. The parents’ difficulty in coping with loss hampers their ability to explore the child’s perspective.

Funding: Dutch Cancer Society, Grant agreement UU2004-2992.
Abstract number: P34
Abstract type: Poster

Quality Indicators to Improve the Organization of Palliative Care: Transfer from European to Asian Context

Effendy C.1,2, Vissers K.1, Woitha K.3, RietPaap J.V.1, Tejawinata S.4, Vernooij-Dassen M.1,2,5, Engels Y.3

1Radboud UMC, IQ Healthcare, Nijmegen, Netherlands, 2Gadjah Mada University, School of Nursing, YogyaCarta, Indonesia, 3Radboud UMC, Department of Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands, 4Dr Soetomo Hospital, Center of Development for Palliative and Pain Relief, Surabaya, Indonesia, 5Radboud UMC, Department of Primary and Community Care, Nijmegen, Netherlands

Background: Quality indicators (QIs) can contribute to quality improvement of palliative care (PC) by providing the key elements of its organization. European QIs have been developed for the organization of PC. The aim of this study was to evaluate the transferability of European QIs in the Asian context.

Methods: A two-round modified RAND Delphi procedure to achieve content and face validity was conducted in Indonesia. The European QIs for the organization of PC for hospitals setting were used as a draft structure and process indicators. Multidisciplinary experts were invited to rate the draft QIs regarding clarity and usefulness.

Results: In total, 78 QIs (78%) considered useful and 22 QIs (22%) were rejected as invalid. Six QIs had high agreement (7, 9) both in Indonesia and European: ‘A palliative care team is available in the hospital’, ‘Consultations with the patient/informal caregivers take place in an environment where privacy is guaranteed’, ‘Before discharge, transfer and admission, information regarding care and treatment is given to the caregivers in the next setting’, ‘A physician and a nurse are essential members of a multidisciplinary palliative care team’, ‘All team members must have certified training in PC’ and ‘Structured clinical records are kept for all patients receiving PC’. Data from 50 patient records showed that > 60% patient records had a structured clinical record.

Conclusions: It is feasible to transfer the QIs for the organization of PC from Europe to Indonesian context. Most of the European QIs were considered useful in Indonesia. This might implicate that there is a strong common path in the organisation of care even in countries with profound economic and cultural differences. In the future, this set of process and structure QIs can be used to monitor and evaluate the quality of PC in Indonesia.

Keywords: Asian, European, palliative care, quality indicator, RAND Delphi procedure

Abstract number: P35
Abstract type: Poster

The Loneliness of Grief in Older Parents: A Qualitative Study on the Lived Experience of Older Parents after the Death of their Adult Child due to Cancer

Van Humbeeck L.1, Piers R.1, Dillen L.2,3, Verhaeghe S.4, Grypdonck M.4, Van Den Noortgate N.1

1Ghent University Hospital, Department of Geriatrics, Ghent, Belgium, 2Ghent University Hospital, Oncology Centre, Ghent, Belgium, 3Federation of Palliative Care Flanders, Vilvoorde, Belgium, 4Ghent University, Department of Social Health and Nursing Sciences, Ghent, Belgium

Background: Approximately 10% of older adults (>70 years) are confronted with the death of an adult child. Often these parents remain in the shadow, as loss experiences are considered as an inevitable part of old age. Given the sharp rise of the ageing population gaining insight in the lived experience of these older parents becomes highly relevant and timely.

Methods: Semistructured interviews with 12 parents (≥ 70 yrs) were analyzed using the constant comparative method as proposed by the grounded theory. The analytic process was supported by NVivo 10 and driven by multidisciplinary researcher triangulation.

Results: When an adult dies, the entourage nearly automatically directs its care and attention towards the grieving process of the bereaved nuclear family (i.e., the spouse and children). Also the older parent(s) themselves focus their care on the nuclear family, at the expense of their own grief. Parental grief at old age is therefore often not recognized and/or acknowledged. Moreover, care-dependent older persons attest to hardly any or no chance to pay one’s last respect. Visiting and maintaining the child’s grave and viewing pictures constitute important (silent) channels to remember and to initiate conversations about and with the deceased child.

Conclusion: The main message is to be susceptible to this silent grief of older parents both in geriatric and oncology care settings. These parents continually search (often in a hidden manner) for ways to stay emotionally connected by keeping belongings and cherishing the memories of the deceased child. The challenge for health care professionals is to find ways tailored to the needs of these parents to give voice to their suffering in silence. Pictures seem to make up an important means to help these parents to narrate bit by bit the life story of their child. They offer a footing to find meaning, solace and connection in the oscillation between felt separation pain and memories.
Abstract number: P36
Abstract type: Poster

From Neighbour to Carer - The Role of Non-kin Carers in End-of-Life Care at Home for Older People Living Alone

Pleschberger S., Wosko P.

UMIT - The Health and Life Sciences University / Institute of Nursing and Care Sciences Research, Department of Nursing Science and Gerontology, Vienna, Austria

Background and aim: A growing number of older people are living in a single household and most of them are female. They form a disadvantaged group of society with regard to preferences for care, especially in the last stage of life. Thereby non-kin carers play an essential role. Due to their contribution non-kin carers try to fulfill older people preferences for dying at home. However, there’s still little research on these non-kin-carers. This study aimed at getting insight into support networks of older people living alone with a specific focus on non-kin-carers and the challenges of end-of-life care.

Method: A qualitative design included narrative interviews in retrospect with non-kin-carers (n=15) aged between 52 and 84 years. As part of the case study approach additional interviews with selected health professionals (n=8) were conducted. Theoretical sampling was applied. Qualitative analysis aimed to reveal a typology of relevant phenomena and themes and was supported by MAXQDA software.

Results: Non-kin-care relationships are characterized by their small beginnings, and transition into care mostly happens subtle. The type of support varies with common challenges towards the end-of-life, especially with regard to bodily aspects of care as well as facing death. Non-kin-carers’ attitudes towards death and dying are grounded in prior experiences, which most of them had. Beside these special support arrangements, advance care planning and additional care services, like palliative care teams or 24h-care services, were preliminaries for home-death of older people in single-households.

Conclusion: Health professionals have to be aware of their needs in order to keep arrangements stable. The future of palliative care will have to consider more complex support networks with non-kin-carers playing an important role.

University of Sheffield, Academic Unit of Supportive Care, Sheffield, United Kingdom

Abstract number: P37
Abstract type: Poster

Recording Voices in Palliative Care: Understanding the Impact of Oral History in Bereavement

Winslow M., Smith S.

University of Sheffield, Academic Unit of Supportive Care, Sheffield, United Kingdom

Background: Oral history captures and preserves patients’ voices and involves them in the process of producing their own life histories. A Macmillan pilot project has created five oral history services in the north of England and Northern Ireland, additional to a service established in Sheffield in 2007. A further study has explored the impact of voice recording, highlighting the value of oral history for patients and the significance of voice recordings in bereavement. The research broadens our understanding of support in bereavement.

Aim: To assess the impact of recording an oral history with palliative care patients, and understand how the recording is received in bereavement by family.

Method: Literature review and survey of life story work in palliative care settings; analysis of an existing archive of oral histories; semi-structured interviews with patients, family, bereavement group members and health care professionals.

Results: Analysis of archival and qualitative interview material has highlighted that family and friends appreciate a voice recording above all else: “One day I suddenly thought I can’t remember his voice.” The recording can be cathartic: “Every time I play it, it sounds like he’s in the room, I get a lot of comfort from it.” And knowledge that the person wanted to make a recording for family, and enjoyed doing so, is important: “I think it helped him. He would have liked making a record of his life, for his children and grandchildren”. Some participants commented that listening to an ill voice or an emotional recording can be difficult, but none regretted receiving a recording.

Conclusions: The study has demonstrated that oral history in palliative care, often recorded with family in mind, has benefits for family before and after bereavement and that oral history services can be part of good palliative care.

Abstract number: P38
Abstract type: Poster

A Comparison of Drugs and Procedures of Care in the Italian Hospice and Hospital Settings in the Final Three Days of Life

West E.

University of Sheffield, Academic Unit of Supportive Care, Sheffield, United Kingdom

Abstract number: P38
Abstract type: Poster

A Comparison of Drugs and Procedures of Care in the Italian Hospice and Hospital Settings in the Final Three Days of Life

West E.

Vrije Universiteit Medisch Centrum, Amsterdam, Netherlands, IRCCS Arcispedale S. Maria Nuova, Reggio Emilia, United Kingdom

Research aims: A palliative care approach involves forgoing certain drugs and procedures, weighing burden
against benefit. We aim to investigate the differences in administration of potentially (in)appropriate drugs and procedures in patients’ final three days of life between cancer patients in hospice and in hospital.

**Study design and methods:** This study utilises data on 271 patients, gathered at baseline of a cluster-controlled trial. Drugs and procedures in the final three days of life were recorded. Drugs were classified as potentially appropriate or inappropriate using results of a previous expert study. Procedures were classed as either diagnostic or therapeutic. Differences between hospice and hospital were tested with chi-square tests and with multivariate logistic regression controlling for age, gender, primary tumour, education, marital status, setting they were referred from and number of days as inpatient.

**Results:** 15% of patients in hospital received five or more inappropriate drugs against 2% of hospice patients. In hospital, when given, inappropriate drugs were frequently stopped in the last three days, e.g. anticoagulents were stopped in 65%. Controlled for patient characteristics hospital patients were 3.5 times more likely (95% CI 1.8-6.8) more likely to receive >3 inappropriate drugs, were less likely to receive >3 appropriate drugs (OR=.083, 95% CI .04 -.18), and were 3.5 times more likely to receive 1 or more diagnostic procedure than hospice patients.

**Interpretation:** The results indicate a positive influence from hospice setting on weighing burden and benefit in use of drugs and procedures. Hospitals often stop potentially inappropriate drugs and diagnostic procedures during the final three days of life, which may indicate that the need for a palliative approach is recognised, but at a much later stage than in hospice.

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**Abstract number:** P39  
**Abstract type:** Poster  
**Title:** How and why People with Amyotrophic Lateral Sclerosis Engage with Health Care Services: A Qualitative Study of Service Users’ Experiences in Ireland  

**Authors:** Foley G.1, Timonen V.1, Hardiman O.2,3  

1Trinity College Dublin, School of Social Work and Social Policy, Dublin, Ireland, 2Trinity College Dublin, School of Medicine, Dublin, Ireland, 3Beaumont Hospital, Department of Neurology, Dublin, Ireland  

**Background:** The care approach in amyotrophic lateral sclerosis (ALS) is palliative and people with ALS access health care services from symptom onset to end-of-life care. Few studies had identified how or why people with ALS engage with health care services.

**Aim:** We aimed to identify key parameters of healthcare experiences among people with ALS in Ireland from their viewpoint.

**Methods:** Using grounded theory method, we sampled a geographically diverse group of people with ALS (n=34) from the Irish ALS population-based register. We conducted in-depth qualitative interviews with them about their experiences of services. We analysed data using open, axial, and selective coding procedures, to build substantive theory about how people with ALS engage with health care services.

**Results:** We found that participants engaged openly with healthcare professionals when they felt in control of their care. Participants equated living with ALS to a life of unremitting loss but adapted to loss by exerting control in their interactions with health care services. Rendering control to service providers on participants’ own terms also engendered feelings of control. Family and life-stage roles were primary contexts to how participants responded to ALS and engaged with services. Participants with dependent children were less accepting of impending death and somewhat more likely to engage with life-sustaining interventions than participants in later life. Participants with family made decisions about care in the interest of family. Participants without family felt they had more freedom than people with family to follow through with their own preferences for care.

**Conclusion:** People with ALS adapt to loss by engaging with health care services on their own terms. Life-course trajectories shape how people with ALS engage with services. Disease progression on its own does not determine how and why people with ALS engage with health care services.

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**Abstract number:** P40  
**Abstract type:** Poster  
**Title:** Development of an Integrated End Stage COPD Assessment Tool  

**Authors:** Whitfield A.M.4, Berry P.2, Jackson C.2, Saba T.5, Au G.3, Martin M.4, Tymon L.2, Bennie M.3  

4Blackpool Teaching Hospitals NHS Foundation Trust, Palliative Medicine, Blackpool, United Kingdom, 5Blackpool Teaching Hospitals NHS Foundation Trust, Respiratory Medicine, Blackpool, United Kingdom, 2Queensway Surgery, Poulton le Fylde, United Kingdom, 3Highfield Surgery, Blackpool, United Kingdom, 5Blackpool Teaching Hospitals NHS Foundation Trust, End of Life Team, Blackpool, United Kingdom  

**Introduction:** Chronic Obstructive Pulmonary Disease (COPD) is a progressive disease ultimately resulting in death, usually in a secondary care setting. Historically,
many of these patients have never had the opportunity to discuss their End of Life (EoL) preferences, resulting in unexpected deaths that neither patient nor family are prepared for.

**Problem:** Patients with COPD are not prepared for the progressive nature of the disease and are dying without identifying their Preferred Place of Care.

**Aim:** Whilst developing a COPD pathway, an identifiable gap was evident relating to discussing EoL care. National guidelines recommended asking the Surprise Question to accompany the Gold Standards Framework prognostic indicators. However, no local assessment tools were available to prompt EoL care discussion and planning for patients with COPD reaching their last year of life. The aim was to have a unified approach to this across primary and secondary care.

**Method:** A working group developed an integrated End Stage COPD Assessment Tool incorporating nationally recognised guidelines. This allows the initiation of a Respiratory EoL Care Bundle at an appropriate stage in the disease trajectory and is closely linked to the time line of the North West EoL Care Model.

**Results:** The Respiratory team are now utilizing these documents to initiate early conversations, maximising treatment options and Advance Care Planning in a systematic manner. This information crosses the interface between primary and secondary care. Early results from the introduction of the COPD Assessment Tool will be presented.

**Conclusion:** The integrated End Stage COPD Assessment Tool prompts clinicians to identify the last year of life for patients with COPD. Used as part of the integrated acute and community COPD pathway this will ensure that this important phase of the patient’s illness is considered and will improve communication of their priorities for care across all care settings.

**Abstract number:** P41

**Abstract type:** Poster

**Predictors of Response to Palliative Care Intervention for Chronic Nausea in Advanced Cancer Outpatients**

Rhondali W.1,2, Yennurajalingam S.1, Chisholm G.1, Ferrer J.1, Kim S.H.1, Kang J.H.1, Filbet M.1,2, Bruera E.1

1MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 2Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France.

**Background:** Nausea is a frequent and distressing symptom in advanced cancer patients. The objective of this retrospective study was to determine predictors of response to palliative care consultation for chronic nausea in advanced cancer outpatients.

**Methods:** Eligible patients included were outpatient supportive care center seen consecutively for an initial consultation and who had one follow-up visit within 30 days of the initial consultation. We reviewed the medical records of 1,273 consecutive patients, and 444 (35%) were found to meet the eligibility criteria. All patients were assessed using the Edmonton Symptom Assessment Scale (ESAS). Nausea response was defined as an improvement of at least 30% between the initial visit and the first follow-up. We used logistic regression models to assess the possible predictors of improvement in nausea.

**Results:** Overall, 112 of 444 patients (25%) experienced moderate/severe chronic nausea (ESAS item score ≥4/10). Higher baseline nausea intensity was significantly related to constipation (r = 0.158; p = 0.046) and all the symptoms assessed by the ESAS (p < 0.001). Sixty-eight of the 112 (61%) patients with moderate/severe nausea at baseline showed a significant improvement at the follow-up visit (p < 0.001). The main predictors for nausea response were improvement of fatigue (p = 0.005) and increased appetite (p = 0.003).

**Conclusion:** Baseline nausea was associated with all the ESAS symptom and improvement of fatigue and lack of appetite predicted a lower frequency of nausea at follow-up. More research is necessary to better understand the association between nausea severity and other symptoms and to predict which interventions will yield the best outcomes depending on the mix and severity of symptoms.

**Abstract number:** P42

**Abstract type:** Poster

**Depressive Symptoms in Cancer Patients’ Last Days of Life: A Nation-wide Retrospective Mortality Study**

Janberidze E.1,2, Pereira S.M.3, Hjermstad M.J.1,4, Knudsen A.K.1,2, Kaasa S.1,2, van der Heide A.3, Onwuteaka-Philipsen B.3, on behalf of EURO IMPACT

1Norwegian University of Science and Technology (NTNU), European Palliative Care Research Centre (PRC), Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Trondheim, Norway, 2St. Olavs Hospital, Trondheim University Hospital, Department of Oncology, Trondheim, Norway, 3VU University Medical Center, EMGO Institute for Health and Care Research, Public and Occupational Health, Amsterdam, Netherlands, 4South Eastern Norway, Oslo University Hospital, Regional Centre for Excellence in Palliative Care, Oslo, Norway, 5Erasmus Medical Center, Department of Public Health, Rotterdam, Netherlands

**Introduction and aims:** Reported prevalence rates of depression in cancer vary considerably, and few studies distinguish between depressive symptoms and a depression diagnosis. Study aims were to study the prevalence...
of depressive symptoms at the last days, their relation with other symptoms and patient and care characteristics.

**Methods:** A stratified sample of all deaths in 2005 was drawn by Statistics Netherlands. Questionnaires on patient and care characteristics of the last phase of life were sent to the physicians (N=6860) who signed the death certificates (response 77.8%). We selected adult cancer patients with non-sudden death and who were conscious until death (n=1521). Depressive and other symptoms were scored for the last 24 hours before death from 1 to 5, recoded to 1=no, 2-3=moderate and 4-5=severe. Multivariate multinominal regressions were used to examine which characteristics were associated with depressive symptoms.

**Results:** 72% were 65 years or above, 43% were females. The prevalence of moderate and severe depressive symptoms was 32% and 6% respectively. The regression analysis showed no relationship between moderate and severe depressive symptoms and gender, pain, dyspnoea, and involvement of a spiritual caregiver. Moderate depressive symptoms were associated with older age and having anxiety, confusion, and fatigue (P< 0.05). Severe depressive symptoms were associated with having anxiety, involvement of a psychologist or psychiatrist, involvement of a palliative care consultant/ pain specialist, and not being attended by a physician working in elderly care.

**Conclusions:** One third of the patients experienced moderate depressive symptoms according to attending physicians in the last 24 hours before death. Anxiety was associated with both moderate and severe depressive symptoms. Symptom distress at the end-of-life calls for special attention.

**Acknowledgment:** EURO IMPACT (FP7/2007-2013, grant agreement 264697); ZonMw the Netherlands.

**Abstract number:** P43
**Abstract type:** Poster

**Care Trajectory: Symptom Burden in Advanced Lung Cancer Patients Referred and Not Referred to Palliative Care**

Hermosa Garcia A.M.1, Baracos V.1, Watanabe S.1, Huot A.2, Mawani A.2, Fainsinger L.1, Chu Q.1, Fassbender K.3

1University of Alberta, Edmonton, AB, Canada, 2Alberta Health Services, Edmonton, AB, Canada, 3University of Alberta, Department of Oncology, Edmonton, AB, Canada

**Background:** Recent literature shows that early Palliative Care (PC) involvement in advanced cancer patients leads to better patient outcomes, improved quality of life and survival. However, when and who should initiate this assessment is not yet well-defined for patients receiving cancer treatment. Early integration of PC may improve symptom burden during the entire trajectory of advanced cancer.

**Methods:** We included advanced lung cancer patients (stage IIIb/IV) from a retrospective cohort consisting in patients referred to PC who died in 2010/2011 and whose treatment, standardized assessment and symptom burden data (Edmonton symptom assessment system-ESAS-) were abstracted from PC program databases. We compared these to data obtained independently from a prospective cohort which included patients under the care of oncologists and died 2012/2013. We also calculated the percentage of assessments with a score ≥ 7 (severe) for each ESAS symptom during the last 100 days of life.

**Results:** 54 patients (23 from prospective, 31 from retrospective) had a median survival of 112 and 24 days, respectively with ages between 42-93 (mean of 58.9 ± 9.9 in the prospective group and 70.4 ± 11.6 in the retrospective group). Lung cancer patients referred to PC experienced clinically severe dyspnea, wellbeing and depression at 17.3%, 8.1% and 1.5% of assessments. By contrast, the % of assessments with clinically severe dyspnea, wellbeing and depression in patients not referred to PC was twice as high as in the retrospective cohort, 36.1%, 19.4% and 8.3% (p=0.004, p=0.023, p=0.046; chi-square).

**Conclusion:** There is a significant prevalence of moderate-severe symptoms in patients with advanced lung cancer not referred to PC and that symptom burden may reach levels normally suggestive of a need for referral to a specialist palliative care consultation services.

**Abstract number:** P44
**Abstract type:** Poster

Quality of Life in Palliative Care Patients - Comparison of Single Items with Assessment Tools

Svetlik A.R., Rolke R., Surges S., Radbruch L.

University Hospital Bonn, Department of Palliative Medicine, Bonn, Germany

**Background:** Maintaining or improving quality of life (QoL) is the primary objective of palliative care. Thus the assessment and measurement of this subjective and variable issue is paramount. However, validated assessment instruments often cannot be used adequately in daily clinical practice because of physical and psychological impairments of the palliative-care patients. The aim of this study was to investigate whether a single question is able to substitute longer QoL questionnaires. Two single item instruments were compared with three comprehensive questionnaires.

**Methods:** Palliative patients from the palliative care unit, palliative home care service and ambulant oncologic palliative patients participated in the survey between May 2011 and March 2012. Correlations between single-items and measurement tools were calculated using the Spearman Rank Correlation for ordinal data and Pearson for metrical data. The QoL
questionnaire FACIT-Pal ("Functional Assessment of Chronic Illness Treatment") and the outcome instruments POS ("Palliative Care Outcome Scale") and the German version of the Edmonton Symptom Assessment Scale ("MIDOS") were used for comparison.

Results: Data was collected and analyzed from 72 patients. The single item on QoL showed a low correlation with POS ($r = -0.41$) and FACIT-Pal ($r = 0.32$). An alternative single item about physical and psychological well-being showed higher correlation with POS ($r = -0.63$) and FACIT-Pal ($r = 0.70$). Total scores of FACIT-Pal correlated significantly with POS ($r = -0.72$) and MIDOS ($r = -0.63$).

Discussion: A single item instrument ("How satisfied are you now with your physical and spiritual well-being?") was superior to a single question on QoL ("How would you evaluate your quality of life in the last weeks?") and can be recommended as a substitute for longer QoL questionnaires. MIDOS and POS correlated highly with FACIT-Pal, indicating that these instruments are comprehensive QoL questionnaires.

Results: All CSNAT domains were utilised. Domains where most support was needed were 'Knowing what to expect' (52%); 'Feelings and worries' (49%); 'Understanding your relative’s illness' (41%). Least support was needed with 'Financial, legal or work issues' (18%) and 'Spiritual needs' (9%). Only 9% added comments under 'anything else', but the majority of these were covered by existing CSNAT domains. Lack of support on CSNAT domains was related to higher grief and distress, in particular 'Understanding your relative’s illness'; ‘Dealing with your feelings and worries'; ‘Looking after your own health problems'; ‘Talking with your relative about their illness’ (all $p<0.0001$).

CSNAT domains appear comprehensive and sufficient in covering the support needs of carers during the patient’s end of life care span and are associated with level of grief and distress post bereavement. A study limitation is the cross sectional design. Analysis of the full dataset will be presented at the conference.

The study was funded by NIHR RfPB.

Abstract number: P45
Abstract type: Poster

Do the Domains of the Carer Support Needs Assessment Tool (CSNAT) Fully Encompass Carer Support Needs in End of Life Care and Relate to Bereavement Outcomes?

Grande G.E., Austin L., Ewing G.

1University of Manchester, School of Nursing, Midwifery & Social Work, Manchester, United Kingdom,
2University of Cambridge, Centre for Family Research, Cambridge, United Kingdom

The CSNAT aims to facilitate comprehensive carer needs assessment. While it has been found to have good validity with current family carers, it may not fully cover support needs over the whole end of life care span, particularly the last days.

Aim: To investigate whether the 14 CSNAT support domains capture carers’ support needs over the whole end of life period and relate to differences in outcomes post bereavement.

Sample: Carers of patients supported by six palliative home care services recruited over 15 months. Preliminary analysis is of the first 447 participants.

Method: Secondary analysis of a postal survey self-completed 4-5 months post bereavement. Measures included carers’ need for more support with CSNAT domains during end of life care, early and current level of grief (Texas Revised Inventory of Grief) and distress (Distress Thermometer).

Statistical analysis: Descriptive and non-parametric correlation analysis (Spearman).

Abstract number: P46
Abstract type: Poster

The Process of Preparedness for Caregiving among Family Members in Palliative Home Care

Holm M., Henriksson A., Wengström Y., Öhlen J.

1Karolinska Institutet, Department of Neurobiology, Care Sciences and Society, Stockholm, Sweden, 2Ersta Sköndal University College and Ersta Hospital, Palliative Research Centre, Stockholm, Sweden, 3Capio Geriatrics, Palliative Care Unit, Stockholm, Sweden, 4Gothenburg University, Sahlgrenska Academy, Gothenburg, Sweden

Background: Preparedness for caregiving has been found to be an important concept in palliative home care where family members are taking a great responsibility for the patient’s care. Low preparedness has been linked to negative consequences and a greater burden for these family members. Preparedness has been defined as the perceived readiness to provide care and could be seen as a continuous process rather than a static condition.

Aim: The aim of the study was to describe the process of preparedness for caregiving among family members in palliative home care.

Method: An interpretive descriptive design was chosen. A strategic sampling method was applied and 12 family members of patients in specialised palliative home care were interviewed, using a semi-structured interview guide. The interviews were analysed by constant comparative analysis, using the software program NVivo.

Results: The process of preparedness for caregiving included three patterns: Aware, adjusting and grieving. The process was not described as linear but rather a continuous
process where the family members were moving between the patterns during the trajectory. In all three patterns, grief was an important factor, affecting the caregiver role and the family members’ preparedness for caregiving.

**Conclusion:** Exploring the process of preparedness for caregiving in family members could bring a greater understanding for this group and provide health professionals with new insights in how to support them.

**Abstract number:** P47

**Abstract type:** Poster

**Burden for Family Carers at the End of Life; A Mixed-method Study of the Perspectives of Family Carers and GPs**

*De Korte-Verhoef M.C., Pasman H.R.W., Schweitzer B.P.M., Francke A.L., Onwuteaka-Philipsen B.D., Deliens L.*

1VU Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands. 2NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands. 3Ghent University & Vrije Universiteit Brussel, End-of-Life Care Research Group, Brussels, Belgium

**Objective:** Since many patients spend most of the time at home at the end of life, this may affect the burden for family carers and constitute a risk factor for the patients’ hospitalisation.

**Aim:** This study aimed to explore the degree and type of family carers’ burden in the final three months of the patient’s life, from the perspective of both carers and general practitioners (GPs), and to assess whether family burden is associated with hospitalisation.

**Methods:** Cross-sectional nationwide quantitative questionnaire study among 194 GPs and 74 family carers of patients who died non-suddenly. Additionally, for the qualitative part of the study, in-depth interviews were conducted with 18 family carers. The degree and type of burden were analysed using descriptive statistics. To assess the level of agreement between the GPs’ and of family carers’ assessment for professionals that will help them understand and anticipate carers’ personal needs.

**Results:** The proportion of family carers experiencing a fairly heavy or severe burden increased significantly from 32% (second and third months before death) to 66% (one week before death). Most carers (95%) felt an emotional burden and 29% felt a physical burden in the final week. Three-quarters of carers did not perceive their burden as a problem because caring often felt rewarding. GPs generally assessed family burden to be higher than the family carers themselves. There was no evidence that patients of family carers experiencing a heavy burden were more likely to be hospitalised.

**Conclusion:** The different assessment of family carers’ burden and the increasing emotional and physical burden of family carers towards the end constitute relevant information for professionals that will help them understand and anticipate carers’ personal needs.

**Abstract number:** P48

**Abstract type:** Poster

**Reasons for Hospitalisation at the End of Life: Differences between Cancer and Non-cancer Patients**

*De Korte-Verhoef M.C., Pasman H.R.W., Schweitzer B.P.M., Francke A.L., Onwuteaka-Philipsen B.D., Deliens L.*

1VU Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands. 2NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands. 3Ghent University & Vrije Universiteit Brussel, End-of-Life Care Research Group, Brussels, Belgium

**Objective:** Many patients are hospitalised during the final phase of life, even though most prefer to receive care at home until the end.

**Aim:** To explore the reasons and characteristics of hospitalisation in the final three months of life for patients who died non-suddenly, with a comparison between cancer patients and non-cancer patients.

**Methods:** A nationwide retrospective cross-sectional survey among Dutch general practitioners (GPs). GPs were asked to recall their last deceased adult patient who died non-suddenly and who was hospitalised in the last three months of life. To analyse the significance of differences between avoidable and non-avoidable hospitalisations, descriptive statistics and Chi-square tests were used.

**Results:** Of the 317 hospitalised patients, 65% had cancer. Most common reasons for hospitalisation in the final three months of life were respiratory symptoms (31%), digestive symptoms (17%) and cardiovascular symptoms (17%). Seventy-three percent of patients experienced an acute episode before hospitalisation and for 46% of patients their own GP initiated the hospitalisation. Compared to non-cancer patients, cancer patients were significantly more often aged under 80 (81% versus 46%), were more often hospitalised because of digestive symptoms (22% versus 7%), had less often an curative treatment goal before the last hospitalisation (6% versus 22%) and less often died in hospital (22% versus 49%).
Conclusions: Respiratory problems were the most common reasons for hospitalisation in the group of patients as a whole. Digestive problems were a frequent reason for hospitalisation in cancer patients, and cardiovascular symptoms in non-cancer patients. Hospitalisation can therefore be anticipated by monitoring these relatively common symptoms. Also, timely communication with the patient is recommended about their preferences for hospital or home treatment in the case of an acute episode.

Abstract number: P49
Abstract type: Poster

Terminal Illness Situation Identified in Chronic Patients: A Retrospective Study of Clinical Records
Campos-Calderon C.1, Guardia-Mancilla P.2, Hernandez-Lopez E.2, Alfaya-Gongora M.M.1, Gorlata-Sanchez B.1, Ojeda-Virto F.1, Montoya-Juarez R.1, Huezo-Montoro C.1, Martinez-Cruz E.1, Garcia-Caro M.P.1

1University of Granada, Granada, Spain, 2Servicio Andaluz de Salud, Granada, Spain, 3University of Granada, Melilla, Spain, 4Servicio Andaluz de Salud, Motril, Spain

Aim: Determine how terminal illness situation (TIS) is identified in medical records of advanced chronic patients, and if there exist differences between cancer or non-cancer patients, and patients identified as in TIS and not identified.

Methods: Retrospective design. Clinical records of chronic patients who died between January and December of 2010 in 4 hospitals of Granada (Spain). Data related to TIS identification were collected for the study, such as when it was identified, how it is written in medical records, or criteria that have been used to identify them. In order to compare cancer and non-cancer patients, and patients in TIS and patients who were not in TIS, parametric tests (T Student and Chi-Square) were conducted.

Results and interpretation: 202 clinical records were reviewed. 40% of them were cancer patients. Mean age was 72.8 years (SD=13.85), and 54% of them were men. In 51% of the medical records reviewed, patients were identified as in TIS. Doctors are more likely to identify cancer patients in TIS, than non-cancer patients (p=0.00). 65% of the patients in TIS were identified in the last seven days of life, and 32% in the last 48 hours. The expression “terminal illness” is more used in cancer patients (p=0.03), by the other hand, “poor prognosis” is more used in non-cancer patients (p=0.00). No statistical differences were found between patients identified in TIS and those who were not identified, related to co-morbidity, age, and key symptoms. Disclosure to families is linked to TIS identification (90%), but only in a 4% the situation was disclosed with patients.

Conclusion: Data should be taken carefully because medical records might differ from clinical reality. TIS identification might be improved, in order to begin earlier a palliative care approach. The use of objective criteria to identify the terminal phase should be taken in account.

Funding: Funding received from Consejería de Salud de la Junta de Andalucía.PI-0670 -2010

Abstract number: P50
Abstract type: Poster

Mortality as a Predictor of the Need for Palliative Care in Patients with Advancing Chronic Obstructive Pulmonary Disease
Snow R.J.1, Vogel K.L.2, Ferris F.D.1, Harrold B.2, Vanderhoff B.1

1OhioHealth, Clinical Transformation, Columbus, OH, United States, 2OhioHealth, Pulmonology, Grant Medical Center, Columbus, OH, United States, 3OhioHealth, Administration, Columbus, OH, United States

Background and aim of this study: Hospice and palliative services in the United States (US) have traditionally focused on patients with cancers and other diagnoses who are approaching the end of their lives (in 2010, the length of stay on hospice care was median 19.1, mean 69.1 days). With the recent focus on better coordination of care for patients with chronic conditions, solutions such as the patient centered medical home have been implemented to achieve the goals of better health, better healthcare and lower costs. Early evidence also suggests that early home- base palliative care could be of value in managing the population of patients with multiple chronic conditions. To better understand the potential need for earlier palliative care, we examined the risk of mortality in the population of chronically-ill patients with Diagnosis Related Group (DRG) 190: Chronic Obstructive Pulmonary Disease (COPD) who have major complications or comorbidities.

Methods: We performed a retrospective analysis on the US Center for Medicare and Medicaid Service (CMS) data for patients living in central and southeast Ohio (approximately 500,000 Medicare beneficiaries). We evaluated mortality of patients over the 18 months following their first hospitalization for DRG190 during 2008-2009.

Results: Of the 3,578 patients identified who were not lost to followup, a total of 634 of these patients died within 180 days (19.4%), 837 died within 360 days (27.8%), and 944 died within 540 days (34.9%) of their initial hospitalization for DRG190.

Conclusion: The risk of mortality over time is fairly linear and significant. With a 1 in 5 chance of dying within 180 days and more than 1 in 3 chance of dying within 540 days, there is potentially a significant role for models that integrate early palliative and hospice care services. These will
likely to improve patients’ experiences, and they may prolong survival and decrease resource utilization.

**Abstract number:** P51  
**Abstract type:** Poster  
**Comparison of Patients with Malignant and Non-malignant Disease in Specialized Palliative Home Care**  
Feddersen B., Doublier L., Lorenzl S., Bausewein C.

University of Munich, Department of Palliative Medicine, München, Germany

**Aims:** To compare the symptom burden and characteristics of care of patients with malignant and non-malignant disease (NMD) who were under the care of a specialized palliative home care team (SHCT).

**Methods:** Retrospective study of patients who died under the care of a SHCT from October 2009 to October 2013. The NMD group included patients with neurological disease and chronic organ failure. We compared initial symptom burden (ranged from 0 = absent to 4 = most severe), total duration of care, number of contacts during on-call, number of emergency doctor contacts and number of hospital admissions. Data are presented as mean and standard deviation. Statistical analysis was performed using t-test comparison of unrelated samples.

**Results:** 726 patients were included, 619 with cancer and 107 with NMD (neurology (n=73); mainly: motoneuron disease (n=41), Parkinson’s disease (n=15), stroke (n=10) and dementia (n=9)) and chronic organ failure (n=34) (mainly failure of the heart (n=16), liver (n=7), lungs (n=7) and renal (n=2)). Duration of care was longer in the group of non-malignant disease (47 (SD 2.5) vs 124 days (SD 19.5); p< 0.0001). In NMD initial symptoms and concerns were higher in the following categories: cardio-respiratory (1.9 (SD 0.14) vs 1.5 (SD 0.05); p< 0.01), neurological (2.8 (SD 0.13) vs 1.5 (SD 0.06); p< 0.001), ethical (0.5 (SD 0.1) vs 0.3 (SD 0.03); p< 0.005) and lower regarding pain (1.2 (SD 0.11) vs 1.8 (SD 0.05); p< 0.001), gastrointestinal (1.6 (SD 0.06) vs 0.9 (SD 0.12); p< 0.001) and wound management (0.13 (SD 0.06) vs 0.4 (SD 0.04); p< 0.01). Number of on-call contacts (1.7 (SD 0.2) vs 1.7 (SD 0.7)), emergency doctor contacts (0.03 (SD 0.01) vs 0.04 (SD 0.02)) and hospital admissions (0.17 (SD 0.02) vs 0.16 (SD 0.05)) did not differ between both groups.

**Conclusion:** Although patients with NMD are longer under the care of a SHCT and differ in their symptom burden, the type of care they receive and the contacts with the health care system are similar.

**Abstract number:** P52  
**Abstract type:** Poster  
**Trajectories of the Multidimensional Dying Experience for Terminally Ill Cancer Patients**

**Tang S.T.**  
Chang Gung University, School of Nursing, Tao-Yuan, Taiwan, Republic of China

**Context:** Studies exploring the trajectories of physical-psychological-social-spiritual dying experiences frequently treat changes in these experiences as consistent across different domains and over time.

**Aim:** This prospective, longitudinal investigation was designed to characterize trajectories of the multidimensional dying experience for cancer patients in their last year of life.

**Methods:** Trajectories of physical-psychological-social-existential dimensions and overall quality of life (QOL) were identified among 313 cancer patients using mixed-effects models to test for linear, quadratic, or cubic changes. Changes in each variable were evaluated for clinical significance using minimal important difference.

**Results:** When patients transitioned to their end of life, symptom distress, functional dependence, anxiety, and depressive symptoms slightly increased, followed by a stable status for approximately 4–6 months, and accelerated dramatically to the first clinically significant changes at 3–4 months before death. Perceived social support and posttraumatic growth declined gradually to clinically significant changes at 1.0 and 4.0 months before death, respectively. Perceived sense of burden to others increased steadily in the last year of life, with no clinically significant changes identified. Overall QOL deteriorated precipitously 10.5 months before death but did not reach a clinically significant change until 2.5 months before death.

**Conclusion:** All dimensions deteriorated in the last year of life, such changes and rates of deterioration are neither universally consistent nor steep across all dimensions. Distinctive dying trajectories were discernible. Recognizing trajectory patterns and tipping points of accelerating deterioration in each dimension help clinicians anticipate times of increased distress, initiate timely, effective interventions to relieve patient suffering, and facilitate high-quality end-of-life care tailored to patients’ needs and preferences.

**Abstract number:** P53  
**Abstract type:** Poster  
**A Retrospective Audit on the Documentation of Treatment Withdrawal in the Intensive Therapy Unit (ITU) of a UK Teaching Hospital**

Wong R., Dhillon A., Fayek S.

1Birmingham Heartlands Hospital, Birmingham, United Kingdom, 2University of Birmingham, Birmingham, United Kingdom

**Background:** Controversy surrounding the Liverpool Care Pathway (LCP) has instigated a government inquiry into current standards of end-of-life care. While the LCP
is not widely instituted on ITU, withdrawal of treatment is often the mainstay of patient care. Existing documentation is often poor and the need for comprehensive guidelines, to standardise the approach to treatment withdrawal, has been identified.

**Aim**: To audit the documentation of treatment withdrawal decisions and assess adherence to current guidelines.

**Method**: This is a retrospective audit of 68 patients in whom treatment was withdrawn, on ITU, between January and October 2012. Information was missing for 11 patients, leaving 57 case notes to be reviewed against local and national standards.

**Results**: Of 1020 admissions, 140 died (13.7% mortality). Treatment was withdrawn in 68 patients (48.6%). The overall withdrawal rate was 6.7%, and the mean time from withdrawal decision to death, was 181 minutes. Entries in the notes concerning the decision to withdraw were clearly documented and dated in 96.5%, with a specific reason for withdrawal in 98.2%. Discussion with relatives, and patients where possible, was documented in 94.7%. A valid DNAR was found in 98.2%, with clear consensus between the critical care team (94.7%) and admitting teams (84.2%). Nursing documentation was good (100%). Religion and patient wishes following death was only recorded in 43.9% of cases. There was some ambiguity on the method of withdrawal, with poorly documented decisions to discontinue ventilation (32.7%) and extubate (19.6%).

**Conclusion**: Good documentation practice overall, facilitated by the use of withdrawal forms. Clear documentation is essential in supporting our decision-making processes. Confusion on the method of withdrawal is largely down to a lack of comprehensive guidance, suggesting future research may be needed to formulate a systematic way of withdrawing life-support measures.

**Abstract number**: P54
**Abstract type**: Poster

**Reviewing the Current Evidence Base for the Pharmacological Treatment of Delirium in Palliative Care: A Structured Literature Review**

**Kanji S.**, **Bush S.H.**

1The Ottawa Hospital Research Institute, Ottawa, ON, Canada, 2The Ottawa Hospital, Department of Pharmacy, Ottawa, ON, Canada, 3University of Ottawa, Department of Medicine, Division of Palliative Care, Ottawa, ON, Canada, 4Bruyere Research Institute, Ottawa, ON, Canada

**Background**: The pharmacological management of delirium is often guided by expert opinion and consensus clinical practice guidelines. Clinical trials of pharmacological treatment exist but their applicability to palliative care is unclear.

**Aims**: To identify trials of the pharmacological treatment of delirium in all clinical settings, including palliative care.

**Methods**: A systematic literature search was conducted in three databases (Cochrane, Ovid Medline, and Embase) from the earliest available records of each up to October 25, 2013. Search terms included “delirium”, “confusion”, “treatment”, “therapeutics”, “antipsychotic agents”, “cholinesterase inhibitors” and “alpha adrenergic agents”.

Results were limited to English, human clinical trials and systematic reviews. Reference lists were also evaluated for relevant trials. Our inclusion criteria were prospective single arm or parallel arm comparative trials.

**Results**: From 436 potentially relevant citations, only 31 trials met the inclusion criteria: 16 randomized controlled trials (RCTs), which included one post-hoc analysis of a RCT, and 15 prospective cohort studies. The 16 RCTs (798 patients in total) ranged in size from 20 to 104 patients. Seven RCTs were placebo controlled. Palliative care patients were not specifically studied in RCTs except for one study of 30 terminally ill AIDS patients. The prospective cohort studies ranged in size from 10 to 79 patients (379 patients in total) and evaluated the response to treatment from primarily atypical antipsychotics over a period of 5 to 7 days. No study specifically sought palliative care patients but four studies (139 patients) evaluated hospitalized cancer patients.

**Conclusion**: The level of evidence for drug treatment in palliative care populations remains moderate to low at this time. Further collaborative research, with pragmatic and rigorous study designs, is needed to increase the current evidence base.

**Abstract number**: P55
**Abstract type**: Poster

**Diagnosis Sensitivity of the Memorial Delirium Assessment Scale (MDAS) Spanish Version**

**Noguera A.**, **Barahona E.**, **Galindo V.**, **Pinhao R.**

1Hospital CC Laguna, Madrid, Spain, 2Hospital de la Cruz Roja, Madrid, Spain, 3Fundacion Jimenez Diaz, Madrid, Spain, 4Centro de Salud Ciempozuelos, Ciempozuelos, Spain

MDAS is a successful tool for delirium evaluation and monitoring. However, it is necessary a more accurate knowledge of its different cut off scorings because it could vary according to the studied population.

The main objective of this study is to evaluate the diagnostic sensitivity of the MDAS Spanish version, recently validated. The secondary objective is to analyze diagnostic differences when used in Hospice or General Hospitals.

**Methodology**: A prospective study was conducted with advanced cancer patients in two settings (Hospice & General Hospital). Delirium diagnosis was established according to clinical criteria and the Confusion Assessment Method. Sen-
sensitivity (S), Specificity (Sp), Positive Predictive Value (PPV), and Negative Predictive Value (NPV), were analyzed according to the ROC curve. MDAS values of different centers were studied with non-parametric tests (Mann-Whitney). Relation between MDAS, delirium and neuropsychiatric comorbidities were analyzed with T and Levene tests.

**Results:** 67 patients were included, 28 with delirium diagnosis (15/40 Hospice and 13/27 General Hospital). MDAS media in delirium group was 13,57 and 5.49 in non delirious. A 7 cut off point showed the better screening diagnosis balance (S 92.6%, Sp 71.8%, PPV 70.1% and PPN 93.33 %). Anxiety and Depression diagnosis were not related with delirium (p<0.44). Dementia diagnosis was related with delirium (p<0.052), but not influenced MDAS diagnosis sensibility (p<0.26). No differences of MDAS sensitivity diagnosis were found between Hospice and General Hospital.

**Conclusion:** As other studies in advanced cancer patients 7 seems to be the better MDAS screening cut off point. No differences were found in MDAS diagnosis sensitivity between advanced cancer patients assisted in Hospice or General Hospitals. It is necessary to design new studies to analyze if it is necessary a higher cut off point in patients with advanced cancer and dementia diagnosis.

**Abstract number:** P56
**Abstract type:** Poster

**Quality Indicators for Palliative Care (Q-PAC): Testing the Feasibility, Usefulness and Face Validity in Palliative Practice**


1Vrije Universiteit Brussel (VUB) & Ghent University, End of Life Care Research Group, Brussels, Belgium, 2Vrije Universiteit Brussel (VUB), Department of General Practice, Brussels, Belgium, 3Ghent University, Department of Pharmacology, Ghent, Belgium, 4VU University Medical Center, EMGO Institute for

**Abstract number:** P57
**Abstract type:** Poster

**Physician-related Barriers for Communication and Patient and Family Centered Decision Making towards the End of Life in the ICU: A Systematic Literature Review**

**Visser M.**, **Houttekier D.**, **Deschepper R.**, **Deliens L.**

1Vrije Universiteit Brussel and Ghent University End-of-Life Care Research Group, Brussels, Belgium, 2EMGO Institute for Health and Care Research and Expertise Center for Palliative Care, Department of Public and Occupational Health, VU Medical Center, Amsterdam, Netherlands

**Aims:** There is an absence of a comprehensive quality indicator set for measuring quality of care in palliative care. We developed such a set containing structure, process and outcome indicators and tested it for feasibility, usefulness and face validity in the field in Belgium.

**Methods:** Feasibility (ie can be measured), usefulness (ie can be used to evaluate and improve practice) and face validity (ie measures, on the face of it, what it purports to measure) were evaluated. We combined a quantitative analysis using questionnaires sent to patients, caregivers, family carers and physicians (all recruited via palliative care services), with qualitative interviews conducted with all participating services. These concerned work load, possibilities for improving care and future use of the indicator set.

**Results:** The response rate was 56% (n=64) for patients, 97% for caregivers (n=117), 56% for family carers (n=108) and 65% for physicians (n=125). Caregivers of the palliative care services confirmed the feasibility, usefulness and face validity of the overall quality indicator set and measurement procedure. Still, 20 (of the 80) indicators showed problems of feasibility and 5 of usefulness. One of them was discarded from the set. The other problematic indicators were improved by either changing the formulation of the indicator or the question(s) used to measure them.

**Discussion:** Based on the results, adjustments to the individual indicators and measurement tools and procedure were made. With some minor adjustments to the quality indicators and measurement procedures our quality indicators are ready for further evaluation and use across several types of palliative care services in Belgium. As soon as these indicators will be systematically used by these services, it will be possible to demonstrate and compare quality, taking into account relevant patient mix confounders, and to evaluate improvement initiatives.
Aims: End-of-life care (EOLC) in intensive care units (ICUs) has shortcomings, including poor communication and shared decision-making (DM). We aim to identify ICU physician related barriers for communication within the team and with patients and families, and patient and family centered DM in EOLC.

Methods: Systematic literature review searching Medline, Embase, Psychinfo and CINahl for studies published from 2003 in English or Dutch. Search terms included: physician, palliative care, EOLC, advance care planning, DNR-orders, ICU. Studies on barriers reported by physicians, nurses and relatives were included. Studies on neonatal or pediatric ICUs were excluded. Study quality was assessed using validated appraisal tools.

Results: 2137 studies were screened, 85 were assessed for eligibility and included in analysis. Data extraction is still ongoing. Reported barriers related to physicians' knowledge, attitudes and practice.

Knowledge: Insufficient awareness of EOLC, legal EOLC framework and definition of futile treatment; lack of awareness of family concern about patient’s quality of life (QOL) and fulfilling patient’s wishes; lack of skills to communicate prognosis and futility to patient and family; physicians are trained to do everything possible. 

Attitude: Focus on measurable data, technological procedures, avert death in the hospital; no recognition of poor prognosis, QOL of the patient, that the patient is dying; no recognition of perspectives of patient, family and nurses.

Practice: Different specialists and rotation of physicians causing delay in reaching consensus, establishing prognosis, and inconsistency of information; availability of resources, time and money invested in patients results in continuation of aggressive care; treatment reaches a point of futility, where finally no time is left for EOLC.

Conclusion: Improving ICU physicians’ communication and shared DM in EOLC may be achieved by addressing knowledge, attitude and practice barriers.

Abstract number: P58

Abstract type: Poster

Experiences of Care for Frail Elders at the End of Life; a Mixed Method Analysis of Quantitative Data and Free Text Responses from a Post-bereavement Survey

Evans C.J.1,2, Morgan M.3, Gao W.1, Sleeman K.1, Gomes B.1, Wright J.4, Higginson I.J.1, OPTCare Elderly

1King’s College London, Cicely Saunders Institute, London, United Kingdom, 2Sussex Community NHS Trust, Brighton and Hove, United Kingdom, 3King’s College London, London, United Kingdom, 4University of Sussex, Brighton and Hove, United Kingdom

Background: People are living longer and die increasingly with frailty and complex co-morbidities. How best to provide end of life to frail elders with non-malignant conditions, is poorly understood. This paper aims to enrich understanding on place of care at the end of life for frail elders by mixed method analysis of free text responses and quantitative data from bereaved carers.

Methods: Post-bereavement survey administered to 882 carers using death registration data. Data comprises textual descriptions of responses to open questions on experiences of care and identifiers of cause of death and place of death for subgroup analysis and quantitative data on service receipt and palliative outcomes. Mixed method analysis using qualitative constant comparative method to identify threads of emergent theory in the textual descriptions and follow in the quantitative data to test using descriptive and inferential statistical analysis.

Results: 40% participants told their stories about frail elders care in the last weeks of life. Place of care included good and poor aspects that related to communication; assistance and support; timeliness of clinical care; cause of death; and recognition of deterioration as a phase of illness. Lack of recognition of deterioration impeded timelessness and quality of service provision, with domiciliary services slow to be put in place and of variable quality.

2) Variation in anticipating, recognising and diagnosing dying impeding identification and attainment of preferred place of care.

3) Disparity in service resource with cancer patients receiving an extra layer of support and care from palliative care services. Conclusions Lack of recognition of deterioration often preceding the terminal phase limited patients and families opportunities to discuss and plan for future care and the last days of life, leading to crisis intervention and hospitalisation at the end of life.

Abstract number: P59

Abstract type: Poster

Compassion: Understandings from the Literature and the Bedside

Sinclair S.1, Chochinov H.2, Hack T.3, Hagen N.4, McClement S.5, Raffin Bouchal S.1

1University of Calgary, Faculty of Nursing, Calgary, AB, Canada, 2University of Manitoba/CancerCare Manitoba, Manitoba Palliative Care Unit, Winnipeg, MB, Canada, 3University of Manitoba, Winnipeg, MB, Canada, 4University of Calgary, Faculty of Medicine, Calgary, AB, Canada, 5University of Manitoba/CancerCare Manitoba, Faculty of Nursing, Winnipeg, MB, Canada

Aims: Compassionate care has long been identified as an essential feature of quality health care, especially in palliative care where the goal of ameliorating suffering is both a unique challenge and specific aim. Remarkably, there is little understanding of what constitutes compassion and its...
effect on patients. In order to address this gap we interviewed dying patients (n=50) understandings and experiences of compassion and conducted a comprehensive scoping review of the literature. This study was funded by the Canadian Institutes of Health Research.

**Methods:** A grounded theory approach (qualitative method) was used to address our area of interest. An interview guide was constructed from the research literature and the previous experience of the research team. Data analysis occurred simultaneously through three stages: Open coding; Axial coding; & Selective coding. The comprehensive scoping review based on Arksey & O’Malley’s (2005) methodology included a comprehensive selection of leading health electronic databases (Medline, CINAHL, Psychinfo etc…) and related disciplines (Social Sciences & Education).

**Results:** The importance of compassion at the end of life was overwhelmingly endorsed by patients, with major categories emerging from the qualitative data:

1) Virtues of Health Care Professionals
2) Relational Space
3) Patient Outcomes
4) Barriers to compassion.

The scoping review identified key themes in the compassion literature: Clinical communication; Patient outcomes; Effect on Spiritual Well Being; Role at the EOL; A mediator of cultural sensitivity.

**Conclusion:** While compassion have been identified by patients, clinicians and health care organizations as an important component of care, little is known about what constitutes compassionate care and its impact on patient well-being. This presentation will present results from both a scoping review and a qualitative study investigating compassion from the perspective of individuals facing the end of life.

**Abstract number:** P60

**Abstract type:** Poster

**Developing an Intervention to Prepare/Support People with Sharing News of a Lung Cancer Diagnosis with Family and Friends**

Ewing G.1, Ngwenya N.1, Farquhar M.C.2, Benson J.2, Bailey S.1, Gilligan D.4, Seymour J.3

1University of Cambridge, Centre for Family Research, Cambridge, United Kingdom, 2University of Cambridge, Department of Public Health and Primary Care, Cambridge, United Kingdom, 3Cambridge University Hospitals NHS Foundation Trust, Oncology Department, Cambridge, United Kingdom, 4Cambridge University Hospitals NHS Foundation Trust., Oncology Department, Cambridge, United Kingdom, 5University of Nottingham, School of Nursing, Midwifery and Physiotherapy, Nottingham, United Kingdom

**Background:** Much research has focussed on breaking bad news (BBN) i.e. on how physicians communicate a cancer diagnosis to patients. There is little understanding of the subsequent process, when patients go home and share bad news (SBN) with family members and friends: a situation faced by over 1.6 million people each year who receive a lung cancer diagnosis worldwide.

**Aim:** To identify key components of an intervention to prepare and support people with sharing news of their lung cancer diagnosis with wider family members and friends.

**Sample:** 20 patients with lung cancer, 17 family members/ friends present at BBN consultations, 41 clinicians involved in BBN consultations and 6 service users with experience of sharing a cancer diagnosis (SBN) with others.

**Methods:**

Stage 1: qualitative interviews with patients and family members, interviews/focus groups with clinicians to examine experiences with BBN and SBN.

Stage 2: workshop with service users, interviews with clinicians to explore feasible intervention strategies. Data digitally recorded, transcribed verbatim. Thematic framework analysis.

**Results:** Patients and family/friends found sharing bad news difficult and complex. A mismatch in perceptions of support with SBN between clinicians and patients indicated the need for a pro-active and universal approach to offering support. Six core elements were identified in SBN (people to be told, information to be shared, timing of sharing, responsibility for sharing, methods of telling others and reactions of those told) which could structure a supportive intervention. SBN is a process that happens over time: which adds to the complexity of intervention delivery.

**Conclusion:** Sharing bad news is a challenging process which is currently largely unsupported. Developing an intervention to prepare patients to share bad news of a lung cancer diagnosis, which often presents at an advanced stage, is highly relevant for palliative care.

**Funder:** Dimbleby Cancer Care

**Abstract number:** P61

**Abstract type:** Poster

**An Exploration of Early Palliative Care in the Adult Cystic Fibrosis Population**

Stevens A.-M.1, Bilton D.2, Walshaw M.3, Faithfull S.4, Knibb W.5, Ross J.R.1,5

1Royal Marsden and Royal Brompton Palliative Care Service, London, United Kingdom, 2Royal Brompton
Background: CF is now a chronic disease of children/young adults (median age of death 29yrs). There is a recognised need for palliative care intervention to aid symptomatic management. CF is now a chronic illness and supporting patients living with the symptoms caused by the disease might benefit from support of palliative care services, but the acceptability of this for patients/staff is relatively unexplored.

Aims: To determine the scope of the need for referral to palliative care in adult patients with CF. To identify how services currently integrate in the UK. To explore staff perceptions of introducing a palliative care service at different stages of the disease trajectory. To explore patient perceptions of ‘palliative care’ and acceptability of palliative care input early in the patient pathway.

Methods and design: A mixed method approach has been used.

Phase 1: A focus group with specialists from CF and Palliative Care was conducted to inform survey development.

Phase 2: A survey of UK CF centres and palliative care teams was conducted to examine the current provision of palliative care to patients with Cystic Fibrosis and perceptions of triggers/barriers to palliative care referral.

Phase 3: Perceptions of patients and staff across 2 units will be explored through semi-structured in-depth qualitative interviews. The results of the individual components of research will be triangulated and used to propose/justify potential model(s) of care to facilitate identification and management of palliative care needs for adult CF patients. This will include triggers for referral and proposed joint-working patterns that might promote closer working between teams, with identification of outcome measures for future trials.

Discussion: The research will provide valuable information to inform the integration of palliative care services for patients with cystic fibrosis and their families and to shape future studies to evaluate palliative care interventions in this group.

Abstract number: P62

Identification of the Last Phase of Life in Dementia: The Views of Nursing Home Staff from across Europe

van Riet Paap J.1, Mariani E.2, Chattat R.2, Koopmans R.3, Kerheve H.4, Leppert W.5, Radbruch L.6,7, Jaspers B.6,7, Vissers K.5, Vernooij-Dassen M.1,9, Engels Y.5

1 Radboud University Medical Center, IQ Healthcare, Nijmegen, Netherlands, 2University of Bologna, Department of Psychology, Bologna, Italy, 3Radboud University Medical Center, Department of Primary and Community Care, Nijmegen, Netherlands, 4Université Paris Descartes, Service Gérontologie, Paris, France, 5Poznan University of Medical Sciences, Department of Palliative Medicine, Poznan, Poland, 6Universitätsklinikum Bonn, Department of Palliative Medicine, Bonn, Germany, 7Malteser Hospital Bonn, Department of Palliative Care, Rhein-Sieg, Germany, 8Radboud University Medical Center, Department of Anaesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands, 9Radboud University Medical Center, Radboud Alzheimer Centre, Nijmegen, Netherlands

Introduction: Palliative care is an approach to improve the quality of life for all patients suffering from life-threatening illnesses. Although palliative care approach is usually applied in cancer care, it can also improve the outcomes of dementia patients and their families. However, it is challenging for professionals to recognize when a person with dementia has entered the advanced stage of the disease. As a consequence, many of their symptoms and needs often remain unrecognized, and adequate palliative care and advance care planning are lacking.

Aim: This study identified the last phase of life in dementia among professionals working in long-term care settings (LTC).

Methods: Members of multidisciplinary teams working in 13 LTC settings located in six countries (France, Germany, Italy, Norway, Poland and the Netherlands) were given a case-vignette on a patient who was diagnosed with dementia nine years ago and recently admitted into a nursing home. Teams were asked to discuss how and when they considered the patient in the case-vignette as patients in need of palliative care. Thematic analysis was used to analyze the data. Codes and associated text fragments were discussed between two researchers in order to categorize them.

Results: Professionals from 13 nursing homes in six countries participated in the vignette study. The vignette led to lively discussions among the multidisciplinary teams. They argued that palliative care starts at the point of recognition of:

1) clinical symptoms of advanced dementia;
2) early phase dementia; and
3) no beneficial effect of medical treatment.

Discussion: This study showed that there is no consensus on the signs indicating when a person with dementia is in need of palliative care. Although steps have been made to improve palliative care for patients with dementia, much remains to improve to provide optimal care for this vulnerable patient group.
**Abstract number:** P63
**Abstract type:** Poster

**What Are the Predictors of Health-related Quality of Life and Cost in Multiple Myeloma? A Meta-analysis**

*Ramsenthaler C.1, Kane P.M.1, Siegert R.J.2, Gao W.1, Edmonds P.M.1, Schey S.A.3, Higginson I.J.1*

1Cicely Saunders Institute, King’s College London, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Auckland University of Technology, Department of Psychology, Auckland, New Zealand, 3King’s College Hospital NHS Foundation Trust, Department of Haematological Medicine, London, United Kingdom

**Background:** Multiple myeloma is associated with a higher burden of disease than other haematological cancers. To understand the determinants of low health-related quality of life (HRQoL) or high cost/health care use could help identify those patients at risk of developing a worse outcome and target services towards them.

**Aim:** To systematically review, assess and analyse the strength of association between different disease factors and the outcomes HRQoL, cost and health care utilisation in multiple myeloma.

**Method:** We searched Medline, Embase, PsycINFO, Cinahl, Assia, the Cochrane library and NHS EED databases, journals and citations using keywords/subject headings for myeloma and QoL or cost/health care use. Inclusion criteria: Studies reporting associations in samples ≥50% myeloma. Fisher’s z method for correlations and random effects meta-analysis.

**Results:** Of 20,883 references, 43 studies with 4,960 participants were included. None reported associations for both outcomes. The largest effect sizes were found for nutritional risk and fatigue (r=-0.51 and -0.54) associated with worse HRQoL. Medium associations were reported for other symptoms and biochemical parameters like M-protein level, creatinine etc. High haemoglobin was a moderate protective factor for HRQoL (r=0.39). Demographic, disease- and treatment-related factors showed weak associations only, except for response (r=0.29, 95%CI 0.24-0.34). Treatment-related factors were the main drivers of cost (days in intensive care, laboratory procedures (r=0.52)). Moderate associations were found for disease stage, duration of maintenance treatment. A higher platelet count was weakly associated with lower costs (r=-0.22, 95%CI -0.38 to -0.05).

**Conclusion:** A model of predictors for HRQoL in myeloma was developed. Early detection of those at risk for developing worse HRQoL or higher cost/hospitalisation should consider symptoms as well as biochemical factors and cannot focus on response or treatment alone.

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**Abstract number:** P64
**Abstract type:** Poster

**Two Methods for Evaluating the Prevalence and Timing of Palliative Care Involvement**

*Cassel B., Del Fabbro E.*

Virginia Commonwealth University, Massey Cancer Center, Richmond, VA, United States

**Aims:**

- Study 1) To devise and test a method for assessing SPC use and timing among hospitalized patients.
- Study 2) To devise and test a method for assessing SPC use and timing among patients with progressive, life-limiting diseases now known to be deceased.

**Study population:**

- Study 1: Approximately 105,000 patients in 5 US hospitals and 1 UK hospital.
- Study 2: Approximately 4,800 decedents from 1 US hospital.

**Methods:** Retrospective analyses of institutional health-care data.

- Study 1: Adult hospitalizations stratified into deaths, survivors with high risk of death, and all others. PC use within each group analyzed.
- Study 2: Patients categorized into 7 disease groups. Date of death determined by national death file, linked to institutional billing data. Analyses conducted at patient level. PC and hospice use and timing analyzed within each disease group.

**Statistics:** Descriptive statistics, odds ratios, median tests.

**Results:**

- Study 1: Similar results across the 6 hospitals (5 US and 1 UK). Approximately 10% of hospitalizations fell into the two PC-relevant strata of deaths and high-risk survivors and had much longer and more intensive hospital stays. SPC teams touched 21-26% of those in the two PC-relevant strata, and only 2% of all other admissions. The stratification helps to interpret the reach of SPC and provides basis for inter-hospital comparisons.

- Study 2: Costs, intensity and frequency of hospitalizations increase each month prior to death. SPC team touched 24% of patients (high=cancer at 29%; low = neuro and kidney at 11% and 12%). Median time of SPC prior to death was less than 3 weeks (high = COPD 23.5 days, cancer 14 days; low = kidney at 4.5 days and cirrhosis at 6 days). These analyses quantify the gaps in SPC delivery to such patients. Study 2 is being replicated at several hospitals with a grant from the California Health Care Foundation.
Abstract number: P65
Abstract type: Poster

Relevant Clinical Issues for Standardized Assessment and Diagnosis of Neuropathic Pain in Patients with Cancer

Brunelli C.1,2, Bennett M.3, Kaasa S.2,4, Sjogren P.3, Fainsinger R.4, Mercadante S.5, Lohre E.5, Caraceni A.1,2
1Fondazione IRCCS Istituto Nazionale dei Tumori, Palliative Care Pain Therapy and Rehabilitation Unit, Milano, Italy, 2European Palliative Care Research Centre (PRC), Department of Cancer Research and Molecular Medicine, Trondheim, Norway, 3Leeds Institute of Health Sciences, University of Leeds, UK, Academic Unit of Palliative Care, Leeds, United Kingdom, 4St. Olav’s Hospital, University Hospital of Trondheim, Cancer Clinic, Trondheim, Norway, 5Section of Palliative Medicine, Department of Oncology, Rigshospitalet, Copenhagen, Denmark, 6University of Alberta, Division of Palliative Care Medicine, Edmonton, AB, Canada, 7La Maddalena Cancer Center, Anesthesia and Intensive Care Unit & Pain Relief and Supportive Care Unit, Palermo, Italy

Background: Recent studies have confirmed neuropathic pain (NP) to be among core domains in cancer pain classification, but agreement on its standardized assessment and diagnosis is lacking.

Aim: This study aims at reaching consensus on the development of a step-wise approach in diagnosing NP in cancer patients: screening, first level evaluation for non-pain specialists and second level evaluation for pain or palliative care specialists.

Methods: A modified two-round Delphi survey involving a sample of 42 international pain experts was carried out to test their consensus on the following issues: unique features of NP in patients with cancer, role of IASP NeuPSIG diagnostic criteria in patients with cancer, patient reported verbal pain descriptors (PR-VPD) for NP screening. For each statement, overall consensus and agreement among experts were measured respectively through median and interquartile range (IQR) values.

Results: On both rounds 29 pain experts out of the 42 identified (69%) responded to the Delphi survey. Overall consensus with the statements and agreement among experts were good: on the first round 25 items out of 33 proposed showed acceptable median and IQR scores; the remaining 8 items reported a median < 7 or an IQR > 3 and, when retested in the second round, only three did not reach acceptable consensus/agreement. In particular the relevance of the four NeuPSIG diagnostic criteria was confirmed, but a defined and specific priority was given to “history of neurological lesion”, “clinical examination” and “diagnostic test” criteria. Based on the Delphi study results a set PR-VPD was then identified for screening and a standardized clinical algorithm was proposed for NP diagnosis.

Conclusion: Although the screening set of PR-VPD and the standardized algorithm are both to be tested in clinical practice, they represent a step forward toward an appropriate and widely recognized assessment and diagnosis of NP in cancer patients.

Abstract number: P66
Abstract type: Poster

Bereavement Care: Bereaved Carers’ Views on Bereavement Support Where Patients Have Been Cared for by the Midhurst Macmillan Specialist Palliative Care Service, UK

Hughes P.M.1, Winslow M.1, Ingleton C.2, Noble B.1
1University of Sheffield, Academic Unit of Supportive Care, Sheffield, United Kingdom, 2University of Sheffield, School of Nursing and Midwifery, Sheffield, United Kingdom

Background: The value of bereavement care is increasingly being recognised in palliative care, particularly in community settings where family members are providing direct care to patients. In the UK, the National Institute for Health and Care Excellence recommends sensitive provision of bereavement services for carers. The Midhurst Macmillan Specialist Palliative Care Service (MMSPCS) is a UK, medical consultant-led, multidisciplinary team providing care in the home, community hospitals and care homes.

Aim and methods: As part of a multi-method evaluation study we conducted a survey of bereaved carers of patients referred to the MMSPCS, using the Views of Informal Carers- Evaluation of Services (VOICES) self-complete postal questionnaire on care received by patients and their family caregivers. We report here on the section on bereavement care.

Results: Response rate was 40.5% (102/252). 83% of respondents reported services at home to be excellent or good, and 78% reported receiving as much support as they wanted. 68% of patients died at home (57%) or in a care home (11%). 23% of carers would have liked another chance to discuss their relative’s death with someone involved in providing care. 47% had been offered bereavement care, and 90% of these found it helpful. 20% of those not receiving bereavement care would have liked to receive such care. Comments from carers included finding it helpful to talk; finding on-going contact important even if feeling support was not needed; and valuing being referred for more specialised counselling. One carer reported a negative experience from support offered.
Abstract number: P67
Abstract type: Poster

**Emergency Visits Are Associated to Poor Outcome in Palliative Care Patients with Advanced Cancer**

*Haltia O.*, *Ariluoma-Liimatainen K.*, *Saarto T.*, *Lehto J.T.*

1Tuusula Health Care Center, Tuusula, Finland, 2Hospital District of Helsinki and Uusimaa, Hyvinkää Hospital, Hyvinkää, Finland, 3Helsinki University Hospital, Department of Oncology, Helsinki, Finland, 4Tampere University Hospital and University of Tampere, Department of Oncology, Hospital District of Helsinki and Uusimaa, Hyvinkää Hospital, Tampere, Finland

Patients with advanced cancer and palliative care frequently visit emergency rooms (ER) in need for symptom control. **Aims:** Aim of this study was to evaluate the symptoms, survival, re-visits and decisions of advanced directives in these patients. **Methods:** We evaluated all the consecutive patients with incurable advanced cancer visiting the ER of Hyvinkää hospital from 1.1.2009 to 31.12.2009. All the patients receiving chemotherapy or curative intent radiation were excluded to achieve a population representing palliative care patients. Data was obtained retrospectively from the patient records. Chi-square test was used to compare patient groups and 95% confidence intervals (CI) were calculated for medians. **Results:** Altogether 112 palliative care patients with advanced cancer visited 277 times in the ER. The mean age of the patients was 70 years (range: 40–96), 54% were men. The most common symptoms on arrival were pain, dyspnoea and infection in 24%, 17% and 16% of the visits, respectively. The median survival after the first visit to ER was 40 days (95%CI: 22–57 and range: 0–344). Furthermore, 37%, 65% and 85% of the patients died in 30, 90 and 180 days, respectively. Sixty-six (59%) of the patients re-visited ER (range: 2–11 visits/patient) and the median time for re-visiting was 19 days (95%CI: 16–22 and range: 1–211 days). Decision of palliative intent care had been applied in 60 (53%) of the patients. The proportion of re-visits were 65% and 62% in patients with and without decisions of advanced directives, respectively (p > 0.05). **Conclusion:** Patients with palliative stage of advanced cancer frequently searched help from ER in need for symptom control. ER visits were associated to poor survival and frequent re-visits reflecting poor quality of end-of-life care. Well-organized palliative care pathway could reduce the need for ER visits.

**Table 1. Patient characteristics.**

<table>
<thead>
<tr>
<th>Type of cancer</th>
<th>n/ % of total</th>
<th>APC applied %</th>
</tr>
</thead>
<tbody>
<tr>
<td>GI-tract</td>
<td>16/14%</td>
<td>56.2%</td>
</tr>
<tr>
<td>Pancreas and biliary tract</td>
<td>18/16%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Lung and pleurae</td>
<td>27/24%</td>
<td>63.0%</td>
</tr>
<tr>
<td>Breast</td>
<td>6/5%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Gynaecologic</td>
<td>6/5%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Prostate</td>
<td>11/10%</td>
<td>54.5%</td>
</tr>
<tr>
<td>Urinary tract</td>
<td>11/10%</td>
<td>54.5%</td>
</tr>
<tr>
<td>Sex M/F</td>
<td>61 (54%)/1</td>
<td>Total 112</td>
</tr>
<tr>
<td>Age</td>
<td>Mean 70.3</td>
<td>Range 40–96</td>
</tr>
</tbody>
</table>

Abstract number: P68
Abstract type: Poster

**Characterisation of Central Brain Processing of Chemotherapy-induced Peripheral Neuropathy**

*Boland E.*, *Selvarajah D.*, *Snowden J.A.*, *Wilkinson I.D.*, *Ahmedzai S.H.*

1Hull and East Yorkshire NHS Trust, Palliative Medicine, Cottingham, United Kingdom, 2University of Sheffield, Supportive Care, Sheffield, United Kingdom, 3University of Sheffield, Diabetes, Sheffield, United Kingdom, 4Sheffield NHS Teaching Hospitals, Haematology, Sheffield, United Kingdom, 5Sheffield University, Radiology, Sheffield, United Kingdom

**Background:** Multiple myeloma (MM) is a haematological cancer of plasma cells. Modern treatments have significantly extended life expectancy in MM, although treated patients often suffer from a chemotherapy-induced peripheral neuropathy (CIPN). Neuropathic pain control is poor which may highlight our lack of knowledge of CNS processing of pain in this patient group. Recent advances in our understanding of human brain function have been driven by the introduction of functional magnetic resonance imaging (fMRI) which can characterise a network of brain areas that activate in response to pain stimuli. **Aim:** To use fMRI to investigate, central brain processing arising from the application of painful stimuli in patients with myeloma who have developed CIPN and compare this to patients with myeloma who were treated with the same therapy but did not develop neuropathy.
Study design and methods: To date, Blood Oxygen-Level Dependent (BOLD) fMRI datasets (3T) have been acquired on 9 myeloma patients with chemotherapy-induced peripheral neuropathy (MM-CIPN) and 9 MM patients without neuropathy. Heat pain stimuli were applied to the dorsum of the foot. Whole brain fMRI datasets were acquired during baseline and hot stimulus. Functional analysis was performed using Statistical Parametric Mapping.

Results: Our preliminary fMRI-group analysis showed that the BOLD response to heat pain stimulation was more marked within the central cerebellum and inferior parietal areas in the MM without neuropathy group and more marked within the anterior insular area in the MM with CIPN group.

Discussion: Our preliminary findings indicate that there might be a modification of the brain’s pain matrix in patients who have developed symptomatic CIPN. If this is confirmed on subsequent analysis, identification of such functional neuroanatomical differences may aid our understanding of the hitherto elusive neuropathic process.

Funding: This study has been funded by an educational grant from Pfizer.

Abstract number: P70

Abstract type: Poster

Development of a National Care Standard for Palliative Care in the Netherlands

Spreeuwenberg C.1, Raats I.2, Teunissen S.3, Evers P.4, van der Rijt C.5, van Tol C.6, van Bommel M.7, Vissers K.8

1Maastricht University, Department of Health Services Research, CAPHRI School for Public Health and Primary Care, Maastricht, Netherlands, 2Dutch Institute for Healthcare Improvement CBO, Utrecht, Netherlands, 3University Medical Center Utrecht, Department of Medical Oncology, Utrecht, Netherlands, 4Dutch Federation of Cancer Patient Organisations NFK, Utrecht, Netherlands, 5Erasmus Medical Center, Cancer Institute, Rotterdam, Netherlands, 6VU Medical Center, Hospice Kuria, Expertise Center Palliative Care, Amsterdam, Netherlands, 7Dutch Comprehensive Cancer Center, Department South, Eindhoven, Netherlands, 8Radboud University Nijmegen Medical Center, Department of Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands

Background: In the Netherlands, organisations of healthcare professionals, patients and scientists jointly develop care standards for the management of specific chronic conditions. These describe qualitatively good care from patients’, medical and organizational perspectives. Themes that apply to chronic conditions in general are addressed in generic care standards.

Aim: To develop a generic care standard for palliative care in the Netherlands, which can be adapted to disease-specific care standards.
Methods: A multidisciplinary working group was set up, consisting of 15 representatives of relevant healthcare professionals, patients, informal carers, scientists, healthcare insurers, supported by a guideline organization.

Using Wagner's chronic care model and shared decision making as a framework, critical elements from national clinical practice guidelines and quality criteria from patients' perspective were collected, analysed and arranged. Relevant stakeholders were invited to comment on the draft and to endorse the final care standard.

Results: Palliative care, as defined by the WHO, should be delivered more explicitly from the moment that a healthcare provider answers negative to the surprise question: "Would you be surprised if this patient dies within one year?" This moment should be explicitly marked. In the care standard, two tables present the basic elements and essential procedures for each patient in a palliative trajectory. These are multidimensional (physical, psychological, social, spiritual) and multidisciplinary approach, advance care planning, patient centeredness and improved communication through an individual care plan.

Conclusion: Various organizations of formal and informal caregivers succeeded in developing this first version of the Dutch palliative care standard, which can be used by all multidisciplinary care teams and settings for patients with intractable diseases.

Supported by: Dutch Ministry of Health, Welfare and Sport.

Abstract number: P71
Abstract type: Poster

Factors Associated with the Goal of Treatment in the Last Week of Life in Older Patients

Smets T.
Vrije Universiteit Brussel, End-of-Life Care Research Group, Brussels, Belgium

Aims: Little is known about the type of care older people of different ages receive at the end of life. The goal of treatment is an important parameter of the quality of end-of-life care. This study aims to provide an evaluation of the main goal of treatment in the last week of life of people aged 85 and older compared with those between 75 and 85 and to examine how treatment goals are associated with age.

Methods: Population-based cross sectional survey in Flanders, Belgium. A stratified random sample of death certificates was drawn of people who died between 1 June and 30 November 2007.

The effective study sample included 3,623 deaths (response rate: 58.4%).

Non-sudden deaths of patients aged 75 years and older were selected (N=1681).

Main outcome was the main goal of treatment in the last week of life (palliative care or life-prolonging/curative treatment).

Results: In patients older than 75, the main goal of treatment in the last week was in the majority of cases palliative care (77.9%). Patients between 75 and 85 more often received life-prolonging/curative treatment than older patients (26.6% vs. 15.8%). Most patient and health care characteristics are similarly related to the main goal of treatment in both age groups. The patient's age was independently related to having comfort care as the main goal of treatment. The main goal of treatment was also independently associated with the patient's sex, cause and place of death and the time already in treatment.

Conclusion: Age is independently related to the main goal of treatment in the last week of life with people over 85 being more likely to receive palliative care and less likely to receive curative/life-prolonging treatment compared with those aged 75-85. This difference could be due to the patient's wishes but could also be the result of the attitudes of care givers towards the treatment of older people.

Abstract number: P72
Abstract type: Poster

National Guideline for Palliative Care for Oncological Patients in Germany: Concept and Integration into Disease-specific Guidelines

Simon S.T.1, Pralong A.1, Geffe V.1, Bausewein C.2, Voltz R.1, on behalf of the German Guideline Group Palliative Care

1University Hospital of Cologne, Department of Palliative Medicine, Clinical Trials Unit (BMBF 01KN1106), and Centre for Integrated Oncology (CIO) Cologne/Bonn, Cologne, Germany, 2University Hospital Munich, Department for Palliative Medicine, Munich, Germany

Aim: To describe the concept of a national palliative care guideline for cancer and ways of integrating this cross-disease concept into disease-specific guidelines.

Methods: Key elements for structuring the palliative care guideline were (1) the main categories of palliative care needs and (2) the available scientific evidence in recent systematic reviews or international guidelines. It was agreed to develop a "horizontal" guideline patients within the German Guideline Programm Oncology (GGPO) on symptoms and other palliative care specific topics, independently from the underlying tumour entity. In addition, all other "vertical" disease specific guidelines are now asked to integrate palliative care aspects that are specific to their tumour entity.

Results: The palliative care guideline will cover seven topics: four clinical symptoms (pain, dyspnneoa, constipation, depression) and three topics considering patients’
broader needs (communication, dying phase, organisation of palliative care services). This guideline will focus on oncological patients and will be both evidence and consensus based. 110 experts and representatives from more than 40 scientific and public organisations are involved in the consensus process. Results from systematic literature searches conducted within the project may serve later as the basis for further guidelines, e.g. for patients with neurological or pulmonary diseases, or for a national disease management guideline.

**Conclusion:** Key challenges for a guideline on palliative care are the integration into other disease-specific guidelines and the identification of topics with enough scientific evidence in the broad range of palliative care issues. The concept of the palliative care guideline presented here may serve as a model to others interested in setting up a cross-disease orientated guideline.

The project is funded by the German Guideline Programm Oncology (GGPO).

**Abstract number:** P73

**Abstract type:** Poster

Evaluation of Dyspnoea Intervention Group in Palliative Care Measured by Cancer Dyspnoea Scale

Stowe E.R.¹, Abbas S.Q.²

¹St Clare Hospice, Day Therapy, Hastingswood, United Kingdom, ²St Clare Hospice, Hastingswood, United Kingdom

**Aim:** To evaluate the effectiveness of a non-pharmacological dyspnoea intervention group (NPDIG), for cancer and non-cancer patients using the Cancer Dyspnoea Scale (CDS) and patient experience questionnaire.

**Background:** Dyspnoea is reported in 24-31% of all palliative patients, and pharmacological intervention is of limited benefit. Efficacy of one to one non-pharmacological dyspnoea management in these patients has been investigated, whereas group programmes has not.

**Method:** Outpatients with dyspnoea were offered the NPDIG, including an education programme of pacing activity, exercise, breathing control and relaxation. The sessions were delivered by a team led by a physiotherapist. Patients completed the CDS, before and after NPDIG. Results for each subcomponent of the CDS (effort, discomfort and anxiety) were analysed using paired t-tests; a p value < 0.05 was considered significant. Six patients completed an anonymised questionnaire covering how they felt the group affected the delivery of the programme and their preference for group or individual sessions.

**Results and analysis:** 23 patients (14 females and 9 males) were offered NPDIG over a 12 month period, of which 19 completed. 2 were unable to complete the group, 2 died. The average age of those completing the programme was 76yrs; 11 patients had COPD, 7 had cardiac failure, 1 had cancer. The mean pre-intervention CDS score was 19.7; the mean for effort, anxiety and discomfort were 9.4, 5.9 and 4.2 respectively. The mean CDS after completion of the programme was 10.8 (p=0.002); the mean for effort, anxiety and discomfort were 5.1 (p=0.001), 2.8 (p=0.014) and 2.9 (p=0.426) respectively. Analysis of questionnaires showed that patients valued the opportunity to share their experience with others.

**Conclusion:** NPDIG is effective at reducing total sense of dyspnoea, as well as the associated effort and anxiety as assessed by CDS. Patients report added benefit of the group experience.

**Abstract number:** P74

**Abstract type:** Poster

The Effectiveness of Phenothiazines for the Relief of Refractory Breathlessness - A Systematic Review

Geffe V.¹, Bausewein C.², Magnussen H.², Heigener D.F.³, Jehser T.³, Kloke M.⁴, Kranz-Oppeg-Rhein B.⁵, Krumm N.⁶, von Leupoldt A.⁷, Loquai C.⁸, Nehls W.⁹, van Oorschot B.¹⁰, Riha S.¹¹, Steins M.¹², Thomas M.¹³, Wollenberg B.¹³, Pralong A.¹⁴, Voltz R.¹⁴, Simon S.T.¹⁵, on behalf of the German Guideline Group Palliative Care

¹University Hospital of Cologne, Department of Palliative Medicine, Clinical Trials Unit (BMBF 01KN1106), and Centre for Integrated Oncology (CIO) Cologne/Bonn, Cologne, Germany, ²University Hospital Munich, Department for Palliative Medicine, Munich, Germany, ³Hospital Grosshansdorf, Center for Pneumology and Thoracic Surgery, Grosshansdorf, Germany, ⁴Hospital Grosshansdorf, Lung Clinic, Grosshansdorf, Germany, ⁵Hospital Havelhoehe, Department of Palliative Medicine, Havelhoehe, Germany, ⁶Kliniken Essen-Mitte, Center for Palliative Medicine, Essen, Germany, ⁷Marienhospital Aachen, Diagnostik- und Therapiezentrum, Aachen, Germany, ⁸RWTH Aachen University, Department of Palliative Medicine, Aachen, Germany, ⁹KU Leuven, Research Group Health Psychology, Leuven, Belgium, ¹⁰University of Mainz, Department of Dermatology, Mainz, Germany, ¹¹HELIOS Klinikum Emil von Behring, Department of Pneumology, Heckeshorn, Germany, ¹²University Hospital of Würzburg, Interdisciplinary Center for Palliative Medicine, Würzburg, Germany, ¹³Fachkrankenhaus Coswig GmbH, Centre for Pulmonary Diseases and Thoracic Surgery, Coswig, Germany, ¹⁴University of Heidelberg, Thoraxklinik, Heidelberg, Germany, ¹⁵University of Lübeck, Department of Otorhinolaryngology, Head and Neck Surgery and Plastic Surgery, Lübeck, Germany

**Aim:** Breathlessness is a common and distressing symptom and often difficult to treat successfully. Phenothiazines are
described to be helpful in the management of breathlessness but their effectiveness is unknown. This systematic review aims to determine effectiveness based on the relevant studies.

Methods: Systematic literature review. Three electronic databases (Medline, Embase, Central) were searched for original papers describing the effectiveness of phenothiazines for the relief of refractory breathlessness.

Results: Four papers (1 CCT, 3 RCT) and one abstract (CCT - fulltext could not be found) were included (N=56). Either participants had a severe (n=18) or stable COPD (n=12) or were healthy. In all trials promethazine has been tested (25-125mg/day) against placebo, diazepam or codeine. In addition, one trial also tested chlorpromazine against mebutroline. Breathlessness-intensity was measured with Visual Analogue Scales (VAS). In summary, there was no evidence for the effectiveness of phenothiazines although there was a slight trend without statistical significance for promethazine. All trials conducted in the 80s had a small number of participants. Current data are missing.

Conclusion: Quality of included studies is low to moderate. Based on the relevant literature, there is no evidence for the effectiveness of phenothiazines for the relief of refractory breathlessness and thus they should not be used for this indication.

The project is funded by the German Guideline Program in Oncology (GGPO).

Abstract number: P75
Abstract type: Poster

Decreased Heart Rate Variability is Associated with Lower Survival in Cancer Patients

Guo Y.1, Koshy S.1, Palmer J.L.2, Yusuf S.W.3, Bruera E.1

1MD Anderson Cancer Center, Palliative Care and Rehabilitation Medicine, Houston, TX, United States, 2American Statistical Association, Alexandria, VA, United States, 3MD Anderson Cancer Center, Cardiology, Houston, TX, United States

Background: Many cancer patients have altered autonomic function as a result of cancer or its treatment. Previous data has shown that autonomic dysfunction is associated with shorter survival in patients with advanced cancer. We examined the association between heart rate variability (HRV), a measure of autonomic function, and survival of cancer patients in a large sample size.

Methods: We examined 673 cancer patients who underwent ambulatory 20-24 hour electrocardiogram monitoring and the time domain (standard deviation of normal to normal beat interval [SDNN]) were calculated using power spectral analysis. We collected demographic information, survival data. We defined survival as the interval between electrocardiogram study and date of death. We compared the survival on those patients with SDNN>=70ms to those with SDNN < 70ms. 455 patients were still alive at the time of data analysis and included in the survival analysis as being censored.

Results: Median age was 60 years (range: 20-79), and 506 out of 673 (72%) were Caucasians. We divided patients into 2 groups: group 1 (n=539) had SDNN>=70ms, group 2 (n=134) had SDNN< 70ms. When comparing the two groups, there is no significant differences in patient’s age, ethnicity, smoking history, body mass index, tumor type, and metastatic sites, past medical history and medication, except the group 2 had significantly higher percentage of male patient (p=0.043), lower ejection fraction and higher percentage of patients were on non-selective serotonin re-uptake inhibitors antidepressant. The patients in group 2 had significant shorter survival (25% patients died by 18.8 weeks) vs. the patient group with SDNN>=70ms (25% patients died by 81.8 weeks) (p< 0.0001).

Conclusion: SDNN< 70ms is associated with shorter survival in patients with cancer. SDNN may be a useful predictor for cancer survival. Intervention that could improve HRV may impact on cancer survival.

Abstract number: P76
Abstract type: Poster

Comprehensive Geriatric Assessments for Nursing Home Residents with Palliative Care Needs: A Systematic Review

Hermans K.1, Spruytte N.1, Cohen J.2, Van Audenhove C.1, Declercq A.1

1KU Leuven, LUCAS, Center for Care Research and Consultancy, Leuven, Belgium, 2Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium

Research aims: Nursing homes become important locations for palliative care. By means of comprehensive geriatric assessments (CGAs), an evaluation can be made of the different palliative care needs of nursing home residents. This review aims to identify all CGAs that can be used to assess palliative care needs in long-term care settings and that have been validated for nursing home residents receiving palliative care. The CGAs are evaluated in terms of psychometric properties and content comprehensiveness.

Study population: Nursing home residents with palliative care needs.

Methods: A systematic literature search in electronic databases MEDLINE, Web of Science, EMBASE, Cochrane, CINAHL and PsycInfo was conducted for the years 1990 to 2012. Psychometric data on validity and reliability were extracted from the articles. The content comprehensiveness of
the identified CGAs was analyzed, using the 13 domains for a palliative approach in residential aged care of the
Australian Department of Health and Ageing (AGDHA).

**Results:** A total of 1368 articles were identified. Seven studies met our inclusion criteria, describing five different
CGAs that have been validated for nursing home residents
with palliative care needs. All CGAs demonstrate moderate
to high psychometric properties. The interRAI PC
covers 12 of the 13 domains for a palliative approach in
residential aged care of the AGDHA. The MQLS covers
eight domains. All other CGAs cover six domains or less.

**Conclusion:** The interRAI PC and the MQLS are consi-
dered to be the most comprehensive CGAs to evaluate the
needs and preferences of nursing home residents receiving
palliative care. Future research should aim to examine the
effectiveness of the identified CGAs and to further validate
the CGAs for nursing home residents with palliative
care needs.

**Abstract number:** P77

**Abstract type:** Poster

**Factors Associated with a Preference for Dying at Home among Terminally Ill Cancer Patients**

Ullersted M.P.¹, Schou-Andersen M.², Jensen A.B.², Neergaard M.A.³

¹Aarhus University, Aarhus, Denmark, ²Aarhus
University Hospital, Department of Onkology, Aarhus, Denmark, ³Aarhus University Hospital, Palliative Team,
Aarhus, Denmark

**Introduction:** A core element in palliative care is to meet
end-of-life preferences of the patients. Earlier studies have
shown socio-economic differences in relation to place of
death. Hence, there is a need to know if such differences
also exist in patients’ preferences for place of death.

**Aim:** The aim of this study was to investigate whether
demographic, socio-economic, or disease-related factors
were associated with the preference for dying at home.

**Method:** A population-based, retrospective questionnaire
study among 198 relatives of deceased cancer patients
was performed in 2007 in the former Aarhus County, Denmark.
The bereaved relatives were asked to state the patient’s
preference concerning place of death at the beginning
and at the end of the palliative period. These data were
combined with data from Danish national health regis-
ters about demographic and socio-economic factors. We
used generalised linear models with log link for Bernoulli
family modelling the Prevalence Ratio (PR).

**Results:** We found a significant positive association at
the beginning of the palliative trajectory between prefer-
ing home-death and being male (PR=1.26 (CI: 1.00;1.58)
(p=0.048)) and a significant negative association when
having a medium income when comparing with a high
income (PR=0.81 (CI 0.67;0.98)(p=0.031)). At the end of
the palliative trajectory a significant negative association
was found between size of community and the likelihood
of preferring home-death, i.e. the association between a
preference for home death and living in a community with
more than 100,000 inhabitants was 0.63 (CI 0.45;0.89)
(p=0.008)) compared with living in a community with less
than 10,000 inhabitants.

**Conclusion:** The study showed that socio-economic fac-
tors such as sex, income and size of community were
associated with the preference for dying at home. More
research is needed to explore to what extent these differen-
ces in preferences are due to social inequality.

**Abstract number:** P78

**Abstract type:** Poster

**Patterns of Place of Death in Chronic Kidney Disease**

Lovell N.¹, Jones C.², Baynes D.², Dinning S.², Vinen K.², Murtagh F.¹

¹King’s College London, Cicely Saunders Institute,
London, United Kingdom, ²King’s College Hospital,
King’s Renal Unit, London, United Kingdom

**Aims:** Meeting preference regarding place of death is an
important marker of quality of care; systematic review
shows 42% end stage kidney disease patients prefer home
death. These patients have high mortality, yet little research
has studied place of death. The aim of this study was to
understand patterns of place of death in patients with chro-
nic kidney disease (CKD) known to a UK renal team.

**Methods:** A retrospective cohort study of CKD patients
stage 4-5 who died over 7 years (2006-2012). Demo-
graphic and clinical variables were collected, including
management pathway and living circumstances. Multi-
variable regression analysis was undertaken to determine
relationship with place of death.

**Results:** 321 patients were included (mean age 82.7, SD
5.21). 61.7% male. 62.9% died in hospital (95% CI 57.5-
68.1%), 21.8% died in their usual residence (95% CI 17.5-
26.6%), and 15.3% died in an inpatient palliative care unit
(95% CI 11.6-19.5%). Management pathway and residen-
tial setting were most strongly associated with place of
death. Patients on the conservative (non-dialytic) pathway
had 4 times the odds of dying out-of-hospital (OR 4.0, 95%
CI 2.1-7.5, P< 0.01). Patients living alone were less
likely to die out-of-hospital (OR 0.3, 95% CI 0.1-0.6, P<
0.01). Patients living in a care home had 5 times the odds
of dying out-of-hospital (OR 5.2, 95% CI 1.8-15.0, P<
0.01). Over time out-of-hospital deaths increased and in
2012 patients had 3 times the odds of dying out-of-hospital
compared to 2006 (OR 3.1, 95% CI 1.0-9.7, P< 0.05).

**Conclusion:** Hospital death predominated all groups,
but place of death varied by management pathway.
Out-of-hospital deaths were higher in the conservative group. This may represent impact of palliative care service development for conservatively managed patients in this unit. This work highlights importance of considering management pathway and living circumstances, so we can meet preferences for place of death in all patient groups.

Abstract number: P79
Abstract type: Poster

Spiritual History-taking in Palliative Home Care: A Cluster Randomized Controlled Trial


KU Leuven, Department of General Practice, Leuven, Belgium

Background: Spirituality has become a core component of palliative care. Health care providers (HCPs) often lack confidence and words to perform a spiritual history-taking.

Purpose: To investigate the effects of performing a spiritual history-taking on spiritual well-being, quality of life, and pain of palliative patients, and on patient-provider trust.

Patients and methods: A cluster randomized controlled trial (RCT) in palliative home care was conducted from February through November 2013. Nurses and general practitioners approached patients with an incurable, life-threatening disease for study participation. HCPs allocated to the intervention arm (IA) participated in a training and performed a spiritual history-taking guided by the Ars Moriendi Model (AMM). HCPs in the control arm (CA) received neither training nor the AMM. Patient-reported outcomes on spiritual well-being (Functional Assessment of Chronic Illness Therapy-Spiritual-12), quality of life (European Organisation for Research and Treatment of Cancer QLQ-C15-PAL), pain (Verbal Rating Scale), and patient-provider trust (Health Care Relationship Trust Scale) were assessed. Statistical analysis on continuous scale scores was performed using a linear model with an unstructured error covariance matrix. Further analysis on ordinal scale scores was performed using a proportional odds model using generalized estimating equations.

Results (available in January 2014): 246 HCPs participated in the study. Until present, 42 dyads completed the protocol (21 in the IA and 21 in the CA). We expect to present data about 50 dyads. The focus of the primary analysis will be on testing whether the change on the FACTIT-Sp-12 scale between pre- and post-measurements is larger for the IA compared to the CA.

Conclusion: RCTs in palliative home care remain uncommon despite evidence favouring end-of-life care in this setting. This RCT contributes to the understanding of the effect of spiritual history-taking on patients’ well-being.

Abstract number: P80
Abstract type: Poster

Examining Family Carer Psychological Distress: Is the Construct Evidence-based?

Washington K.1, Rakes C.2, Parker Oliver D.1

1University of Missouri, Department of Family & Community Medicine, Columbia, MO, United States,
2University of Maryland Baltimore County, Department of Education, Baltimore, MD, United States

Background: Depression and anxiety (often strongly correlated) are often used to conceptualize psychological distress. Yet, to many, anxiety and depression seem qualitatively different, and understanding these differences may have an important impact on the lives of family carers of seriously ill patients, who are at risk of poor psychological health.

Research aims: This study examined the nature of psychological distress for hospice family carers. Research questions were

1) What is the structure of psychological distress for hospice family carers?
2) To what extent are depression and anxiety as distinct constructs of distress supported by hospice family carer data?

Study population: The sample was comprised of 229 informal carers of adult patients receiving hospice services from an agency in an urban setting in the Southeastern United States.

Study design and method: Volunteer participants completed the 9-item Patient Health Questionnaire (PHQ-9) and the 7-item Generalized Anxiety Disorder (GAD-7) scale.

Method of statistical analysis: Confirmatory Factor Analysis and Structural Equation Modeling techniques were used to determine the relationships among psychological distress factors and whether a second-order factor reduced the unexplained variance in the model. A wide array of fit indices was examined to determine best fit.

Results and interpretation: Depression and anxiety were highly correlated (r = 0.865, p < .001) in the best fitting model. The inclusion of a second-order factor (psychological distress) significantly increased rather than decreased the unexplained variance in the model (p < .0001), suggesting that coarser measures of psychological distress may prove sufficient as initial screening tools; however, subsequent assessment of carers would benefit from consideration of depression and anxiety as discrete constructs.

Extramural support: This study was supported by a grant from the John A. Hartford Foundation.
Hospice Staffs’ Evaluation of the Sacred Art of Living and Dying Spiritual Education Programme

Hayden D., Bates U.

Our Lady’s Hospice & Care Services, Dublin, Ireland

**Background:** Healthcare education in spirituality is essential for staff to fulfil their responsibility in meeting spiritual needs. Yet a dearth of published literature evaluating spiritual education outcomes exists. Furthermore, there is limited consideration of the long term impact on healthcare professionals’ spiritual perspectives and practice.

**Aim:** The overall aim was to evaluate the long-term influence of the Sacred Art of Living and Dying (SALD) spiritual education on participants’ spiritual perspectives and work practice. Focusing on the Irish hospice that hosted the programme, this paper primarily reports on staffs’ views and recommendations for future spiritual care programmes.

**Research question:** ‘What are hospice staffs’ perceptions of the Sacred Art of Living and Dying (SALD) spiritual education programme?’

**Methods:** A multi-strategy, post-test, fixed design using self-completion retrospective questionnaire and Reed’s (1987) Spiritual Perspective Scale (n=161, response rate 40%), followed by a focus group interview (n=6) were conducted two years post SALD programme using purposeful sampling. Based on the findings, a second focus group consisted of existing hospice staff who attended the programme (n=8).

**Results:** The study reports a high level of satisfaction with the SALD programme; very strong spiritual perspective ratings; and largely increased levels of awareness and confidence to engage in spiritual care that benefited most participants’ personal and professional lives. This occurred through a process of spiritual discovery and integration of spirituality into everyday life, which for some led to transformation.

**Conclusion:** Effectual spiritual care teaching involves exploring practitioners’ inner ability to walk on sacred ground, and requires cultural and contextual awareness and sensitivity grounded in strong spiritual wisdom.

Patient-centered Integrated Palliative Care Pathways in Advanced Cancer and Chronic Disease: A Systematic Review

Van Beek K.A., Siouta N., Menten J.

University Hospital Leuven, Radiotherapy-Oncology and Palliative Medicine, Leuven, Belgium

**Background:** The concept of palliative care (PC) largely originates from cancer care, but is increasingly applied to patients with chronic diseases. Although PC improves the quality of life of these patients at lower costs, patients are often transferred between home and other care settings during the last phase of life and large variations exist in (non)treatment strategies in advanced cancer and chronic disease. The current study aims to identify existing initiatives for integrated PC by conducting a systematic literature review of existing models, guidelines and clinical pathways of integrated PC in cancer and chronic disease.

**Search strategy:** Cochrane Central Register of Controlled Trials, PubMed, EMBASE, CINAHL, AMED, BNI, WoS, NHS Evidence and Google were searched. BMJ supportive & palliative care, European journal of palliative care, Journal of Pain and Symptom Management, Palliative Medicine and Medicina Palliativa and reference lists from included studies were handsearched.

**Data collection:** Two reviewers screened all the search results and full text of articles were reviewed by both reviewers, discrepancies were resolved by consensus. Data were extracted from papers meeting the inclusion criteria using a data extraction form. Included record were assessed by a numerical scoring system (Hawker et al). A narrative synthesis will be used for reporting.

**Conclusion:** Current health care delivery for patients with advanced illnesses is not optimal from both a quality of care perspective and an economic perspective. Large variations in treatment trajectories and (non)treatment strategies in those with advanced illness indicate a lack of consensus on optimal treatment pathways, and large risks for overburdening of informal caregivers. This systematic review aims to describe the existing models, pathways and guidelines of integrated PC in cancer and in chronic diseases. We will be able to present the results at the upcoming EAPC congress.

Prevalence of Functional Iron Deficiency Anaemia in Advanced Disease in a UK Hospice

Neoh K., Bennett M.

The University of Leeds, Academic Unit of Palliative Care, Leeds, United Kingdom

Anaemia is a common cause of fatigue in patients with advanced disease. Although bone marrow suppression and blood loss are commonly described, functional iron deficiency (FID) or the anaemia of chronic disease is increasingly recognised as an important aetiology. A retrospective review of blood results taken from patients admitted to a UK hospice was conducted to estimate the prevalence of FID.
Methods: All admissions to the hospice from August 2012 to July 2013 were identified. Blood testing taken closest to the admission date was used to assess the degree and cause of anaemia.

Results: Laboratory data on 238 patients were available. 91% had a cancer diagnosis. Prevalence of anaemia was 68% using WHO criteria: 24% (mild, Hb 110-130g/l in men, 110-120g/l in women), 39% (moderate, Hb 80-109g/l) and 5% (severe, Hb< 80g/l). Median haemoglobin was 105g/L (IQR 92-113 g/l). The most reliable markers of iron restricted erythropoesis (reticulocyte haemoglobin and percentage of hypochromic cells) were not available on a standard full blood count and not routinely requested. 87 (54%) of anaemic patients had C-Reactive Protein checked within a month of admission; it was raised in 84 (52%) indicating an inflammatory process.

Prevalence of FID: Of the 162 anaemic patients, 110 (68%) had blood results in keeping with FID. 17 (11%) had results in keeping with blood loss; 6 (4%) patients had evidence of either bone marrow suppression or renal failure; 23 (14%) had possible iron deficiency anaemia; 6 (4%) of patients had a macrocytosis (B12 or folate deficiency).

Conclusion: Anaemia was common in this population; 44% had moderate to severe anaemia. FID is estimated to have a prevalence of up to 68% in anaemic patients; it is a significant but under-recognised cause of anaemia in advanced disease. Limitations of this research include the lack of review of patients’ management and symptoms. Further research is needed to confidently diagnose FID and target treatments for anaemia.

Abstract number: P84
Abstract type: Poster

Assessing Palliative Care in Parkinson’s Disease - Development of the NAT: Parkinson’s Disease

Richfield E.W.1, Girgis A.2, Johnson M.1

1Hull York Medical School, Supportive care, Early diagnosis and Advanced Disease, Hull, United Kingdom
2Ingham Institute for Applied Medical Research South Western Sydney Clinical School, UNSW Medicine, UNSW, Translational Cancer Research Unit (TCRU), Sydney, Australia

Background: Parkinson’s disease (PD) is a common life limiting neuro-degenerative condition, where treatment strategies remain largely symptomatic. Despite calls for improved access to palliative care, provision remains sporadic. Barriers to palliative care include poor identification and triage of unmet need.

The Needs Assessment Tool: Progressive Disease (NAT:PD), originally developed for cancer and subsequently adapted for heart failure, examines three main areas; “patient wellbeing”, “ability of caregiver to care for patient” and “caregiver wellbeing”.

Aims: To adapt the NAT:PD for use in Parkinson’s disease.

Method: We conducted

i) systematic literature review and qualitative synthesis of palliative and supportive care need in PD
ii) a qualitative study (interviews and focus groups) exploring the experience of patients and carers, including some with dementia. Data were organised according to NAT category, with new categories produced where needed. Each category was then adapted, iteratively, to ensure the new tool incorporated all constructs arising from the qualitative studies. Selected clinicians from palliative, geriatric and neurological disciplines were consulted on the final product, to improve face and content validity.

Results: Adaptations were made to each of the NAT categories. The main change is the addition of a new section to help identify sub-groups at high risk of unmet palliative need in PD. These “red flags” include; symptoms (hallucinations, recurrent falls, axial instability and aspiration), admission to 24 hour care and failure to attend clinic. Question stems have been used where possible, to reduce word count and enhance ease of use.

Conclusions: The NAT format has now been adapted for PD. As a prompt for clinicians, suitable for everyday clinical use, it has the potential to overcome a principal barrier to recognition, triage and management of palliative care need in PD. Clinimetric testing of validity and reliability is underway.

Abstract number: P85
Abstract type: Poster

Deliberative Panels: Developing Recommendations for Supporting Stakeholder and User Involvement:

Brearley S.G.1, Blake S.2, Milligan C.3, Seamark D.2, Thomas C.3, Turner M.1, Wang X.4, Payne S.A.1

1International Observatory on End of Life Care, Lancaster University, Lancaster, United Kingdom, 2Honiton Group Practice, Honiton, United Kingdom, 3Faculty of Health and Medicine, Lancaster University, Lancaster, United Kingdom, 4Department of Psychology, Leeds Metropolitan University, Leeds, United Kingdom

Background: It is recognised that research in Palliative Care needs to integrate stakeholder and user engagement. Alongside research planning and conduct this can also assist in developing recommendations for policy and clinical practice.

Aim: This paper considers a Deliberative Panel approach to the dialogic processing of preliminary data findings
from family carer’s reflections on dying at home (Unpack-

cing the Home). Though similar to consensus techniques

in qualitative research, this approach aims to engage key

stakeholders in the process of transforming research find-

ings into policy recommendations.

**Methods:** Two deliberative panels with a total of 31 key

stakeholders were held in the UK (Lancaster and London).

Key stakeholders included policy makers, clinicians, aca-

demics and service users. A four phase deliberative panel

was adopted.

- Phase 1: presentation of preliminary data findings;
- Phase 2: facilitated discussions;
- Phase 3: feedback of discussions and identification of

recommendations to change policy/practice;
- Phase 4: ranking of recommendations for presenta-

tion to policy makers.

**Results:** Four overarching areas of recommendations for

policy and clinical practice were identified:

i) practical strategies need to be developed to sup-

port family carers at home (key workers, caregiver

needs, assistance with medication management,

and bereavement follow up);

ii) guidance is needed on information (initiatives

such as “tell me once”, and information on support

before and after death);

iii) the importance of place of care over place of

death and the potential for the voluntary sector to pro-

vide support; and

iv) a radical review is needed of the way in which per-

sonal social care is provided in order to meet the

individualised needs of family carers.

**Conclusion:** This paper suggests a strategy for palliative

care researchers to integrate their findings into practical

policy recommendations in a transparent and integrative

manner, based on public values and attitudes.

**Abstract number:** P86

**Abstract type:** Poster

**Palliative Care Needs in Breathless Patients with

Advanced COPD or Lung Cancer over Time: Results

from a Cohort Study**

Weingärtner V.1,2, Scheve C.2, Gerdes V.2, Schwarz-

eywill M.3, Prenzel R.4, Bausewein C.2,5, Higginson I.J.6,

Voll R.1, Simon S.T.1,2, on behalf of PAALiativ

1University Hospital of Cologne, Department of Palliative

Medicine, Clinical Trials Unit (BMBF 01KN1106), and

Centre for Integrated Oncology (CIO) Cologne/Bonn,

Cologne, Germany, 2Institute of Palliative Care (ipac)

(BMBF 16KT0951), Oldenburg, Germany, 3Protestant

Hospital Oldenburg, Department of Palliative Medicine,

Oldenburg, Germany, 4Pius-Hospital Oldenburg, Clinic

for Internal Medicine, Oldenburg, Germany, 5University

Hospital Munich, Department for Palliative Medicine,

Munich, Germany, 6King’s College London, Cicely

Saunders Institute, Department of Palliative Care, Policy

and Rehabilitation - WHO Collaborating Centre for

Palliative Care and Older People, London, Germany

**Aims:** Understanding the patterns of palliative care (PC)

needs in patients with advanced diseases over time is impor-
	ant to improve care and patients’ quality of life. The aim

of this study was to describe the trajectories of PC needs in

breathless patients with advanced disease over time.

**Methods:** This cohort study assessed breathless patients

(modified Borg scale ≥0) with COPD (GOLD stage III/

IV) or lung cancer (LC, any stage) in Germany monthly by

up to 12 telephone interviews. PC needs were measured by

the Palliative care Outcome Scale (POS) which consists

of ten items to be rated from 0 (best) to 4 (worst) and an

open question on distressing problems. We used descrip-

tive analysis. POS sum-score, single items and relevant

needs (scores ≥3) were compared between COPD and LC

at baseline and forward over time.

**Results:** Eighty-two patients (50 COPD, 32 LC), mean

(SD) age 67 (8) years, 36% female, were included. Both

disease groups had similar levels of PC needs over time

(means COPD 8.1-10.3, LC 7.7-10.0). The most relevant

need was “information” in both groups. In LC, “other sym-

toms” increased over time while “pain” was more rele-

vant in COPD at later study stages. “Wasted time” was

the least relevant need in both groups. Patients with hig-

her level of breathlessness also had higher levels of PC

needs in both groups. Frequently reported problems in-

cluded symptom impact, general weakness, anxiety about

the future, familiar, financial or care related trouble.

**Conclusion:** Similar levels of PC needs exist in breathless

patients with advanced COPD or LC in Germany that last

over time. This suggests, improved attention is required to

assess existing needs in the provision of care for these pa-

tients. Since information was the most relevant unmet need

in both groups, communication skills should be advanced

in medical training to improve this situation.

**Funding:** This study is part of a project which was funded

by the German Federal Ministry of Education and Research

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**Abstract number:** P87

**Abstract type:** Poster

**Is Continuous Reaction Time a Reliable Instrument to

Detect Cognitive Deterioration?**

Matuoka J.Y.1, Kurita G.P.2, Sjøgren P.1, Pimenta

C.A.M.1

1University of São Paulo, School of Nursing, Medical

Surgical Nursing, São Paulo, Brazil, 2Rigshospitalet,
Section of Palliative Medicine, Multidisciplinary Pain Centre, Copenhagen, Denmark, 3Rigshospitalet, Section of Palliative Medicine, Copenhagen, Denmark

Objectives: To validate continuous reaction time as measurement of sustained attention in patients with advanced cancer.

Methods: 178 outpatients with advanced cancer and 79 healthy volunteers underwent continuous reaction time (CRT) and answered a questionnaire regarding demographic and clinical status. Controls had no depression or anxiety, didn’t use psychotropic agents and had mini mental (MEEM) score > 26. Discriminant, convergent and divergent validity (depression, anxiety, fatigue, pain, sleep and MEEM) and reliability were analyzed by SPSS v.15.0.

Results: Considering that groups were different regarding sex, age and schooling, analysis of covariance was performed, controlling those variables. No differences between volunteers and patients were observed in CRT (p>0.05). There was no correlation between pain, sleep, fatigue and CRT (r=0.01 to 0.05). Results of CRT were weak positive correlations between anxiety and CRT (r=0.13; p=0.04) and depression and CRT (r=0.12 to 0.16; p=0.01 to 0.05) were observed. Also, there was a weak negative correlation between MEEM and CRT (r=−0.22 to −0.25; p>0.001). Nine volunteers and 34 patients were submitted to a second CRT assessment (3–7 days after first measurement) but no difference was observed (p>0.05).

Conclusion: No differences were observed between patients’ and volunteers’ performance on CRT, and the few significant correlations between CRT, anxiety, depression and MEEM were poor. The instrument’s inability to distinguish between cognitive function of sick and healthy people and to associate with clinical symptoms suggests that CRT may not be a suitable instrument to advanced cancer patients. Further study is essential to find reliable ways to detect such impairment.

Abstract number: P88
Abstract type: Poster

Developing a Framework for Palliative Cancer and Dementia Care: Quality Indicators to Guide Clinical Practice

van Riet Paap J.1, Vernooij-Dassen M.1,2,3, Dröes R.-M.3, Vissers K.4, Engels Y.4

1Radboud University Medical Center, IQ Healthcare, Nijmegen, Netherlands, 2Radboud University Medical Center, Radboud Alzheimer Centre, Nijmegen, Netherlands, 3VU University Medical Centre, Department of General Practice & Elderly Care Medicine and Department of Psychiatry, Amsterdam, Netherlands, 4Radboud University Medical Center, Department of Anaesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands

Purpose: Large numbers of vulnerable patients are in need of palliative care. However, a wide gap exists between the knowledge of best practices in palliative care and their use in every day clinical practice. To bridge this gap this study aimed to compose a generic set of quality indicators (QIs) that can help to assess the organisation of palliative care for patients with cancer and those with dementia.

Methods: This study consisted of two phases. First, a multidisciplinary, international panel of experts participated in a modified RAND Delphi procedure to compose a set of palliative care QIs based on existing sets of QIs on the organisation of palliative care. Panellists participated in two written rounds and one consensus meeting. The panel’s median votes were used to identify the final set of QIs. Second, the final set of QIs was tested in a pilot study to assess the organisation of palliative care in five European countries. Adherence to the QIs, measured in a pre-post test, determined the usefulness of the QIs.

Results: The expert panel considered 23 QIs useful after three Delphi rounds. These QIs represented key elements of the organisation of good clinical practice and entered the pilot study. QIs considered useful were related to the structure of palliative care, such as the availability of palliative care teams, the availability of special facilities to provide palliative care for both patients and their relatives, and the presence of educational interventions for professionals. Included QIs were also related to the process of palliative care, such as the documentation of pain and other symptoms, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

Conclusion: This set of QIs combined existing sets of QIs particularly on the organisation of palliative care. Applying these QIs in a large variety of settings addressing not only cancer but also dementia care in different European countries is unique.

Abstract number: P89
Abstract type: Poster

Experiences of Patients, Family Caregivers and Professional Caregivers with Integrated Palliative Care in Europe: Development of a Patient Study Protocol in Five Countries

van der Eerden M.4, Csikos A.2, Busa C.2, Radvanyi I.2, Payne S.3, Radbruch L.4, Menten J.5, Hasselaar J.6, Groot M.6, InSup-C Consortium

1Radboud University Medical Centre, Anesthesiology, Pain, Palliative Medicine, Nijmegen, Netherlands, 2University of Pecs Medical School (UP), Pecs, Hungary, 3University of Lancaster (ULANC), Lancaster, United Kingdom, 4University Hospital Bonn, Bonn, Germany, 5Catholic University Leuven, Leuven, Belgium, 6Radboud University Medical Centre, Nijmegen, Netherlands
Background: Integration of palliative care in treatment pathways, palliative care networks and institutional collaborations in health services delivery seems to be a promising approach to reduce fragmentation and discontinuity. Integrated Palliative Care (IPC) approaches in Europe are largely unknown and under-investigated. Evidence is largely based on evaluation of individual services and proxy views. More research is needed to explore experiences of patients, however national ethical requirements complicate doing prospective patient studies in palliative care. Patient studies at international scale that must fulfil ethical requirements of several countries are even more complicated. Therefore it is necessary to develop a patient study protocol which can be implemented in five European countries.

Aim: To develop a patient study protocol that can be implemented in five European countries in order to explore experiences of patients with cancer, COPD and CHF, family and professional caregivers with IPC.

Methods: Ethical procedures in each partner nation were investigated in order to know which requirements needed to be met. A template protocol was developed by InSup-C (EC FP7 funded) research teams and discussed in InSup-C meetings. This template was adjusted to the most strict requirements.

Results: A study protocol for a longitudinal patient study in five European countries has been developed. This includes perceived quality of life, quality of care, burden/rewards of care giving, symptoms and collaboration between caregivers in the patient’s care network. Some regulations (e.g. safety reporting) have been adjusted to country specific regulations provided that these would not alter the study procedures.

Conclusion: It is feasible to develop a palliative care patient study protocol that can be executed in five European countries. The patient study protocol will be implemented in Spring 2014.

Abstract number: P90
Abstract type: Poster

Development and Pilot Test of the Liverpool Care Pathway to Improve End-of-Life Care in Acute Geriatric Hospital Wards: A Phase I-II Trial Following the Medical Research Council Framework

Verhofstede R.
Vrije Universiteit Brussel, Brussels, Belgium

Background: To improve the quality of end-of-life care, the Liverpool Care Pathway for the Dying Patient (LCP) was developed in the UK. Although the LCP is used widely around the world, there is a lack of sound evidence supporting its use. The studies that have been performed show that the LCP contributes to cancer patients’ quality of life in the dying phase. It is unknown whether similar effects can be achieved in elderly patients dying in acute geriatric hospital wards.

Objective: To develop and pilot test a Flemish version of the LCP document and an 8-step implementation program within the acute geriatric hospital ward.

Methods: Medical Research Council Framework (MRC) phases 0, I and II were performed. In phase 0, we reviewed the literature on the LCP and its implementation in hospitals. In phase I, a Flemish version of the LCP and an 8-step implementation program were developed. In phase II, the intervention was piloted in the geriatric ward of Ghent University hospital. To evaluate the feasibility and acceptability of the intervention, extensive field notes were made during the implementation process and semi-structured interviews were conducted with nurses and geriatricians.

Results: Analysis of our field notes indicate a difficult decision making process about the start of the LCP. Once started, health care staff experience the LCP as a time-consuming document to complete. However, they also indicate that its use improves the overall documentation and communication between health care staff and patient/family.

Conclusions: Preliminary results of our pilot study show positive effects of the LCP in a geriatric patient population and demonstrate that use of the LCP and our 8-step implementation program are feasible and acceptable to both nurses and geriatricians. A phase III cluster randomized controlled trial to evaluate the effectiveness of the LCP is currently being performed.

Abstract number: P91
Abstract type: Poster

Raising the Profile of End of Life Care Needs for Patients Dying from Liver Disease - Using National Mortality Data

Verne J., Pring A.
Public Health England, Knowledge and Intelligence South West, Bristol, United Kingdom

Background: Liver disease is the underlying cause for 2% of all deaths. During a decade, deaths from liver disease increased 25% and will continue rising. Liver disease deaths are often associated with stigma. Many patients have complicated social circumstances with little family or social support.

Aim: To understand and publicise the characteristics and place of death of people dying from liver disease in order to improve care.

Methods: A descriptive analyses of deaths registration data for England, 2001-11 (Office for National Statistics), cohort defined using ICD-10 coded underlying (UCOD) and contributory causes of death (CCOD) that included
alcoholic, fatty, viral and other chronic liver diseases and liver cancer.

**Results:** The number of people who die with liver disease as UCOD has risen from 9,231 in 2001 to 12,538 in 2011, averaging 10,850 (2% of all deaths). On average ~16,000 people (3.4% of all deaths) died each year with liver disease as either UCOD or a CCOD. The most common UCOD are alcoholic liver disease and liver cancer (0.8% and 0.5% of all deaths). Deaths from liver disease are more common in males and age at death is young (90% are under 70 years old, one in ten of all deaths in 40-49 year olds). More (2.3 fold) people die of liver disease from the most deprived quintile (3,148 p.a.) than the least deprived (1377 p.a.). 71% of people with liver disease as UCOD died in hospital compared with 56% for all causes of death. Hospital death rates varied from Viral liver disease (86%) to liver cancer (48%).

**Conclusions:** Liver disease patients differ from the majority of dying patients due to young age, deprivation and hospital as a place of death. Life threatening, acute-on-chronic exacerbations, co-morbidities and psychosocial problems frequently complicate their end of life care. More focus needs to be given in the hospital setting to recognition of and preparation for the possibility of death in liver patients as this is where most will end their lives.

**Abstract number:** P92
**Abstract type:** Poster

**Gatekeeping in Palliative Care Research: A Systematic Review of Reasons**

*Kars M.C.*, *van Thiel G.J.M.W.*, *van der Graaf R.*, *de Graeff A.*, *Moors M.*, *van Delden J.J.M.*

1UMC Utrecht, Medical Ethics, Utrecht, Netherlands, 2UMC Utrecht, Medical Oncology, Utrecht, Netherlands

**Introduction:** Research in palliative care is essential to improve therapies. Studies report indicate that gatekeeping -a phenomenon that patients who are eligible for inclusion are not approached for participation- hampers palliative care research.

**Aim:** To identify who are gatekeepers in palliative care research and to list their reasons for gatekeeping in order to work towards a thoughtful patient centred approach of gatekeeping

**Method:** A ‘review of reasons’ was conducted, according to a well described model that integrates the systematic PRISMA approach and the identification of reasons using strategies common in qualitative research.

**Study identification:** After screening of 700 unique papers published from 2000, 24 papers were relevant to the research question. Qualitative software (NVivo) supported the systematic identification of gatekeepers and their motives.

**Findings:** Six types of gatekeepers were identified: doctors, nurses, research ethics committees, management and researchers. The most mentioned reason for gatekeeping was the fear of burdening a vulnerable patient. This reason was often reinforced by the pursuit of comfort and well-being, in line with palliative care goals. Other reasons for gatekeeping were feeling uncomfortable by disclosure of health status, to avoid family burden, having doubts about the importance or quality of the study, logistical obstacles and a range of reasons related to personal attitude and expertise. The reasons mentioned often appeared to be a result of intuitions.

**Conclusions:** A variety of actors, including researchers, experience situations in which they felt it would be inappropriate or even harmful to approach an eligible patient. Intuitions more than considerations seemed to underlie the reasons mentioned. There is a need for a normative framework to evaluate gatekeeping.

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**Abstract number:** P93
**Abstract type:** Poster

**Emotional Impact of Transferring Advanced Cancer Patients from Oncology to Palliative Care**


Institut Catalán d’Oncologia, IDIBELL, Palliative Care Service, L’Hospitalet de Llobregat, Spain

**Objectives:** To assess the opinion of cancer patients (pts) transferred to the Palliative Care Outpatient Clinic (POC). Specifically, we sought patient opinions on the information they received about the transfer, their experience between the moment their oncologist informed them of the transfer but before the initial consultation at POC, and their expectations of care at the POC.

**Material and methods:** Opinion survey in consecutive pts referred to POC. Prior to the 1st POC visit, nursing staff contacted pts by telephone to schedule an appointment and resolve doubts.

**Results:** Of 274 pts enrolled, 269 signed the informed consent form & were evaluable. Mean age was 67 and 65% of pts were male. Most pts (85%) were referred from Medical Oncology. M1 was 68%, median PPS 70%, and 42% of pts received anticancer treatment. Median time from diagnosis was 1.3 years. Pt feelings regarding the transfer were: liked (27%); indifferent (67%); didn’t like (2%); don’t know (7%). Although most pts (67%) reported that
the oncologist explained the transfer rationale, the remaining pts answered “don’t remember” (17%), “No” (10%), or “don’t know” (6%). Pt reported “Reason for consultation” were pain (43%), shared care/follow up (25%), to prevent problems (12%), to manage problems other than pain (9%), and don’t know (11%). When informed of transfer to POC, 23% pts reported unease/worry, although this decreased to 16% after a mean of 3 days ($P=0.009$). Before the first consultation, 91% believed the POC would help them while 9% expected to get worse.

**Conclusions:** In a group of pts with advanced cancer and early intervention, transfer to POC is perceived with calm (liked or indifferent=84%), with most pts (91%) expecting to be helped. The main perceived reason for referral was pain, although shared follow up and prevention of future problems were also perceived as important. Early contact before the consultation could positively influence pts emotional state.

**Abstract number:** P94

**Abstract type:** Poster

**From the Spectacular to the Subtacular; Experience of Hospital Care for Patients with Advanced Respiratory Illness Following Emergency Admission**

**Bailey C.** 1, Hewison A. 2, Griffiths F. 3, Staniszewska S. 3, Karasouli E. 4, Lovick R. 4, Munday D. 3

1University of Birmingham, Nursing, Birmingham, United Kingdom, 2University of Birmingham, Health and Population Sciences, Birmingham, United Kingdom, 3University of Warwick, Warwick, United Kingdom, 4N/A, N/A, United Kingdom

**Background:** Despite the increase in emergency admissions of patients with lung cancer and Chronic Obstructive Pulmonary Disease (COPD), little is known about the patient experience in hospital. Understanding this is important to ensure that services are organised and patients receive high quality, compassionate care.

**Research aims:** To explore the experience of patients with advanced Lung Cancer and COPD following emergency admission.

**Design and methods:** Qualitative, critical case study involving semi-structured interviews with 39 patients (15: COPD, 24: lung cancer), 50 health care professionals and 20 family/informal carers. Patients were recruited from three hospitals in England. Interviews took place after emergency admission and following discharge or transfer to a hospital ward. Interviews were transcribed and analysed thematically.

**Results:** Patients were satisfied with their initial emergency treatment but expressed concerns about care in the subsequent phase of hospital admission particularly lack of attention to their individual needs, lack of recognition by staff of the expert family, poor communication about management plans, and lack of continuity between primary and secondary care.

**Interpretation:** Findings offer important insights into hospital care near the end of life. Despite processes in place to prevent emergency admission, the nature of advanced respiratory disease predisposes patients to emergency admission. The initial treatment of the acutely ill patient was likened to a ‘spectacular trajectory’ of care however once stabilised, this is replaced with a ‘subtacular’ approach which involved less direct input and a lack of attention to continuing supportive and palliative care needs. This has implications for hospitals providing end of life care where more attention needs to be given to the organisation and delivery of care.

**Abstract number:** P95

**Abstract type:** Poster

**Living and Dying with Advanced Chronic Liver Disease: Negotiating Uncertainty**

**Kimbell B., Kendall M., Boyd K., Murray S.A.**

University of Edinburgh, Centre for Population Health Sciences, Edinburgh, United Kingdom

**Background:** The number of patients dying with advanced chronic liver disease is rising dramatically. Little is known about the experiences of these patients and their families. Palliative care services traditionally focused on cancer and more recently on other types of organ failure, but liver disease is relatively neglected.

**Aims:** To explore the dynamic physical, psychosocial, spiritual and information needs of patients and their family and professional carers, and to review their use of health, social and voluntary services.

**Methods:** Qualitative, multi-perspective, serial in-depth interviews. Patients with different causes of liver disease were recruited in hospital. They and their family carers were interviewed up to 3 times over one year. Single interviews were undertaken with case-matched professionals. Interviews were recorded, transcribed and analysed using grounded theory methods and NVivo 9.

**Results:** 15 patients and their carers were recruited and 53 interviews conducted. Uncertainty was the key theme experienced across all domains and by all participants: patients, family carers and professionals. This related to the nature of the illness, the unpredictability of disease pathway and prognosis, poor communication and information-sharing, and complexities of care. Coping strategies demonstrated a continuous quest to manage uncertainty. The ubiquitous uncertainty meant that a care planning approach was hard to introduce.

**Conclusion:** This is the first serial interview study of this patient group. It identifies uncertainty as the pervasive
central factor in the experiences of patients, family and professional carers. Uncertainty makes planning important but difficult to start. The more it is needed, the less it is done: an inverse planning law. Given its critical impact, uncertainty must be addressed if people with advanced liver disease are to benefit from the same levels of supportive and palliative care as those with cancer. Study funded by the ESRC.

Abstract number: P96
Abstract type: Poster

The Experiences of Palliative Care Health Service Provision for People with Non-malignant Respiratory Disease and their Caregivers: An All-Ireland Study

McVeigh C.1, Reid J.1, Hudson P.1,2, Larkin P.J.3, Porter S.1

1Queen’s University Belfast, School of Nursing and Midwifery, Belfast, United Kingdom, 2Centre for Palliative Care, St Vincent’s Hospital and Collaborative Centre of The University of Melbourne, Melbourne, Australia, 3University College Dublin, School of Nursing and Midwifery, Dublin, Ireland

Background: The majority of patients diagnosed with a malignant life threatening and incurable disease will have access to palliative care provision. However, it is less clear if the same standards of palliative care are available to those with non-malignant respiratory disease.

Aims: To explore the perception of palliative care health service provision for people with non-malignant respiratory disease and their caregivers living in rural and urban parts of the North and South of Ireland.

Methods: A qualitative study based on broad interpretivism that consisted of two stages of data collection conducted in two rural and two urban areas across the Island of Ireland. Stage one involved semi-structured interviews with 17 bereaved family caregivers of patients that had died (between three to eighteen months previously) from interstitial lung disease, chronic obstructive pulmonary disease or bronchiectasis. Stage two was comprised of four focus groups with 18 multidisciplinary healthcare professionals involved in the care of these patients and their caregivers across the four sites. The data was analysed using thematic analysis.

Results: This study yielded three overarching themes:

1) Dealing with uncertainty
2) Lack of consistency in care delivery
3) Role ambiguity

Conclusion: The findings of this study suggest that caregivers of patients with non-malignant respiratory disease are often unaware of the role that they take in the care of their loved one. For some patients and caregivers a lack of information leads to uncertainty about the nature and trajectory of the illness and the support they receive varies according to their geographical location as a result of inconsistency in the provision of palliative care services. The outcomes of this study provide a critical first step in the development of more responsive palliative care for this client group and their family caregivers.

Funding: Department of Employment and Learning Northern Ireland.

Abstract number: P97
Abstract type: Poster

Pursuing Knowledge Synthesis, Consensus and Collaboration Regarding Delirium Research: An Overview of the SUNDIPS (Studies to Understand Delirium in Palliative Settings) Program


1Bruyere Continuing Care, Division of Palliative Care, Dept of Medicine, Dept of Epidemiology and Community Medicine, University of Ottawa, Bruyere and Ottawa Hospital Research Institute, Ottawa, ON, Canada, 2Bruyere Research Institute, Division of Palliative Medicine, Dept of Medicine, University of Ottawa, Ottawa, ON, Canada, 3Ottawa Hospital Research Institute, Ottawa, ON, Canada, 4Ottawa Hospital, Palliative Medicine, Ottawa, ON, Canada, 5Bruyere Continuing Care, Division of Palliative Care, Ottawa Hospital, Dept of Medicine, University of Ottawa, Bruyere Research Institute, Ottawa, ON, Canada, 6Bruyère Continuing Care, Palliative Medicine, Ottawa, ON, Canada, 7University of Ottawa, Ottawa, ON, Canada, 8McGill University, Montreal, QC, Canada, 9Universite Laval, Quebec, QC, Canada, 10University of Alberta, Palliative Medicine, Edmonton, AB, Canada, 11Flinders University, Adelaide, Australia, 12MD Anderson Cancer Center, Houston, TX, United States

Context: Delirium generates patient and family distress in addition to management challenges for clinical practitioners in palliative care (PC). It presents major research challenges and thus it is under-researched.

Aims: To engage a broad multidisciplinary cadre of delirium researchers, knowledge users and opinion leaders in knowledge gap identification, research priority setting and exploratory collaboration towards future research studies on delirium in PC.

Methods: We combined input from delirium researchers and knowledge users (n=31) at a 2-day international delirium study planning meeting with relevant pre- and post-
meeting literature searches. Subsequently, we obtained further epidemiological input and formulated an analytic framework for future research on delirium in PC. An online survey of meeting participants was used to prioritize the research questions arising in the framework. As a knowledge dissemination exercise, multiple manuscripts were submitted for publication.

**Results:** We targeted 3 major investigational domains for delirium in PC settings as subprograms of research:

(i) epidemiological issues,
(ii) experiential or phenomenological aspects and
(iii) effectiveness of management strategies in established delirium.

We identified knowledge gaps in relation to occurrence rates, assessment, risk factors, prevention, management and outcome prediction of delirium in PC. Specific challenges were identified with proposed solutions for study population, settings and assessment and ethics. The importance of identified research questions was validated in the online survey. Manuscripts are in press regarding assessment tools, ethical and experiential aspects, management and guidelines.

**Conclusions:** There is a compelling case to address the delirium knowledge gaps in PC settings through adequately powered, multicentre collaborative studies, in addition to mixed methods for the complex experiential aspects.

**Abstract number:** P98
**Abstract type:** Poster

**Cancer Symptom Clusters and Demographic Characteristics**

Aktas A.1, Walsh D.1, Rybicki L.2

1Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Cleveland, OH, United States, 2Cleveland Clinic Lerner Research Institute, Department of Quantitative Health Sciences, Cleveland, OH, United States

**Introduction:** Little is known about demographic variations in cancer symptom clusters (SC). We aimed to determine whether SC are associated with age, gender, race, performance status (PS), or primary cancer site.

**Methods:** Among 922 advanced cancer patients with symptom data, hierarchical cluster analysis identified 7 SC. Comparisons were made between patients with and without each cluster using the chi-square test (age < 65 vs. ≥65 years; gender female (F) vs. male (M); race Caucasian (C) vs. African American (AA); 10 primary site groups (PSG), or Wilcoxon rank sum test (ECOG PS 0–4). A p value < 0.05 indicated statistical significance.

**Results:** 83% of patients were C, 52% ≥65 years, 56% M, and 55% ECOG PS 3–4 Most common PSG were lung (25%) and genitourinary (18%). Fatigue/anorexia-cachexia cluster was associated with race (58% AA vs. 68% C, p=0.032) and PSG (range 47% melanoma to 83% pancreas, p=0.012); Neuropsychological cluster was associated with older age (29% ≥65 vs. 39% < 65, p<0.001) and race (22% AA vs. 36% C, p=0.001). Upper GI cluster was associated with female gender (16% M vs. 22% F, p=0.035) and PSG (range 8% Head & Neck to 32% pancreas, p=0.035). Nausea/Vomiting cluster was associated with younger age (35% ≥65 vs. 43% < 65, p=0.010) and female gender (33% M vs. 47% F, p<0.001). Aerodigestive cluster was associated with male gender (36% F vs. 44% M, p=0.010) and PSG (range 24% pancreas to 58% Head & Neck, p<0.001). Debility cluster was associated with race (33% AA vs. 44% C, p=0.016) and poor PS (range 17% PS0 to 54% PS4, p<0.001). Pain cluster was associated with younger age (88% ≥65 vs. 92% < 65, p=0.028).

**Conclusions:** We identified 7 SC whose prevalence were influenced by age, gender, race, PS, or primary cancer site. Demographic characteristics may warrant different clinical approaches to patient care. Identification of these differences may help develop more effective cancer treatment and management strategies.

**Abstract number:** P99
**Abstract type:** Poster

**Attention to Bereavement in Palliative Care. Analysis of the Services Provided in Spain**

Lacasta-Reverte M.A.1, Limonero J.T.2, Garcia A.3, Barahona H.4

1Hospital Universitario La Paz, Cuidados Paliativos, Madrid, Spain, 2Faculty of Psychology, Universidad Autónoma, Barcelona, Spain, 3Social Work, Comunidad, Madrid, Spain, 4Palliative Care Unit, Clinical Hospital San Carlos, Madrid, Spain

**Introduction:** Attention to bereavement in palliative care is essential, as indicated by the European Palliative Care Subcommittee of the EEC (1991).

**Aim:** Identify the type of bereavement attention conducted by Spanish palliative care teams and describe the role of each professional.

**Methods:** An observational and descriptive study was conducted by survey sent by e-mail and by fax to all Spanish Palliative Care Teams. The data were analyzed using SPSS 20.0 for Windows. Descriptive indices and Chi squared analysis were calculated. The alpha value assumed for considering significant p value was in all cases <.05.

**Results:** Of the 261 teams 78 teams responded (response rate 30%). Most teams provided home palliative care. 78% of the teams attended grief. The 10% attending bereavement
only before death, 10% only after and 80% before and after combines preventive work and specific intervention if it is necessary. The data show that attention to “all families” and “primary caregivers” before and after the death was conducted by all professionals engaged. However, the family members who “demanded” specific counseling or attention by present emotional problems or difficulties in the mourning process, were treated especially by psychologists. It should be noted that half of the teams had specific bereavement programs. The workplace or the autonomous community (geographical area) does not determine when teams attend bereavement (p<.05).

Conclusions: This study extends and complements the information on the performance of Spanish palliative care teams, and provides an updated radiography of palliative care situation in our country. This knowledge can help political and economical decision process in the development and implementation of palliative care services. It is necessary to define precisely the activity carried out by different professionals, and establish standardized criteria or performance protocols, analyzing the effectiveness of grief care programs.

Abstract number: P100
Abstract type: Poster

Actual and Preferred Place of Death as Quality Indicators for Palliative Care?

De Roo M.L., 1 Miccinesi G., 2 Onwuteaka-Philipsen B.D., 1, Van Den Noortgate N., 3 Van den Block L., 4 Bonacchi A., 2, Donker G.A., 3, Lozano Alonso J.E., 5, Moreels S., 7, Deliens L., 1, Francke A.L., 1, 5, on behalf of EURO IMPACT

1 VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, 2 Cancer Prevention and Research Institute, ISPO, Clinical and Descriptive Epidemiology Unit, Florence, Italy, 3 Ghent University Hospital, Department of Geriatrics, Ghent, Belgium, 4 Vrije Universiteit Brussel, End-of-life Care Research Group Vrije Universiteit Brussel and Ghent University, Brussels, Belgium, 5 NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands, 6 Regional Ministry of Health, Government of Castilla y León, Public Health Directorate General, Valladolid, Spain, 7 Scientific Institute of Public Health, Public Health and Surveillance, Health Services Research, Brussels, Belgium

Background: Dying at home and dying at the preferred place of death have been suggested as indicators of high-quality palliative care. More insight is needed in their usefulness as quality indicators.

Aims: To describe whether previously developed quality indicators (the percentage of patients dying at home) and ‘the percentage of patients who died in their place of preference’ are feasible and informative, and to describe the scores on these quality indicators in four European countries.

Methods: A dynamic retrospective cohort study was conducted, based on registrations from representative GP networks regarding home-dwelling patients who died non-suddenly in Belgium (n=1036), the Netherlands (n=512), Italy (n=1639) and Spain (n=565). The relationship between the quality indicators and care characteristics was assessed using logistic regression models.

Results: ‘The percentage of patients dying at home’ ranged between 35.3% and 50.6% in the four countries, while ‘the percentage of patients dying at their preferred place of death’ ranged between 67.8% and 86.0% for patients whose preference was known. Both indicators were strongly associated with palliative care provision by the GP (odds ratios of 1.55-13.23 and 2.30-6.63 respectively). The quality indicator concerning the preferred place of death offers a broader view than the indicator concerning home deaths, as it takes into account all preferences met in all locations. However, GPs did not know the preferences for place of death in 39.6% to 70.3%.

Conclusion: GPs know their patients’ actual place of death, making the percentage of home deaths a feasible indicator for collection by GPs. However, patients’ preferred place of death was often unknown to the GP. We recommend using information from relatives as long as information from GPs on the preferred place of death is lacking. Timely communication about the place where patients want to be cared for at the end of life remains a challenge for GPs.

Abstract number: P101
Abstract type: Poster

Care Provided in the Last Three Months of Life of Cancer Patients: A Nationwide Study in Four European Countries

Ko W., 5 Deliens L., 1, 5 Miccinesi G., 3, Giusti F., 3, Moreels S., 5, Donker G., 5, Onwuteaka-Philipsen B., 5, Zurriaga O., 6, 7, Lopez-Maside A., 6, Van den Block L., 1, 8

1 Vrije Universiteit Brussel (VUB) and Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2 EMGO Institute for Health and Care Research, Public and Occupational Health, and Palliative Care Expertise Centre, VU Medical Centre, Amsterdam, Netherlands, 3 Cancer Prevention and Research Institute, ISPO, Clinical and Descriptive Epidemiology Unit, Florence, Italy, 4 Scientific Institute of Public Health, Public Health and Surveillance, Brussels, Belgium, 5 NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands, 6 Public Health Directorate General, Health Department, Valencia, Spain, 7 Spanish Consortium for
Lifeworld for Patients in the Hospice Setting

"Keep All Thee 'Til the End": Reclaiming the Lifeworld for Patients in the Hospice Setting

West E.1, Onwuteaka-Philipsen B.1, Philipsen H.2, Higginson I.J.3, Pasman H.1

1Vrije Universiteit Medisch Centrum, Amsterdam, Netherlands, 2Maastricht University, Department of Medical Sociology, Maastricht, Netherlands, 3King’s College London, Cicely Saunders Institute, London, United Kingdom

Research aims: St Christopher’s Hospice was founded to provide specialist care to the incurably ill. We studied the dimensions of difference that set St Christopher’s Hospice apart from hospital care of the dying, focusing on physical space and social organisation.

Study design and methods: Material (notes from meetings, speeches and reports) spanning between 1953 - 1980 from the Cicely Saunders Archive were analysed qualitatively. Of 81 boxes, 31 with information on considerations of the physical environment of St Christopher’s Hospice were selected. Through thematic analysis, quotes were found and analysed using open coding.

Results: Five themes were developed by EW, and corroborated with HRWP and BP. Data was gathered from 15 of 31 boxes. Themes emerged from the analysis, linking physical/social space with the philosophy of palliative care. Next to the overarching theme ‘home/homelike’ these were: “community”: “We have planned wards rather than single rooms, for we want there to be a community life for the patients.” “consideration of others”: “relatives might be enabled to stay and carry out quite extensive care for the patient.” “link with outside world”: “Good public transport and a feeling of openness to the world outside are chief among the needs of any unit for terminal care.” “privacy”: “Space is planned for a change of scene for the patients, for silence and privacy.”

Interpretation: The hospice philosophy functioned as the catalyst for the development of the physical environment of St Christopher’s Hospice. Taking Habermas’ concept of lifeworld it seems that, in contrast to acute care, the need for hospice to formulate their own lifeworld to support and fully engage patients was central. As lifeworlds are culture-sensitive, this underlines the need for variation in design and organisation of hospices across the world.

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Abstract number: P103
Abstract type: Poster

Avoidability of Hospitalisations at the End of Life, from the General Practitioners’ Perspective; A Mixed Method Study

De Korte-Verhoef M.C.1, Pasman H.R.W.1, Schweitzer B.P.M.1, Francke A.L.1,2, Onwuteaka-Philipsen B.D.1, Deliens L.1,3, Expertise Center Palliative Care VUmc

1VU Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, 2NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands, 3Ghent University & Vrije Universiteit Brussel, End-of-life Care Research Group, Brussels, Belgium

Abstract number: P102
Abstract type: Poster

“Keep All Thee ‘Til the End”: Reclaiming the Lifeworld for Patients in the Hospice Setting

West E.1, Onwuteaka-Philipsen B.1, Philipsen H.2, Higginson I.J.3, Pasman H.1

1Vrije Universiteit Brussel(VUB), Department of Family Medicine, Brussels, Belgium

Aims: This is an international study across four European countries (Belgium[BE], the Netherlands[NL], Italy[IT] and Spain[ES]) between 2009 and 2011, comparing care provided in the last three months of life to cancer patients, using representative general practitioner(GP) networks.

Methods: GPs reported weekly by questionnaire on medical end-of-life care, communication and dying circumstances for all deceased cancer patients within their practice who died non-suddenly (+18y). Descriptive statistics and multivariable logistic regressions (BE as reference category) were conducted.

Results: We included 2037 patients from four countries. Four out of five patients lived at home or with family in their last year of life and 80-95% had palliation as the most important treatment goal in the last week of life. Over 50% of patients had at least one transition in the last three months of life. One third of patients in BE, IT and ES had a last week hospital admission and died there. Cross-country differences on the provision of end-of-life care to cancer patients included GPs in NL being more involved in palliative care (67%) than in other countries (35%-49%) (OR 1.9), and end-of-life topics less often discussed in IT or ES than in BE or NL. Preference of place of death was less often expressed in IT and ES (32-34%) than in BE and NL (49-74%). Between 66% (IT) and 87% (NL) of cancer patients died in their preferred place when this was known by GPs. 88% to 98% of patients were estimated to have distress from at least one physical symptom in the final week of life and between 48% and 100% at least one distressing psychological symptom.

Conclusion: While palliation was the main treatment goal for almost all cancer patients at the end of life in all countries, late hospital admission and hospital deaths remained frequent. The common findings across countries might imply issues like reducing terminal transitions and achieving a preferred place of death remained challenging in many countries.

Abstract number: P103
Abstract type: Poster

Avoidability of Hospitalisations at the End of Life, from the General Practitioners’ Perspective; A Mixed Method Study

De Korte-Verhoef M.C.1, Pasman H.R.W.1, Schweitzer B.P.M.1, Francke A.L.1,2, Onwuteaka-Philipsen B.D.1, Deliens L.1,3, Expertise Center Palliative Care VUmc

1VU Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, 2NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands, 3Ghent University & Vrije Universiteit Brussel, End-of-life Care Research Group, Brussels, Belgium
Abstracts

Background: Many patients are hospitalised in the last months of life. Little is known about the avoidability of these hospitalisations.

Aim: To explore whether and how hospitalisations could have been avoided in the last three months of life, according to general practitioners (GPs) in the Netherlands.

Methods: A sequential mixed method design is used, starting with a cross-sectional nationwide survey among GPs. GPs were asked about their most recent patient who died non-suddenly and who was hospitalised in the last three months of life. Additionally, 18 of these GPs were interviewed in depth about the situation surrounding hospitalisation. To analyse the significance of differences between avoidable and non-avoidable hospitalisations, descriptive statistics and Chi-square tests were used. To analyse the qualitative part of this study, a thematic analysis was conducted.

Results: According to 77 of the 317 GPs (24%), the hospitalisation in the final three months of their patient’s life could have been avoided. Of all avoidable hospitalisations, 46% could have been avoided by proactive communication with the patient, 36% by more communication between professionals around hospitalisation, 28% by additional care and treatment at home, and 10% by patient and family support. In the in-depth interviews, GPs confirmed the aforementioned strategies, but also mentioned various barriers in daily practice, such as the timing of proactive communication with the patient with palliative care needs, the incompleteness of information transfer in acute situations and the lack of awareness among patients and family that death is near.

Conclusions: A proactive approach could avoid some of the hospitalisations at the end of life, in the opinion of GPs. More insight is needed in communication and psychological barriers preventing early end-of-life discussions.

Abstract number: P104
Abstract type: Poster

Regional Variations in Place of Cancer Death in Children and Young People (CYP)

Gao W.1, Verne J.2, Davies J.M.1, Peacock J.3, Morris C.4, Greenough A.5, Higginson I.J.1

1King’s College London, Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Public Health England, Knowledge & Intelligence Team (South West), Bristol, United Kingdom, 3King’s College London, Division of Health and Social Care Research, NIHR Biomedical Research Centre at Guy’s and St Thomas’ NHS Foundation Trust, London, United Kingdom, 4National Cancer Research Institute, Consumer Liaison Group, Leeds, United Kingdom, 5King’s College London, Neonatal Intensive Care Unit, London, United Kingdom

Background: Regional variations in place of death (PoD) may reflect differences in a range of underlying factors. This study aims to evaluate these variations and the associated factors.

Data and methods: A population-based, cross-sectional study (N=5,432 cancer deaths 2001-2010). Regional variations in PoD (Hospita, Home, Hospice and Elsewhere) were described for four new commissioning board regions in the National Health Service, England. The factors (age, sex, cancer type, number of contributing causes of death, deprivation, urbanisation indicator, region) associated with the variations were evaluated using proportion ratio (PR) derived from 2 log-binomial regression models (home or hospice vs hospital).

Results: The annual number of CYP cancer deaths was similar across the four regions (9.5-10.1 per million population). Hospital was the most common PoD in all but the South region (London: 57.1% [53.8-60.4%]; Midlands & East: 46.6% [44.2-49.2%]; North: 46.9% [44.5-49.4%]; South: 39.7% [37.1-42.4%]). London had the lowest proportion of at home deaths (31.4% [28.3-34.5%]) and South the highest (45.0% [42.3-47.7%]). Hospice deaths did not vary much across the regions (9.3% [7.3-11.2%] to 11.8% [10.1-13.5%]).

The lower level of home deaths in London than in North region (PR 0.86 [0.77-0.96] vs hospital) was persistent in multivariate analysis. Compared to hospital death, 0-14 age group (PR 1.27 [1.20-1.35] vs 15-24 years), brain cancer and bone tumor (PR 1.61 [1.47-1.77] & 1.99 [1.82-2.18] vs Leukemia and Lymphoma) were associated with higher chance of home death; while people who living in more deprived (PRs 0.68-0.90) and urban areas (PR 0.89 [0.81-0.97]) were less likely to die at home.

Interpretation: Socio-demographic and clinical factors play important roles in place of cancer death in children and young people. Further research is needed to explore other factors involved and how to incorporate these findings in improving end of life care.

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Abstract number: P105
Abstract type: Poster

Compassionate Communities: Supporting People to Talk More Openly about Death, Dying, Loss and Care

McLoughlin K.E.1, Rhatigan J.2, Richardson M.2, McGloughlin C.2, Macken C.2

1The Irish Hospice Foundation, HFH, Dublin, Ireland, 2Milford Care Centre, Limerick, Ireland

Background: Health Promoting Palliative Care (HPPC) offers society the opportunity to change the way it views end of life care by taking a population-based health approach to issues associated with death, dying, loss and
care. The adoption of a HPPC is gaining momentum internationally. In Ireland, Milford Care Centre (MCC) is the first and only specialist palliative care provider to consider strategically and invest financially in the area of HPPC. This paper considers the project development and outcomes to date.

**Aim:** To document and evaluate the Compassionate Communities Programme at MCC.

**Method:** The evaluation was completed using a mixed methods approach to data collection, drawing on questions proposed within the Developmental and RE-AIM evaluation frameworks. These methods included a comprehensive literature and demographic review, extensive desktop review of project outputs, focus groups, telephone and in-depth interviews. The data from these methods was woven together to evaluate each activity within each strand of the project and was cumulated to evaluate the project as a whole.

**Results:** Milford Care Centre’s innovative Compassionate Communities pilot project has continued to work positively toward its aim “To enrich and support society to live compassionately with death, dying, loss and care and to demonstrate and evaluate the process of developing a compassionate community model in an Irish context”. A considerable amount has been achieved across the three strands of project activity focusing on:

1. A whole population approach;
2. Engaging Communities; and
3. Development of a social model of care.

**Conclusion:** Evidence indicates that the project has potentially touched the hearts and minds of tens of thousands of people internationally. The evaluation explores important opportunities for development and learning in the Irish context and is an important contribution to the small, developing evidence base for HPPC internationally.

**Abstract number:** P106

**Abstract type:** Poster

**Depression in Cancer: Its Implication for Psychosocial Care towards Improved Outcome: A Perspective from a Developing Country**

Olagunju A.T.¹, Aina O.F.¹, Sarimiye F.O.², Olagunju T.O.³

¹College of Medicine, University of Lagos, Psychiatry (Psychosocial Oncology), Lagos, Nigeria, ²University College Hospital, Radiotherapy, Ibadan, Nigeria, ³Health Service Commission, HIV/Infectious Diseases and Related Cancers, Lagos, Nigeria

**Aims:** Depressive symptomatology with the psychosocial correlates is a common valid indication for psychosocial care and mental health services in oncology. This study aims to evaluate the burden of depression and describe the associated factors among cancer participants in a developing context.

**Methods:** A designed questionnaire, Centre for Epidemiological Studies Depression Scale Revised (CES-DR) and the Schedule for Clinical Assessment in Neuropsychiatry (SCAN) were administered by the researchers on 200 participants made up of attendees of a Nigerian hospital with histological diagnoses of cancer. The data were analysed with statistical package of social sciences version 15.

**Results:** Majority of participants, 85.5% were females and the commonest type of malignancy was breast cancer (51.0%). Ninety-eight (49.0%) participants had significant depressive symptomatology (CES-DR scores of ≥16) as against the diagnosis of depression in 55 (27.5%) participants following SCAN interview. A substantial proportion of subjects 36 (65.5%) had moderate depression, 15 (27.3%) were mildly depressed and 7.2% had severe depression. In this study, diagnosis of depression among cancer patients was significantly associated cancer stage ($p < 0.006$), duration of cancer ($p = 0.048$), pain ($p < 0.001$), physical complication ($p < 0.001$) and past family history of mental illness ($p = 0.002$). However, pain and duration of cancer were predictive of depression.

**Conclusions:** A significant burden of depression was observed in cancer patients, and moderate to severe levels of depression were noted in majority of those depressed. Psychosomatic factors like advanced duration/cancer stage, pain, physical complications and family history of mental illness were related to depression. However, pain and longer duration of cancer predict depression in them. Thus, this study underscores the need to adopt comprehensive cancer care with full inclusion of psychosocial interventions for improved overall outcome.

**Abstract number:** P107

**Abstract type:** Poster

**Barriers to Advance Care Planning in Cancer, Heart Failure and Dementia Patients: A Focus Group Study on the Views and Experiences of General Practitioners**

De Vleminck A.¹, Pardon K.¹, Beernaert K.¹, Deschepper R.¹, Houttekier D.¹, Van Audenhove C.², Deliens L.¹, Vander Stichele R.¹

¹Ghent University & Vrije Universiteit Brussel (VUB), End-of-Life Care Research Group, Brussels, Belgium, ²KU Leuven, LUCAS, Leuven, Belgium, ³Ghent University, Heymans Institute, Ghent, Belgium

**Background:** The long-term and often lifelong relationship of general practitioners (GPs) with their patients is considered to make them the ideal initiators of advance care planning (ACP). However, in general the incidence
of ACP discussions is low and ACP seems to occur more often for cancer patients than for those with dementia or heart failure.

**Objective:** To identify the barriers, from GPs’ perspective, to initiating ACP and to gain insight into any differences in barriers between the trajectories of patients with cancer, heart failure and dementia.

**Method:** Five focus groups were held with GPs (n=36) in Flanders, Belgium. The focus group discussions were transcribed verbatim and analyzed using the method of constant comparative analysis.

**Results:** Three types of barriers were distinguished: barriers relating to the GP, to the patient and family and to the health care system. In cancer patients, a GP’s lack of knowledge about treatment options and the lack of structural collaboration between the GP and specialist were expressed as barriers. Barriers that occurred more often with heart failure and dementia were the lack of GP familiarity with the terminal phase, the lack of key moments to initiate ACP, the patient’s lack of awareness of their diagnosis and prognosis and the fact that patients did not often initiate such discussions themselves. The future lack of decision-making capacity of dementia patients was reported by the GPs as a specific barrier for the initiation of ACP.

**Conclusion:** The results of our study contribute to a better understanding of the factors hindering GPs in initiating ACP. Multiple barriers need to be overcome, of which many can be addressed through the development of practical guidelines and educational interventions.

**Abstract number:** P108
**Abstract type:** Poster

‘Sooner Rather than Later...’ - Exploring Communication between Healthcare Professionals, Patients and Families Where Recovery is Uncertain

**Bristowe K.1, Carey I.2, Hopper A.3, Shouls S.2, Prentice W.4, Caulkin R.2, Higginson I.J.1, Koffman J.S.1**

1King’s College London, Cicely Saunders Institute, Palliative Care, Policy & Rehabilitation, London, United Kingdom, 2Guy’s and St Thomas’ NHS Foundation Trust, Palliative Care, London, United Kingdom, 3Guy’s and St Thomas’ NHS Foundation Trust, General Medicine, London, United Kingdom, 4King’s College Hospital NHS Foundation Trust, Palliative Care, London, United Kingdom

**Background:** The importance of keeping patients and families informed of changing clinical situations and of shared decision making are widely accepted. However, recent reports have highlighted the devastating effects of poor communication or of a failure to be open and honest with patients and families, particularly for those in hospital and approaching the end of life.

**Research aims:** To explore patient, family and healthcare professionals’ (HCPs) experiences of communication in the acute hospital setting where recovery is uncertain.

**Study design and methods:** Semi-structured qualitative interview study. 11 patients and 12 family caregivers were purposively sampled (by age, gender, disease, ethnicity), from two London hospitals. 20 HCPs were also purposively sampled (specialty, profession, seniority). Recruitment ceased once data saturation was achieved. Interviews were transcribed verbatim and analysed using thematic analysis.

**Results:** Consistency, clarity, communication skills and adequate time were important to all. Patients and family caregivers described the distress engendered by inconsistent or conflicting information, the importance of sensitivity and the challenges of accepting the unknown. In parallel, HCPs experienced challenges in establishing what the family already know, responding to family dynamics and in managing expectations. Patients and families highlighted loss of a ‘point of contact’, and feelings of abandonment at weekends and overnight, whilst HCPs related insufficient time to convey important information, amplifying fear of causing additional distress.

**Conclusions:** The importance of keeping patients and families informed and involved in decisions is evident. However, HCPs require the skills, support, guidance and time to provide regular, consistent and appropriate updates to facilitate this, particularly when there is concern that the patient may not recover from the current episode of illness.

**Funding:** Guy’s and St Thomas’ Charity.

**Abstract number:** P109
**Abstract type:** Poster

The GPs’ Role in Decisions about Palliative Chemotherapy

**Buiting H.M.1, Dalhuisen F.1, Gunnink-Boonstra N.2, Terpstra W.2**

1Comprehensive Cancer Center the Netherlands (iKNL), Rotterdam, Netherlands, 2Onze Lieve Vrouwe Gasthuis (OLVG), Amsterdam, Netherlands

**Introduction:** Little information is available about the role of the general practitioner (GP) in the care for advanced cancer patients, while receiving chemotherapy (CT). This is remarkable since GPs in the Netherlands often know their patients and their families for a long time and also play a pivotal role in palliative care when there are no reasonable CT options available anymore. GPs may assist patients to attain a shared decision-making process concerning difficult CT-decisions. We aimed to map the actual and preferred role of the GP in the decision-making about CT.
Study design and methods: Secondary thematic content analysis of qualitative interviews among 15 patients with an advanced form of colorectal or breast cancer who had received at least one line of CT.

Results: Patients reported that after GPs’ initial referral to the hospital, the contact with the GP was only infrequent, and if so, not about CT-decisions. Although most of the patients felt no need to contact the GP while receiving CT, they often arranged a consultation about euthanasia. They further reported that they felt that they could count on their GP, if needed. Patients nevertheless sometimes reported that they would have expected some personal interest, especially in situations when they knew that the oncologist had contacted the GP. They further reported that they were sometimes looking for someone who took into account their life-story and psycho-social issues and not specifically the objective (physical) consequences of their disease.

Interpretation: Palliative chemotherapy involves frequent hospital visits; in this phase, the role of the GP seems limited especially with respect to CT-decisions. A more pro-active role of the GP may assist advanced cancer patients while deciding about CT. Such involvement may optimize high-quality decision-making and accordingly, high-quality care in a vulnerable patient group in their last stage of life.

Abstract number: P110
Abstract type: Poster

Palliative Care in Advanced Dementia: A Qualitative Study Exploring the Views of Consultants Involved in Dementia Care

Ellis A.1, Gough N.2, Brewer K.1

1King’s College London, Gerontology, London, United Kingdom, 2St Christopher’s Hospice, London, United Kingdom

Background: Advance care planning (ACP) enables patients to establish and document their future care preferences in advance of a time where they may lose capacity to do so. The 2013 EAPC guidelines recommend that people with dementia should be offered ACP as soon as the diagnosis is made and be given regular opportunities to revisit their plans.

Aims: To explore the views of consultants from different specialities involved in dementia care regarding the development and implementation of successful ACP.

Methods: Thirteen semi-structured interviews were conducted among a purposive sample of consultant geriatricians, old age psychiatrists and palliative care physicians. Interviews were audio-recorded, transcribed verbatim and analysed using the framework approach.

Results: All three groups of consultants identified potential benefits associated with ACP including the avoidance of unnecessary hospital admissions and providing patient centred end of life care in a familiar environment. However there was disagreement over when to introduce ACP, with psychiatrists and geriatricians highlighting the potential to cause patient distress if offered at diagnosis. Palliative care consultants expressed the need to begin discussions as early as possible, reflecting their previous experiences of being involved with patients in the latter stages of dementia when capacity is lost. Patients were perceived as unreceptive to ACP and a wider change in societal perceptions was seen as necessary before more people would engage with this process. There was also uncertainty voiced about which professional group should take a lead in initiating ACP, with no speciality identifying this as solely their responsibility.

Conclusions: This study highlights the need for clarity over which speciality involved in dementia care should initiate ACP discussions. Future research exploring the acceptability and timing of ACP in both patients and medical professionals is needed.

Abstract number: P111
Abstract type: Poster

Quality of Life and Palliative Care Needs of Caregiver’s for People Living with Advanced Heart Failure: A Systematic Narrative Review of the Literature

Breslin L.C.1, Fitzsimons D.1,2, McIlfatrick S.J.1,3

1University of Ulster, Institute of Nursing and Health Research, Belfast, United Kingdom, 2Belfast Health and Social Care Trust, Belfast, United Kingdom, 3All Ireland Institute for Hospice and Palliative Care, Dublin, Ireland

Background: The important contribution of palliative care (PC) for non-malignant conditions, such as heart failure (HF) is increasingly recognised. Despite this, evidence suggests that end-of-life care in HF is poor, characterized by high levels of symptoms; inadequate support and poor quality of life (QoL) for both patients and carers. Whilst caregiver’s have been identified as a priority for PC research, there is limited research on the QoL and PC needs for this specific group.

Aim: To explore and evaluate the evidence on QoL and PC needs for carer’s for patients with advanced HF.

Methods: Six databases (CINHAL PLUS, Cochrane, EMBASE, Medline, PsychInfo, SCOPUS) were comprehensively searched to identify relevant journal articles, using specific index terms. Strict eligibility criteria for selecting documents for review were applied. Studies which met the inclusion criteria were retrieved, data were extracted and quality assessed before narrative synthesis was conducted.

Results: A total of 590 articles were retrieved and after removing duplicates and scanning titles, abstracts and full
text, 9 relevant peer-reviewed articles were identified. A thematic analysis of the studies revealed six core themes in relation to the caregivers needs:

(1) support;
(2) information;
(3) time with professionals;
(4) to feel valued;
(5) communication;
(6) self-care.

Conclusions: The evidence on QoL and PC needs of caregiver’s for HF patients has not been comprehensively evaluated. To date, studies have focused on the experiences of bereaved caregivers or their satisfaction with end-of-life care, with only one article focusing on the caregiver’s PC needs. Research is warranted in this area, specifically exploring what the QoL and PC needs are for caregivers, in order to inform how PC programs should be integrated into the care plan for HF patients.

Abstract number: P112
Abstract type: Poster

Audit of Care of Patients Presenting with Stage III or IV Pancreatic Cancer to a Tertiary Hepatobiliary Unit
De Vos S.M.1,2, Cooke C.1,2
1University Hospitals of Leicester, Palliative Care, Leicester, United Kingdom, 2LOROS Hospice, Palliative Care, Leicester, United Kingdom

Prognosis in pancreatic cancer is poor irrespective of treatment. Distressing symptoms are common, particularly pain. Optimising quality of life, and providing good symptom control and end of life care are thus essential. Government initiatives have prioritised improving the quality of end of life care in hospitals. An audit was performed reviewing care given to patients presenting with advanced pancreatic cancer to a tertiary hepatobiliary unit, to highlight areas in which care might be improved.

Retrospective case notes audit of patients diagnosed with stage III or IV pancreatic cancer, who died over a 6 month period.

Median survival time from diagnosis was 3.7 months. All patients were told their illness was incurable around diagnosis, but estimated prognosis was only discussed with 32% (those who asked). 23% of patients offered chemotherapy deteriorated before commencing chemotherapy. 72% of those given chemotherapy failed to complete the planned course, predominantly due to disease progression. 60% of patients had jaundice, 89% of whom underwent biliary drainage procedures. 67% needed repeated procedures, resulting in longer hospital stays. 65% of patients were referred to the Hospital Palliative Care Team, most often for symptom control (84%). There was limited evidence of advance care planning, with preferred place of death only discussed with 32% of patients at the tertiary unit. 27% of patients died in an acute hospital.

Pancreatic cancer is often rapidly progressive with a short prognosis and significant symptom burden. Palliative chemotherapy and biliary drainage procedures can improve quality and length of life, however in many patients, their disease progresses despite such interventions. Support and training for staff in palliative care and communication skills are potential areas for improvement: to help staff empower patients to make informed decisions about their treatment and care, and in turn achieve their preferences for end of life care.

Abstract number: P113
Abstract type: Poster

End of Life Decision Making in Patients with an Implantable Cardioverter Defibrillator (ICD): Exploring the Reality
Hill L.1,2, Mc Ilfatrick S.1,3, Taylor B.1, Dixon L.2, Fitzsimons D.1,2
1University of Ulster at Jordanstown, Nursing, Belfast, United Kingdom, 2Belfast Health and Social Care Trust, Acute Services-Heart Failure, Belfast, United Kingdom, 3All Ireland Institute of Hospice and Palliative Care (AIHPC), Belfast, Ireland

Aim: The ICD is pivotal in prevention and treatment of life threatening arrhythmias in heart failure. Implantation rates are rising throughout Europe but the therapeutic benefit of an ICD at end of life remains uncertain. Deactivation could potentially enhance dignity and prevent unnecessary shocks. Aim: To examine decision-making for patients with an ICD at end of life.

Method: A retrospective case note review (n=59) of patients in a regional implantation hospital, identified as deceased during a 12 month period. Medical charts of 44 of these patients were successfully retrieved and augmented with electronic records. Data on demographics, ICD therapies, end of life discussions, cause and location of death were coded and recorded on SPSS prior to analysis.

Results: Mean age at death was 73 years, with 86% male (n=38). Only 6 patients had a documented pre-implant discussion with no evidence of a dialogue on deactivation. One patient received an external shock while dying, despite his ICD being deactivated. End of life was discussed with 22 patients (50%); median time from discussion to death was 6 days. Majority of discussions were led by a Cardiologist or Physician, with one initiated by Specialist Nurse. Next of kin was present in 8 of the discussions and in 14 patients this led to a DNR order, with onward
referral to Specialist Palliative Care in 10 cases. However on 5 occasions deactivation was not addressed. The end result was 16 (36%) patients underwent device deactivation while 1 kept the device active. Information on the cause of death was available on 39 patients, of which 33% had a sudden cardiac death (n=13).

**Conclusion:** Patients are not adequately informed pre-implant or when health deteriorates about device deactivation. Specialist nurses could address this gap in understanding. As 1/3 of these patients died suddenly, it is uncertain whether or not they experienced painful shocks in the last few minutes of life.

**Abstract number:** P114
**Abstract type:** Poster

**Symptom Burden and Oncologist Prognostication in Advanced Soft Tissue Sarcoma**

Gough N.¹, Ross J.², Koffman J.³, Riley J.², Judson I.⁴

¹Royal Marsden Hospital NHS Trust, Palliative Care, London, United Kingdom, ²Royal Marsden and Royal Brompton Palliative Care Service, London, United Kingdom, ³King’s College London, Cicely Saunders Institute, London, United Kingdom, ⁴Royal Marsden Hospital, Sarcoma, London, United Kingdom

**Background:** Little is known about symptom burden (SB) in advanced soft tissue sarcoma (ASTS): anecdotal evidence suggests SB remains low before a rapid escalation toward the end of life. A greater understanding of SB and evaluation of oncologist prognostication may improve symptom control, communication and encourage timely support services referrals e.g. palliative care (PC).

**Aims:** To examine and compare baseline SB and clinician estimation of overall survival (OS) in 2 different ASTS treatment groups:

(i) new ASTS diagnosis starting palliative chemotherapy [FLC] and
(ii) new decision to stop active treatment [NFT].

**Methods:** In one UK ASTS centre, 61 consenting patients completed the Memorial Symptom Assessment Scale at recruitment: patients were followed up until death or study end.

**Results:** Baseline mean physical symptom number was 12.4 [Stand dev. 6.3] in FLC and 17.1 (6.8) in NFT. The 5 most prevalent symptoms in the FLC group: pain 79% (rated severe in 29%), fatigue 69% (26), difficulty sleeping 62% (26), lack of appetite 57% (14) and sweats 52 (12). The 5 most prevalent symptoms in the NFT group: fatigue 90% (rated severe 50%), pain 85% (30), shortness of breath 75% (25), difficulty concentrating 75% (25) and Drowsiness 75% (40).

At study end 22/41 FLC and 19/20 NFT patients had died: median FLC OS: 149 days (Range 42 - 503) and median NFT OS: 38 days (5 - 244). Of the 41 deaths, OS was overestimated in >50% of cases.

**Conclusion:** Patients undergoing NFT have a significant SB comparable to other cancers at ‘end’ stage. However, SB in newly diagnosed patients is also considerable including pain / fatigue that may be under appreciated/ detected. ASTS oncologists overestimate OS consistent with data in cancer globally. The findings support the need for better detection and management of symptoms which may warrant earlier PC referrals.

**Abstract number:** P115
**Abstract type:** Poster

**Challenges of the Organisation of Palliative Care: Identification of Barriers and Facilitators in Five European Countries**

van Riet Paap J.¹, Vernooij-Dassen M.¹ ², Brouwer F.¹, Meiland F.¹ ², IJliffe S.³, Davies N.³, Leppert W.⁵, Jaspers B.⁷ ⁸, Mariani E.⁹, Sommerbakk R.¹ ¹⁰, Vissers K.¹ ¹¹, Engels Y.¹ ¹¹

¹Radboud University Medical Center, IQ Healthcare, Nijmegen, Netherlands, ²Radboud University Medical Center, Radboud Alzheimer Centre, Nijmegen, Netherlands, ³EMGO Institute for Health and Care Research, Department of General Practice & Elderly Care Medicine, Amsterdam, Netherlands, ⁴VU University Medical Center, Alzheimer Center, Amsterdam, Netherlands, ⁵University College London, Department of Primary Care & Population Health, London, United Kingdom, ⁶Poznan University of Medical Sciences, Department of Palliative Medicine, Poznan, Poland, ⁷University of Bonn, Department of Palliative Medicine, Bonn, Germany, ⁸University of Goettingen, Clinic for Palliative Medicine, Goettingen, Germany, ⁹University of Bologna, Department of Psychology, Bologna, Italy, ¹⁰Norwegian University of Science and Technology (NTNU), Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Trondheim, Norway, ¹¹Radboud University Medical Center, Department of Anaesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands

**Introduction:** Interventions to improve the organisation of palliative care encounter challenges beyond the usual problems of implementation in health care because of its complex and changing needs for care. This study, therefore, aimed to explore barriers and facilitators with regard to interventions to improve the organisation of palliative care in five European countries.
Methods: Semi-structured individual and focus group interviews were conducted with purposefully selected health care professionals. Constant comparative method was used to analyze the data. Codes and text fragments were shared between the researchers to develop a consensus codebook. Categories were derived from the codes and discussed between the researchers. Two researchers compared the national findings and organised these into themes.

Results: In total, 36 individual and 9 focus group interviews were conducted in five European countries. Barriers and facilitators were inductively categorised into 16 categories and arranged into a framework for both barriers and facilitators, consisting of aspects influencing the implementation strategy, individual professionals, group dynamics, the organisational context, and the local political - economical context.

Discussion: This study identified various aspects that either facilitated or hindered strategies to improve the organisation of palliative care. The complex organisation of palliative care is different in each country, making it difficult to compare barrier and facilitators between countries. However, many interviewees mentioned various aspects (e.g. lack of time due to lack of staff) that were present in all countries, while they also mentioned aspects that were specific for their situation. Country specific and generic barriers and facilitators were therefore identified. These barriers and facilitators can be used by professionals and policy makers in Europe to develop tailored strategies to improve the organisation of palliative care.

Abstract number: P116
Abstract type: Poster

Sharing Bad News: Understanding the Communication Processes of a Lung Cancer Diagnosis

Ngwenya N.1, Farquhar M.2, Benson J.2, Gilligan D.3, Bailey S.4, Seymour J.5, Ewing G.1

1University of Cambridge, Centre for Family Research, Cambridge, United Kingdom, 2University of Cambridge, Institute of Public Health, Primary Care Unit, Department of Public Health & Primary Care, Cambridge, United Kingdom, 3Cambridge University Hospitals NHS Foundation Trust, Oncology, Cambridge, United Kingdom, 4Cambridge University Hospitals NHS Foundation Trust, Cancer Clinical Trials, Cambridge, United Kingdom, 5University of Nottingham, Faculty of Medicine & Health Sciences, Nottingham, United Kingdom

Background: There is growing evidence that patients are influenced by other people when making decisions about their health. However there is still little understanding of how patients communicate private information on their cancer diagnosis. Research indicates that this form of self-disclosure can aid psychological adjustment and wellbeing in patients.

Aim: To understand communication processes used by patients with advanced lung cancer when sharing news of their diagnosis with wider family members/friends.

Sample: 20 patients with lung cancer, 17 family members/friends present at bad news consultations and 6 service users with experience of sharing a cancer diagnosis with others.

Methods: Interviews with patients and family members; workshop discussion with service users to explore how patients can be supported with sharing their diagnosis. Thematic framework analysis guided by Petronio’s Communication Privacy Management theory was used to explore how people communicate private information and create privacy boundaries.

Results: Patients reported that people’s responses to their diagnosis were difficult to deal with and had an impact on their illness experience. Family members present during consultations were involved in sharing the news as “co-owners” which sometimes affected their own emotional state, as they had to share according to the privacy rules that patients created. Service users described how as patients they felt that they owned the news and wanted to have control over who had access to the information and how much information they had access to.

Conclusion: There are principles that inform the way individuals decide to give others access to private information which health care professionals can use to support patients. Interventions to support patients in sharing bad news may help improve psychological adjustment to a lung cancer diagnosis and thus have implications for enhancing palliative care services.

Funded by: Dimbleby Cancer Care

Abstract number: P117
Abstract type: Poster

Towards a Pain Free Hospital: Comparative Effectiveness and Cost of a New Pre-emptive Screening and Treatment System for Oncology Outpatients

Williams J.E.1, Peacock J.L.2,3, Gubbay A.1, Ellard R.1, Raftery J.5, Sauzet O.3, Pattison N.6, Ross J.R.7,8

1Royal Marsden NHS Foundation Trust, Department of Anaesthetics and Pain Management, London, United Kingdom, 2Kings College London, Division of Health and Social Care Research, London, United Kingdom, 3Guy’s and St Thomas’ NHS Foundation Trust and Kings College London, NIHR Biomedical Research Centre, London, United Kingdom, 4University of Southampton, Faculty of Medicine, London, United Kingdom, 5Universität Bielefeld, AG Epidemiologie & International
Background: Cancer pain remains a major public health problem as many as one in two patients attending oncology outpatients. We aimed to determine whether a new ‘proactive screening and treatment system’ for pain, is effective/cost-effective when compared with ‘usual care’.

Methods: We screened 1074 patients attending routine head & neck oncology outpatient clinics over 18 months, for severity of pain. 156 patients identified with moderate/severe pain were randomly allocated to receive either ‘enhanced pain control intervention’ (including pain treatment, follow up, reassessment and education) or ‘usual care’.

The primary outcome was overall pain severity index, with secondary outcomes including quality of life, patient satisfaction and mood, and costs, assessed over 3 months.

Results: Over 3 months, pain scores reduced significantly in both groups but there was no significant difference in pain severity index between the groups (difference 0.36; 95% CI [-0.29, 1.01]). The intervention group reported significantly higher ‘patient satisfaction’ (difference -0.30; [-0.60, -0.15]). Costs were higher in the intervention group, £656 per patient vs. £215 per patient. Patients in the intervention group reported a slightly greater increase in quality of life but this was not statistically significant. Cost effectiveness analysis showed that the probability of the intervention being effective did not exceed 0.5 at any level of willingness to pay.

Conclusions: The primary outcome was not significantly different between the 2 groups. The intervention was not cost effective, costing more but delivering very small additional benefit. Screening for pain was easily performed and effective at identifying patients in pain. Once patients with pain were identified and linked to good quality pain services, significant improvements in pain scores were obtained. We did not demonstrate a benefit of ‘enhanced pain services’ over the good quality of ‘usual care’ in this study centre.

Abstract number: P118
Abstract type: Poster

Non Opioid and Adjuvant Analgesics in 2282 European Patients with Advanced Cancer

Paulsen O.1,2, Kotlinska-Lemieszek A.3,4, Kaasa S.2,5, Klepstad P.6,7

1Telemark Hospital Trust, Department of Medicine, Palliative Care Unit, Skien, Norway, 2Norwegian University of Science and Technology (NTNU), Faculty of Medicine, Department of Cancer Research and Molecular Medicine, European Palliative Care Research Centre (PRC), Trondheim, Norway, 3Poznan University of Medical Sciences, Palliative Medicine Chair and Department, Poznan, Poland, 4University Hospital of Lord’s Transfiguration, Hospice Pallium, Poznan, Poland, 5St. Olavs Hospital, Trondheim University Hospital, Department of Oncology, Trondheim, Norway, 6Norwegian University of Science and Technology (NTNU), Faculty of Medicine, Department of Circulation and Medical Imaging, Trondheim, Norway, 7St. Olavs Hospital, Trondheim University Hospital, Department of Anaesthesiology and Intensive Care Medicine, Trondheim, Norway

Aims: Clinical guidelines recommend treating cancer pain according to the WHO pain ladder. This cross-sectional study was explored to identify differences in use of non opioid and adjuvant analgesic drugs between countries.

Methods: Cancer patients using strong opioids from 17 centers in 11 European countries were recruited. All drugs taken within 24 hours were recorded. The use of non opioids and adjuvant analgesics was assessed.

Results: 54% of the 2282 included patients used paracetamol or NSAIDs. Paracetamol was used in 31.2%; ranging from 1 percent in Germany to 59 percent in Sweden and Norway. NSAIDs were used in 29.9 percent; 9 % in Norway vs 57 % in Germany and Switzerland. This was mainly due to the use of Metamizole, which was used in 42 % of the patients in the two latter countries. Diclofenac was the second most utilized NSAID, used by 8.6 % of patients. 49 % of the patients received corticosteroids (CSs); dexamethasone was the drug of choice in 55 % of the cases. CSs were most commonly used in Italy, Sweden and Iceland by more than 60 % of patients, with a median dose of 3-5.5 mg (dexamethasone equivalent doses (DED) per day). Germany, Switzerland and United Kingdom used CS in 34-43 percent of cases and in a significant higher dose of 6 - 8 mg (median DED per day). CSs and NSAIDs were prescribed together in 14 % of cases, increasing the risk for gastrointestinal complications. Antiepileptics were used in 18 %, and amitriptyline in 5 % of patients; these drugs were most often prescribed in Germany, Iceland, Sweden, and Italy.

Conclusion: Non opioid analgesics and corticosteroids were frequently prescribed in advanced cancer patients treated with a WHO step III opioid. There were large differences in prescription patterns, drugs of choice, and doses across the countries concerning the non opioid and adjuvant analgesic drugs. This demonstrates the need for evidence based guidelines also for the use of non-opioids in cancer pain treatment.
Abstract number: P119
Abstract type: Poster

Awareness of the European Association for Palliative Care (EAPC) Framework for Sedation in Palliative Care: An Internet-based Survey

Abarshi E.¹, Payne S.², EURO IMPACT STUDY

¹International Observatory on End of Life Care, Lancaster University, Division of Health Research, Lancaster, United Kingdom, ²Lancaster University, Division of Health Research, Lancaster, United Kingdom

Background: The European Association for Palliative Care (EAPC) considers palliative sedation an important therapy in the care of selected palliative care patients, used for relieving refractory symptoms and suffering. In 2009, a framework offering recommendations for this practice was developed and published.

Aim: To assess EAPC member awareness of the Framework for palliative sedation, and also to collate published and unpublished guidelines on the practice.

Design: A 90-day online survey, undertaken between August and October 2012 generated responses from 99 members in 36 countries. Of 51 collective members representing various countries, 23 responded (response rate 41%). Questionnaire completeness rate was >80%.

Results: Two-thirds of responses were from countries in Europe, while the remaining third were received from Africa, Asia, North and South America. Disciplines commonly-associated with palliative care provision were represented: physicians, nurses, pharmacist, chaplain, and researcher. Majority of respondents (70%) reported that they were aware of the Association’s recommended framework for palliative sedation. Though half of the respondents reported having national guidelines on palliative sedation, they were more frequently aware of the Association’s guidelines than them. Twenty-two institutional and national guidelines were submitted, and these varied in length, source, language, and content.

Conclusion: Despite methodological shortcomings, this survey shows that the provision of guidance for collective members was regarded as an important form of support. However, the need to monitor uptake of clinical guidelines and international recommendations is warranted.

Abstract number: P120
Abstract type: Poster

A Standardised Approach for Comparing Guidance Documents on Sedation Practices in Palliative Care

Abarshi E.¹, Rietjens J.², Caraceni A.², Payne S.¹, Deliens L.¹, Van den Block L.², EURO IMPACT STUDY

¹International Observatory on End of Life Care, Lancaster University, Division of Health Research, Lancaster, United Kingdom, ²ERASMUS MC, University Medical Center Rotterdam, Rotterdam, Netherlands, ³Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, ⁴Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano, Italy, ⁵European Palliative Care Research Center, EAPC Research Network, Trondheim, Norway, ⁶VU University Medical Center, EMGO Institute for Health and Care Research, Amsterdam, Netherlands

Background: Sedation in palliative care has received growing attention in recent years; and so have guidance documents i.e. guidelines, position statements, and protocols. Little is known about the content and methodological quality of these materials. Recent research suggests that large variations exist in sedation usage till death. However, a standardized approach that systematically compares related documents, across nations, associations and governmental bodies is lacking. The Appraisal Guideline Research and Evaluation (AGREE) instrument, though a valuable tool for comparing guidelines, is hardly well-suited for the subject of palliative sedation, given the lack of consensus with its definitions, indications, usage, and ethics.

Aim: To report an approach designed to facilitate thorough and systematic comparison of all guidelines and guidance documents on palliative sedation.

Method: The authors, members of a multidisciplinary and international group of palliative care researchers, identified themes and clinical issues based on evidence and expert consultations, and so developed a user-friendly checklist. They conducted a systematic search for published and unpublished guidelines, in multiple databases (PubMed, CancerLit, CNAHL, Cochrane Library, NHS Evidence, and Google Scholar) and relevant internet resources. Collected data were analysed. Overall, we selected 241 guidance documents.

Results: Twenty-one comparable documents emerged from 12 different countries: but only 8 were published in international peer-review journals. Quality of documents varied somewhat. Five practice guidelines were written in English and contained key recommendations found in the EAPC Framework.

Conclusion: The resulting comprehensive checklist allowed multi-level comparison. Also the results provided valuable insight into core elements of selected guidance documents on palliative sedation; their similarities, differences, and extent to which they compared with the EAPC framework.

Abstract number: P121
Abstract type: Poster

Edema of the Lower Extremities in the Dying Trajectory of Cancer

Tavares F.A.
Edema has been identified as a predictor for short-term survival. However, most of the prognostic models that include edema have been developed and validated in Asian populations, not eligible for antineoplastic therapy. To our knowledge no study has examined the longitudinal course of edema in patients with cancer and its relationships with comorbidities and drug treatments.

**Aims:** To determine the onset time of lower limb edema (LLE) in the trajectory of cancer; to analyze the impact of comorbidities, functional status and prescriptions on incidence and resolution of LLE.

**Methods:** Longitudinal observational cohort study over a 10-month period; cancer patients enrolled in a hospital-based Palliative Care program; ≥1 assessment for inclusion; Palliative Performance Scale (PPS) and ongoing diuretics, calcium blockers, steroids, non-steroid anti-inflammatory drugs at each visit; edema graded as absent, mild or moderate/severe; time counted backward from death up to the first positive assessment for edema; statistics: descriptive, Kaplan Meier curves, chi-square and logistic regression.

**Results:** Among 194 patients (median age 69y, 53% male, median survival 30 days, 28% gastrointestinal cancer, 29% modifying therapy) 108 (56%) developed LLE. Most (70%) showed LLE at baseline. In median 16 days elapsed between the first positive assessment and death. Edema was more frequent in females (OR 1.4 p=0.03), patients on diuretics (OR 2.2 p< 0.001) and with ascites (OR 6.5 p< 0.001). Serum albumin and the onset time of LLE were slightly correlated (r 0.37 p< 0.001). Edema resolution was significantly poor survival.

**Conclusions:** LLE was a common and late feature in the trajectory of our cohort. Further studies exploring other anatomic locations of edema, risk factors and the effects of early treatment are needed.

**Abstract number:** P122

**Abstract type:** Poster

**Prevalence of Delirium in Patients with Advanced Cancer Disease Admitted to a Palliative Care Unit. Observational Study during a 6-year Period**

Landa Teran C.P.1, Farriols Danés C.2, Ruiz Ripoll A.I.1, Planas Domingo J.2

1Centre Fòrum-Hospital del Mar, Parc de Salut Mar, Department of Geriatrics, Barcelona, Spain, 2Hospital de l’Esperança, Parc de Salut Mar, Universitat Autònoma de Barcelona, Universitat Pompeu Fabra, Palliative Care Unit, Department of Medical Oncology, Barcelona, Spain, 3Hospital del Mar, Institute of Neuropsychiatry and Addiction, Department of Psychiatry, Barcelona, Spain

**Research aims:** To analyse the overall prevalence and the prevalence associated with sociodemographic and tumoral factors, in patients admitted to a Palliative Care Unit (PCU) diagnosed with advanced cancer disease.

**Study design and methods:** Observational study during a 6-year period (2007-2012). Inclusion criteria: patients admitted to a PCU suffering from an advanced cancer disease. Exclusion criteria: non-oncological terminal disease. Variables: delirium (Diagnostic and Statistical Manual of Mental Disorders IV), sociodemographic data, primary tumor location, tumor stage, pain, death during PCU stay.

**Results:** Of the 1995 patients discharged in the study period, 1826 met the inclusion criteria, 62.5% men and 37.5% women, mean age 72.4 ± 12.5 years, The main primary tumor location were lung (24.3%) and colorectal (14.1%); 78.4% were metastatic disease; 41.5% suffered from pain; 76.3% died during admission. The overall prevalence of delirium was 27.2% (497). In the group of patients with delirium, the mean age was 72.3 ± 11.7 years, 66% men; primary tumor location: 25.8% lung, 14.5% colorectal; 77.3 metastatic disease; 58% suffered from pain; 79.9% died during admission. It was analysed prevalence of delirium in patients ≤ 75 years (27.6%) in comparison with >75 years (26.8%). In the statistical analysis within gender, delirium was more prevalent in men (29%) than in women (24%). Within primary tumor location, the major prevalence of delirium were in brain (39.7%), liver (36%) and kidney-urinary tract (34.5%) tumors.

**Conclusion:** The prevalence of delirium in advanced cancer patients admitted to a PCU was 27.2%. Prevalence of delirium was not associated with advanced age. Delirium was more prevalent in men, and in brain, liver and urinary tract tumors.

**Abstract number:** P123

**Abstract type:** Poster

**Restorative Care for Palliative Patients: A Retrospective Clinical Audit of Outcomes for Patients Admitted to an Australian Inpatient Palliative Care Unit**

Runacres F.I.1, Gregory H.2, Ugalde A.3

1St Vincent’s Hospital Melbourne, Fitzroy, Australia, 2Calvary Health Care Bethlehem, Caulfield, Australia, 3Centre for Palliative Care, Kew, Australia

**Background:** Restorative care is a subset of rehabilitation that aims to improve quality of life through restoration or
maintenance of function. Outcomes for restorative care programs delivered by palliative care units have not adequately been assessed.

**Aims:** The primary objectives are to examine the outcomes of a restorative care program in an inpatient palliative care unit, including discharge destination, performance status changes and length of stay. Secondary objectives are to identify the population referred for restorative care, and describe the program provided.

**Methods:** Retrospective clinical audit of consecutive patients admitted to an Australian palliative care unit for restorative care from July 2010 to December 2011. Frequencies and descriptives were used to describe the sample, and independent samples t-tests evaluated differences between means for primary outcomes.

**Results:** 79 admissions met inclusion criteria. Mean age was 76.5 years and 43 (54.4%) were male. 95% patients had a malignant diagnosis; the majority lung cancer (24%), 16 patients (20%) were discharged home, 51 (65%) died, and 12 were transferred (15%). Of the patients discharged home only 6 (7.5% all patients) improved their performance status. Those discharged home had a significantly shorter length of stay (17 days compared to 39; p < 0.05). Patients discharged home also had significantly better Australia-modified Karnofsky Performance Status (AKPS) and Resource Utilisation Groups-Activities of Daily Living (RUG-ADL) scores upon admission than others (both p < 0.05).

**Conclusion:** The majority of patients referred for restorative care died during the admission, with only 20% being discharged home. Patients discharged home most commonly experienced maintenance and not improvement in performance status. A successful discharge home was associated with a shorter length of stay. Implications and recommendations for successful restorative care will be presented.

No external funding obtained.

**Abstract number:** P124

**Abstract type:** Poster

**Concordance between Clinician and Patient Severity Ratings of Palliative Care Symptoms: An Evaluation of an Admission Assessment**

*O Reilly M.1, Meagher D.2, Larkin P.3, Conroy M.4*

1Milford Care Centre & University of Limerick, Limerick, Ireland, 2University of Limerick, Limerick, Ireland, 3University College Dublin, Dublin, Ireland, 4Milford Care Centre, Limerick, Ireland

**Aims:** To investigate if clinician assessment of patient’s symptoms, concords with the patient’s self-assessment. To determine if concordance increased, post review of the admission assessment, (the intervention).

**Methodology:** Consecutive inpatients were interviewed within 72 hours of admission. Audits of the clinicians’ assessment documentation relating to the interviewed patients were conducted pre and post intervention. Concordance between patients’ self-ratings and the clinicians’ assessment was determined. Clinicians completed quantitative surveys pre and post intervention.

**Results:** Pre intervention, there were no differences in patients self reported severity ratings of pain and distress. Post Intervention, analysis showed significant agreement between patient self-assessment and clinician assessment of pain and distress. There were significant differences in self-assessed pain severity ratings in patients who were assessed as experiencing pain by clinicians, when compared to those patients that clinicians assessed as not being in pain [Patients with pain (n=30) Md = 6.00 vs. patients with no pain (n=16) Md = 0.00; p = .005, r = 0.62]. Patients assessed as experiencing distress (n=18) reported higher severity ratings of distress, in comparison to those that clinicians did not identify as experiencing distress (n=23) (Md = 4.00 vs. Md = 0.00; p = .044, r = 0.315). Significantly more staff (n=30; 88%) agreed that palliative care domains were comprehensively assessed post intervention in comparison to 59% (n=19) pre intervention (p=.011).

**Conclusion:** Following the re-evaluation of an admission assessment process and re-introduction of a multidisciplinary proforma, we found an increase in the rate of assessment of key palliative care domains and improved concordance between clinician and patient self-assessment. This admission assessment process should be tested in other Hospices, to determine if results can be replicated.

**Funding:** Irish Hospice Foundation

**Abstract number:** P125

**Abstract type:** Poster

**Palliative Care Knowledge of Registered Nurses and Doctors in an Acute Irish General Hospital**

*McCarthy S.*

Mercy University Hospital, Palliative Care CNS, Cork, Ireland

**Background:** Palliative care is evolving to meet the needs of an aging population, and broadening its scope to care for those with non-malignant conditions. 60% of the Irish population will die in an acute hospital or care facility with literature informing us that hospital staff have little understanding of the philosophy underpinning palliative care or the appropriate time to refer.

**Aim:** To compare palliative care knowledge held by registered nurses and doctors working in an acute Irish Hospital.

**Method:** A cross sectional quantitative research design, using the Palliative Care Quiz for Nurses (PCQN) was...
completed by participants (n=100). Demographic data recorded gender, age, qualifications, clinical area of employment and personal experience of palliative care outside of place of employment. An open-ended question was included to elicit greater insight into participant’s personal understanding of the role of the hospital based team.

**Results:** Professionals were found to have a modest understanding of palliative care. Notably 76% believed that palliative care is not compatible with aggressive therapies while 6% believed that only cancer patients receive palliative care. For 13% palliative care was synonymous solely with end of life care. Statistically significant differences were seen between professionals for three items relating to symptom management with an obvious gap in relation to pharmacology. Examining variables revealed that greater years of experience did not equate to higher knowledge levels but those working in oncology recorded a slightly higher knowledge score.

**Conclusions:** Initiatives need to be adopted to address highlighted areas of knowledge deficits. Palliative care should be included in induction modules to healthcare facilities with ongoing educational sessions tailored to the needs of each professional group. Replicating the study with a larger population would reinforce need for ongoing education and support of staff.

**Abstract number:** P126

**Abstract type:** Poster

When Do you Consult a Palliative Care Team?: Education and Experience Change Awareness

Yogo H.1, Sasara T.2, Yasukawa M.3, Nakasone R.3, Uehara K.3, Uehara N.3, Shimajiri T.1

1Tomishiro Central Hospital, Anaesthesiology, Tomigusuku, Japan, 2Yuaikai Nanbu Hospital, Palliative Medicine, Itoman, Japan, 3Tomishiro Central Hospital, Tomigusuku, Japan

**Aims:** The idea of “early palliative care” started to spread in Japan when Governmental Cancer Control Act was enacted in 2006. Recently, some studies reported this care significantly improved quality of life. However, it has not become common yet and many patients are referred to palliative care team (PCT) at the end-of-life stage. Therefore, we decided to analyze the timing of consultation in order to enhance the awareness of palliative care of medical staff.

**Methods:** A questionnaire with multiple-choice questions to select the appropriate PCT consultation timing from “diagnosis”, “inform”, “admission”, “beginning of cancer treatment”, “emergence of pain and other distressing symptoms” and “end-of-life” and an open question was distributed to physicians (n=120), nurses (n=257) and other specialists (n=75) at a 380-bed district general hospital in Japan in January 2013.

**Results:** Response rate of 53% of physicians, 91% of nurses and 84% of other specialists were obtained. While the earliest phase “diagnosis” was selected by 55% of nurses and 46% of other specialists, only 27% of physicians selected this phase (p=0.001 vs. others, chi-square test). Among physicians, younger physicians had the tendency to select “diagnosis”. “Emergence of pain and distressing symptoms” was selected by 57% of junior staff, which is significantly higher than the rate of junior residents (14%), senior residents (29%) and senior staff (24%) (p=0.007, chi-square test). Open question showed that junior residents, nurses and other specialists prefer earlier palliative care. Junior residents learned the necessity of palliative medicine at medical schools unlike junior staff. At the same time, junior staffs consider themselves to be able to manage most symptoms. Senior staffs understand the importance of PCT from their experience.

**Conclusion:** There is a difference in awareness regarding the phase of PCT consultation among professions. Education and experience also seem to affect the awareness.

**Abstract number:** P127

**Abstract type:** Poster

No Such Thing as Bad Publicity? Qualitative Study of Medical Students’ and Newly Graduated Doctors’ Awareness of Media Attention to End-of-Life Care and their Self-identified Learning Needs

Edge H., Yardley S.

Keele University, Stoke-on-Trent, United Kingdom

**Aims:** There has been considerable media attention surrounding end-of-life care, notably the Liverpool Care Pathway, applying additional pressures on doctors’ negotiation of end-of-life care. The study aim was to establish the level of awareness and impact of media attention on medical students and newly graduated doctors. Research questions: How are these cohorts responding to additional media attention with regards to their professional duties? What are their self-identified learning needs?

**Methods:**

1. Literature review: systematic searching of literature regarding medical personnel, media and end-of-life care.
2. Media analysis: 3 purposely-selected national newspapers were searched for coverage of the Liverpool Care Pathway. Relevant articles underwent thematic analysis.
3. Focus groups: Medical students (n=8) and junior doctors (n=8) were recruited. 3 longitudinal sessions were conducted exploring: (1) awareness and impact of media publicity; (2) responses to media articles; (3) the emerging analysis and perceptions.
of learning needs. Data was audio-recorded, transcribed verbatim and analysed using qualitative thematic analysis.

Results: Key themes from our media and focus group sessions concerning the impact of media attention to end-of-life care, participants’ perceptions and their concerns will be presented. We will discuss the implications including the identification of learning needs concerning end-of-life care and professional duties.

Conclusion: There has been little published previously exploring the impact media has on newly qualified doctors and their practice. External influences on medical practice can influence understandings of a phenomenon and challenge or even legitimize particular practices. This study provides important insights into medical students’ and junior doctors’ perceptions and learning needs regarding end-of-life care.

Funding: This research is funded by ‘Primary Care and Health Sciences, Keele University.’

Abstract number: P128
Abstract type: Poster

Transitions between Health Care Settings in the Final Three Months of Life in Four EU Countries

Van den Block L.1,2, Lara Pivodic L.1, Pardon K.1, Donker G.3, Miccinesi G.4, Van Casteren V.3, Vega Alonso T.5, Deliens L.1, Onvuteaka-Philipsen B.7

1Vrije Universiteit Brussel (VUB) & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Vrije Universiteit Brussel (VUB), Department of Family Medicine, Brussels, Belgium, 3NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands, 4Cancer Prevention and Research Institute, ISPO, Florence, Italy, 5Scientific Institute of Public Health, Brussels, Belgium, 6Public Health Directorate Junta de Castilla y León, Valladolid, Spain, 7Department of Public and Occupational Health, EMGO Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Amsterdam, Netherlands

Background: Although burdensome transitions between health care settings appear to be related to poor quality in end-of-life care, there is a lack of population-based cross-country comparative data needed to develop an effective public health policy on end-of-life care on a national and EU level.

Method: Nationwide mortality follow-back study with data collection in Belgium, Netherlands, Italy (2009-2010) and Spain (2010-2011) via representative Networks of GPs ie surveillance systems representative of all GPs in a country. All GPs reported weekly, on a standardized registration form, every deceased patient (>18 year) in their practice and identified non-sudden deaths.

Results: Of 4791 non-sudden deaths, 59%, 55%, 60% and 58% of patients were transferred to other care settings at least once in the final three months of life in BE, NL, IT and SP respectively, and 10%, 5%, 8% and 12% of patients were transferred 3 times or more in that period (p<.001 in multivariate analyses adjusting for age, sex, cause of death, dementia diagnoses). In all countries, these figures were higher for patients residing at home than for care home residents. Respectively 10%, 8%, 10% and 13% of patients in BE, NL, IT and SP (p=0.04) experienced burdensome end-of-life transitions defined as a transfer in the last three days of life or three or more hospitalizations in the last three months of life. Most often occurring final transitions in all countries were transfers to a hospital and patient wishes were cited as a reason for these transfers in 27% 39% 9% and 6% of cases in BE, NL, IT and SP respectively (p<.001).

Conclusion: End-of-life transitions between settings are common across countries, in particular late hospitalizations for people residing at home, and burdensome transitions occur among one in ten patients. Frequency and type vary according to country as do reasons for terminal hospitalizations, suggesting room for improvement in end-of-life care in several countries.

Abstract number: P129
Abstract type: Poster

Place of Death for People with Parkinson’s Disease: A Population Level Comparison of Ten Countries


1King’s College London, Department Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 3Cancer Prevention and Research Institute, ISPO, Florence, Italy, 4University of Pecs Medical School, Pecs, Hungary, 5Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 6Hospice Waikato, Hamilton, New Zealand, 7University of Alberta, Edmonton, AB, Canada, 8University of Texas, M.D. Anderson Cancer Center, Houston, TX, United States, 9Dongduk Women’s University, Seoul, Korea, Republic of, 10Instituto Andaluz de Función Pública, Andalusia, Spain

Context: Most people would prefer to be cared for, and to reach the end of life in familiar surroundings, with hospital
appearing to be less sought and appropriate as an end-of-life care setting. However, little is known about place of death in Parkinson’s disease (PD). Our aim was to examine variation in place of death of people with PD across European and non-European countries compared to demographic, social, residential and health care system related factors.

**Methods:** We used death certificate data from Belgium, France, Italy, Hungary, Czech Republic, New Zealand, Canada, Mexico, South Korea and Spain to identify people who died from PD using ICD-10 codes. We examined associations between place of death and sex, age, educational attainment, marital status, urbanization level, availability of hospital and long term care (LTC) beds using $\chi^2$ tests and multivariable logistic regression analyses.

**Results:** A large majority died in hospital in Hungary (60%) and South-Korea (75%). In Canada (42%), France (40%), Czech Republic (39%) and Spain (38%) a substantial proportion died in hospital. In contrast, the majority died in LTC-settings in New Zealand (71%) and Belgium (52%), or at home in Mexico (73%) and Italy (51%). The chances of dying in hospital were higher for males than females (4 countries: Belgium, France, Italy and Canada), patients younger than 80 years (4 countries: Belgium, France, Italy and Mexico), married patients (3 countries: France, Hungary and Canada), and those living in a strongly urbanized environment where a higher availability of hospital beds exists (1 country: Italy).

**Conclusion:** In European and non-European countries a substantial proportion of PD deaths occurred in hospitals. Country and disease-specific characteristics need to be considered when developing end-of-life care strategies to support terminal care and death in alternative appropriate care settings. EC funded.

**Abstract number:** P130
**Abstract type:** Poster

“And then I Said to my Mum: Take it Easy!” The Perspective of Children with Life-limiting Conditions in Homecare Settings

Oetting-Roß C., Research Group “Famile - Family Health in the Lifecourse”

University of Applied Sciences Osnabrück, Osnabrück, Germany

**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 each year. The number is increasing. Little is known about these children, especially about their experiences, their perception of their own situation and the care they receive. This paper is part of an ongoing study, focussing on experiences of seriously ill children and aims to reconstruct these from different perspectives.

**Methods:** After ethical approval, qualitative interviews were conducted with five life-limiting ill children and adolescents, with their parents and one professional caregiver (n=17). For this paper, two of the families were selected. A grounded theory approach was chosen and interpretation involved a process of continuous reflection, analysis and elicitation. First a case portrait of each family is written, followed by case comparisons.

**Results:** The perspectives of two life-limiting ill children and their families are juxtaposed, one with professional home care of 20 hours per day seven days a week and another child with the same level of care. For the latter the mother is the main caregiver, supported by a voluntary hospice carer. The preliminary analysis indicates that understanding the interaction between children and their parents furnishes insights about the children’s experiences.

**Conclusion:** For developing specific interventions for children with life-limiting conditions in domestic palliative care situations and quality criteria for paediatric palliative homecare, a deeper understanding of children and families is a prerequisite, which shows clearly the necessity to create space for expressing experiences.

This study is funded by the Federal Ministry of Education and Research, Germany

**Abstract number:** P131
**Abstract type:** Poster

A New Once-a-Day Fentanyl Citrate Patch (Fentos® Tape) Could Be a New Treatment Option in Patients with Achieving Inadequate Cancer-related Pain Control Using a 72-hour Traditional Transdermal Matrix Fentanyl Patch

Koike K., Terui T., Ishitani K.

Higashi Sapporo Hospital, Palliative Care Medicine, Sapporo, Japan

**Introduction:** The approved and recommended dosing interval for transdermal fentanyl(Durotep® MT) is every 72 hours. However, some patients require a shorter dosing interval to obtain adequate pain relief.

**Objectives:** Fentos® Tape was developed in Japan since June 2010. We investigated analgesic effects of Fentos® Tape in patients with achieving inadequate pain control using Durotep® MT.

**Aims of this study:** To assess the analgesic efficacy and economic analysis of Fentos® Tape for cancer patients receiving Durotep® MT not lasting 72 hours.

**Methods:** A retrospective analysis of 445 cancer patients treated with Durotep® MT at the Higashi Sapporo Hospital.

1) The change in average pain intensity(P1) from 48 hours baseline (0 to 48 hours after application of Durotep® MT) to the 3rd day (48 to 72 hours after),
measured with NRS. We could switch to Fentos® Tape after day 12 if pain relief was inadequate for the entire 72-hour dosing interval.

2) The change in average PI from 24 hours baseline (0 to 24 hours after switching to Fentos® Tape) to the 3rd day (48 to 72 hours after switching), and the 5th day (96 to 120 hours after switching).

3) A comparison of the cost-effectiveness of Fentos® Tape and Durotep® MT dosing interval of 48 hours.

Results: At 3rd day after application of Durotep® MT, 45 patients (10.1%) showed the increase in PI of 30% or more from baseline PI. 38 of the 45 patients (84.4%) were converted to comprehensive palliative care (PC) treatment. Little is known about the daily practice of the use of PS in German specialized PC institutions in the context of existing national and international recommendations.

Purpose: This study’s primary objective is to explore how PS is used in German specialized PC institutions with reference to the EAPC framework.

Methods: The heads of all 605 Palliative Care Units, Hospices, Specialized Outpatient Palliative Care Teams and Specialized Outpatient Pediatric Palliative Care Teams listed in official address registers were invited personally by phone call to take part in an online questionnaire survey about the clinical practice of PS in their institution.

Results: Answers from 221 institutions were included (response rate 37.2%). Considerable differences of the frequency of PS exist between single institutions. The estimated percentage of patients treated by PS ranges from 0% to 80% of all patients treated per year (mean 6.7%). Some PC specialists report to discuss PS as treatment option for every patient they see. Main indications for PS as mentioned by the respondents were dyspnea, agitation, acute bleeding and pain. 73.6% of the participants usually plan intermittent PS. Specific evaluation and documentation tools are rare. 36.2% of study participants are not familiar with the EAPC framework (original or translation).

Conclusion: The use of PS in Germany is heterogeneous. The mean estimated percentage of patients receiving PS in Germany is similar to findings in other European countries. The wide range we found may be due to uncertainties concerning definitions. Broad use of specific guidelines and documentation tools could help to gain safety in the use of PS. Implementation of the EAPC framework into clinical practice is still inconsistent in Germany. Here more education and research is urgently needed.

Abstract number: P132
Abstract type: Poster

The EAPC Framework on Palliative Sedation and Actual Clinical Practice in Germany - A Questionnaire Based Survey

Klein C., Klosa P., Heckel M., Bronnhuber A., Ostgathe C., Stiel S.

University Hospital Erlangen, Department of Palliative Medicine, Erlangen, Germany

Background: Palliative sedation (PS) can be offered to patients with intolerable symptom burden that is refractory to comprehensive palliative care (PC) treatment. Little is known about the daily practice of the use of PS in German specialized PC institutions in the context of existing national and international recommendations.

Purpose: This study’s primary objective is to explore how PS is used in German specialized PC institutions with reference to the EAPC framework.

Methods: The heads of all 605 Palliative Care Units, Hospices, Specialized Outpatient Palliative Care Teams and Specialized Outpatient Pediatric Palliative Care Teams listed in official address registers were invited personally by phone call to take part in an online questionnaire survey about the clinical practice of PS in their institution.

Results: Answers from 221 institutions were included (response rate 37.2%). Considerable differences of the frequency of PS exist between single institutions. The estimated percentage of patients treated by PS ranges from 0% to 80% of all patients treated per year (mean 6.7%). Some PC specialists report to discuss PS as treatment option for every patient they see. Main indications for PS as mentioned by the respondents were dyspnea, agitation, acute bleeding and pain. 73.6% of the participants usually plan intermittent PS. Specific evaluation and documentation tools are rare. 36.2% of study participants are not familiar with the EAPC framework (original or translation).

Conclusion: The use of PS in Germany is heterogeneous. The mean estimated percentage of patients receiving PS in Germany is similar to findings in other European countries. The wide range we found may be due to uncertainties concerning definitions. Broad use of specific guidelines and documentation tools could help to gain safety in the use of PS. Implementation of the EAPC framework into clinical practice is still inconsistent in Germany. Here more education and research is urgently needed.

Abstract number: P133
Abstract type: Poster

Pain, Depression, Dyspnea and Systemic Inflammation Markers in Advanced Cancer Patients

Castillo M.R.1, Benitez-Rosario M.A.1, Abreu-González P.2, Feria M.3

1Hospital Universitario Nuestra Señora de Candelaria, Unidad de Cuidados Paliativos, Santa Cruz de Tenerife, Spain, 2Universidad de la Laguna, Departamento de Fisiología, Santa Cruz de Tenerife, Spain, 3Universidad de la Laguna, Departamento de Farmacología, Santa Cruz de Tenerife, Spain

Objective: We assessed if pain, depression and dyspnea were associated with blood systemic inflammation and nutritional markers in terminal cancer patients.

Methods: A prospective cohort study was carried on with cancer patients attended by our palliative care unit until death. Informed written consent for the study was obtained from every patient. A blood sample was taken in the first evaluation of the patient; were selected as markers: neutrophil-lymphocyte ratio (NLR) ≥5, platelet-lymphocyte ratio (PLR) ≥300, albumin (Al), cholesterol (Ch), transferring (Tt) and Prognostic Nutritional Index (PNI) (albumin +5 x total lymphocyte count) < 45. Patients were grouped by the presence in the illness course of any type of pain, psychological disorders (anxiety and depression, according to DSM-III-R criteria, with pharmacological treatment) and dyspnea (equivalent to III-IV levels of NYHA). Kolmogorov - Smirnov, Mann-Whitney U, Spearman correlation and Pearson x2 tests were performed with SPSS 21.

Results: 213 patients, median of age of 69 years (range 17-104), (63 % male, 37% female) were assessed. The median time from blood sampling to death was 43 days
(range 4-280). 63%, 36% and 60% of the patients, without differences between sexes, experienced cancer pain, dyspnoea and psychological disorders, respectively. \( A_l \) vs \( A_d \) was associated with pain (2.9 vs 2.7; p=0.006) and psychological disorders (3.0 vs 2.8; p=0.06). Pain and dyspnoea were not related with the other selected markers. Psychological disorders were associated with Ch_{(mg/dl)} (171 vs 151; p=0.02), NLR (median) (10 vs 13; p=0.02), PLR ≥300 (54% vs 45%; p=0.01) and inversely with PNI< 45 (9 vs 91%; p=0.01). These data were not affected by survival.

**Conclusions:** In advanced cancer patients, plasmatic systemic inflammation and cachexia markers are not related with pain and dyspnea. Psychological disorders were associated only with PLR ≥300 but not with plasmatic cachexia markers.

**Abstract number:** P134  
**Abstract type:** Poster  

**Quality of Care for Cancer Patients on Home Parenteral Nutrition: Development of Key Interventions and Outcome Indicators Using a Two-round Delphi Approach**


1University Hospitals Leuven & Department of Pharmaceutical and Pharmacological Sciences, Department of Pharmacy, Leuven, Belgium, 2Research Centre for Pharmaceutical Care and Pharmaco-economics, Department of Pharmaceutical and Pharmacological Sciences, Leuven, Belgium, 3University Hospitals, Department of Gastroenterology, Leuven, Belgium, 4School of Public Health, Centre for Health Services and Nursing Research, Leuven, Belgium, 5Western Norway Research Network on Integrated Care, Helse Fonna, Haugesund, Norway, 6St Orsola-Malpighi Hospital, University of Bologna, Center for Chronic Intestinal Failure, Department of Gastroenterology and Internal Medicine, Bologna, Italy, 7Erasme University Hospital, Department of Gastroenterology, Brussels, Belgium, 8KTB Tumor Biology Center at Albert-Ludwigs-University, Gastroenterology and Nutrition Service, Freiburg, Germany, 9Hospital General Universitario Gregorio Marañón, Nutrition Unit, Madrid, Spain, 10Charité University Hospital, Humboldt-University, Department of Surgery, Berlin, Germany, 11University of Milan, Milan, Italy

**Aims:** Clear recommendations on how to guide patients with cancer on home parenteral nutrition (HPN) are lacking as the use of HPN in this population remains a controver-

sial issue. Therefore, the aims of this study were to rank treatment recommendations and main outcome indicators to ensure high-quality care and to indicate differences in care concerning benign versus malignant patients.

**Methods:** Treatment recommendations, identified from published guidelines, were used as a starting point for a two-round Delphi approach. Comments and additional interventions proposed in the first round were reevaluated in the second round. Ordinal logistic regression with SPSS 2.0 was used to identify differences in care concerning benign and malignant patients.

**Results:** Twenty-seven experts from five European countries completed two Delphi rounds. After the second Delphi round, the top three most important outcome indicators were:

1. quality of life (QoL),
2. incidence of hospital readmission and
3. incidence of catheter-related infections.

Forty-two interventions were considered as important for quality of care (28/42 based on published guidelines, 14/42 newly suggested by Delphi panel). The topics “liver disease” and “metabolic bone disease” were considered less important for cancer patients, together with use of infusion pumps (p= 0.004) and monitoring of vitamins and trace elements (p= 0.000). Monitoring of QoL is considered more important for cancer patients (p= 0.03).

**Conclusion:** Using a two-round Delphi approach, we developed a minimal set of 42 interventions that may be used to determine quality of care in HPN patients with malignancies. This set of interventions differs from a similar set developed for benign patients.

**Abstract number:** P135  
**Abstract type:** Poster  

**Inner Curriculum in Palliative Care Professionals: Awareness Measurement**

*Galiana L.*, *Sansó N.*, *Barreto P.*, *Oliver A.*, *Cebolla A.*, *Soto A.*, *Collette N.*, *Barbero J.*, *Benito E.*

1University of Valencia, Valencia, Spain, 2Ibsalut, Palliative Care Program of the Balearic Islands, Palma de Mallorca, Spain, 3University Jaime I, Castellón, Spain, 4Santa Creu i Sant Pau Hospital, Barcelona, Spain, 5La Paz Hospital, Madrid, Spain

**Aims:** The Mindful Attention Awareness Scale (MAAS) is a 15 item instrument measuring the general tendency to be attentive and aware of one’s experience in daily life. The aim of this work is to examine awareness and the properties of this scale focusing on palliative care professionals.

**Method:** A cross-sectional design on 387 surveyed Spanish palliative care professionals from different disciplines
was carried out. The mean age was 46.84 (DT = 8.87) and 77.7% were women. The survey included socio-demographic questions, the MAAS and psychological variables. A confirmatory factor analysis (CFA) was estimated with the 15 Likert scale items proposed by the original authors. As this model did not appropriately fit the data, a new CFA was conducted, and classical and structural equation modeling estimates of reliability were also reported.

**Results:** The first model using the complete original scale showed adequate overall fit ($c^2_{fit} = 149.954, p < .01$; $CFI = .907$, $GFI = .880$; $SRMR = .054$; and $RMSEA = .075$). Nevertheless, some problems arose with the analytical fit: the explained variance of four items did not reach .200. A second model, just retaining 11 items from the scale, had better overall and analytical fit: the $c^2_{fit}$ was 268.139 ($p < .01$), $CFI$ was .935, $GFI$ was .896, $SRMR$ was .049, and $RMSEA$ was .082; with minimum explained variance of .309 for item 5. Internal consistence was also improved with this modification, with a little increase in both $a$ and $GLB$, with inter-item correlations higher than .500.

**Conclusion:** A detailed report of MAAS scores in the palliative care professionals was offered. Results pointed out better properties of the scale in this context when a shorter version is used. Further research using alternative psychometric approaches would clarify this latter point.

**Funding:** This research is partially funded by Spanish Society for Palliative Care (SECPAL).

**Abstract number:** P136  
**Abstract type:** Poster  
**Language Based Methodologies with a Focus on Ethics. The Case of Metaphors of Hope among Palliative Care Professionals**  

**Olsman E.**¹, **Duggleby W.²**, **Nekolaichuk C.³**, **Willems D.¹**, **Leget C.⁴**

¹Academic Medical Center, University of Amsterdam, General Practice, Section of Medical Ethics, Amsterdam, Netherlands, ²University of Alberta, Faculty of Nursing, Edmonton, AB, Canada, ³University of Alberta, Faculty of Oncology, Division of Palliative Care Medicine, Edmonton, AB, Canada, ⁴University of Humanistics, Ethics of Care, Utrecht, Netherlands

**Aims:** To describe metaphors of hope among palliative care professionals and to describe implications for language based methodologies that focus on ethics.

**Methods:** Semi-structured interviews with palliative care professionals, which were recorded and transcribed. Metaphors of hope were analyzed and clustered, drawing from narrative theories. Researchers discussed the results of their analyses until they reached consensus. Member checking and observation of palliative care settings was done (triangulation).

**Results:** Of the 64 participants, 41% were physician, 34% nurse, 20% chaplain and 5% had another profession. Mean age: 48.42 years (SD 9.27). 72% were female. Participants described their own hope, palliative care patients’ hope and families’ hope with four metaphors. These metaphors included a central value and a bodily dimension.

1) **grip:** hands and feet (body) helped patients and professionals to remain upright, which provided them safety (value);
2) **source:** inside, in the heart (body), from which patients and professionals drew strength (value) to cope with difficulties;
3) **tune:** could be heard with the ears (body) and harmony (value) characterized the relationship between professionals and patients;
4) **vision:** was seen with the eyes (body) and professionals tried to offer perspectives (value).

**Conclusion:** Our findings indicate that the metaphors of hope may help palliative care professionals to broaden their communication repertoire. That is particularly important when they or their patients get stuck in their framing of hope. More importantly, our findings show that analysis of language use, and particularly analysis of metaphors, is an excellent way of understanding an invisible phenomenon. Metaphor analysis shows how research participants make this phenomenon visible by connecting it to something tangible like the body. Metaphors’ rhetorical functions furthermore show ethical dimensions that influence communication in clinical practice.

A part of this abstract has been accepted for publication by Journal of Pain and Symptom Management.

**Abstract number:** P137  
**Abstract type:** Poster  
**Comparing the Accuracy of the D-PaP and the PaP Score in Patients with Diagnoses Other than Cancer**  

**Tavares F.A.**

Hospital Cuf Infante Santo, Unidade de Cuidados Paliativos de Aguados, Lisboa, Portugal

The Delirium-Palliative Prognostic Score (D-PaP) seems to predict more accurately 30-day survival of advanced cancer patients than PaP. Large-scale validation studies are lacking but PaP shown to be reliable in patients approaching death from diseases other than cancer.

**Aims:** To evaluate the prognostic accuracy of D-PaP in patients with non-cancer diagnoses; to compare its accuracy with the original tool.

**Methods:** Over a one-year period D-PaP [Karnofsky performance status $KPS$, clinical prediction of survival $CPS$, anorexia, dyspnea, total white blood cell count,
lymphocyte %, and delirium (Confusion Assessment Method)] was determined, by the same physician, at admission to an acute palliative care unit, for all patients with a main diagnosis other than cancer. Survival was defined as the difference between the death date and the date of enrolment. Survival curves were estimated using the Kaplan-Meier method. The discriminating ability was assessed using the area under the receiver operating characteristic curve ROC.

**Results:** Data from 44 [23 males, median age 84 y (range 64-95), 52% dementia] out of 50 patients enrolled are available. 36% had KPS ≤30, 23% a CPS ≤4 weeks and 35% were profoundly lymphopenic. At the last follow-up 21 patients had died, with a median survival of 199 days (Q1 to Q3, 103-295). Twenty, 17 and 7 patients were included, respectively, in D-PaP group A, B and C. The proportion surviving ≥30 days was 0.85 (A), 0.82 (B) and 0 (C). The estimated median survival, in days, (and 95% confidence intervals) was 252 (198–307) (A), 133 (37–229) (B) and 8 (5–11) (C). The Kaplan-Meier curves showed a linear trend for survival (log-rank test $p=7.96$, $p=0.005$). The agreement between groups in D-PaP and PaP was good ($k=0.54$). The area under ROC of D-PaP was 0.71 (95% CI 0.56-0.87) compared to the 0.70 (0.54–0.86) for PaP.

**Conclusion:** More studies should validate the suggested accuracy of D-PaP in progressive non-malignant disorders in distinct care settings.

**Abstract number:** P138
**Abstract type:** Poster

**Suffering in Silence: A Qualitative Study on the Repercussions of Having an Adult Child with Cancer on the Life of Older Parents**

*Van Humbeeck L.*, *Piers R.*, *Dillen L.*, *Verhaeghe S.*, *Grypodonck M.*, *Van Den Noortgate N.*

1Ghent University Hospital, Department of Geriatrics, Ghent, Belgium, 2Ghent University Hospital, Oncology Centre, Ghent, Belgium, 3Federation of Palliative Care Flanders, Vilvoorde, Belgium, 4Ghent University, Department of Social Health and Nursing Sciences, Ghent, Belgium

**Background:** With increased life expectancy the chance that older people face a cancer diagnosis in an adult child augments. We aimed to gain insight into the lived experience of these older parents of an adult child with cancer, as research attention for this topic has been scarce (Van Humbeeck et al., 2013).

**Methods:** Interview data of 22 parents (≥70 yrs) were analyzed with support of NVivo 10 based on the principles of grounded theory.

**Results:** ‘Suffering in silence’ emerged as the core category encapsulating parents’ experiences of shielding and unwillingly being shielded by their child. First, some parents feel in the margin of events, as their child informs them on a ‘here and now’ basis. Second, older parents experience a multitude of feelings and considerable distress, often contained in front of their child. Older parents consciously try to keep up the facade of normalcy by portraying an optimistic view and upbeat attitudes.

A balancing act was described between being involved without disturbing and keeping an appropriate distance. While older parenthood is characterized by decreasing levels of parental involvement, a renegotiation of the parenting position takes place due to the cancer diagnosis in their child and most parents resume their parental responsibilities by means of ‘being there’, in many forms and intensities. The envisaged parenting is influenced by their relationship history, their degree of care dependency and the marital status of their child.

**Conclusion:** Older parents’ experience a delicate balancing act on two areas

1. between shielding their child and being shielded by their child, and
2. between being involved and keeping an adequate distance.

Faced with their child’s illness, older parents are confronted with overwhelming feelings often underestimated by their close environment. Health care professionals can play a pivotal role in protecting the autonomy and privacy of adult children while practicing family-focused care.

**Abstract number:** P139
**Abstract type:** Poster

**Official Specialization in Palliative Medicine. An European Study on Programs Features and Trends**

*Bolognesi D.*, *Centeno C.*, *Biasco G.*

1Academy of Sciences of Palliative Medicine, Bentivoglio, Italy, 2Institute for Culture and Society (ICS), University of Navarra, Pamplona, Spain, 3Giorgio Prodi’ Center for Cancer Research, Alma Mater Studiorum, University of Bologna, Bologna, Italy

**Background:** Specialization in Palliative Medicine has grown rapidly since the 2000s. The EAPC Atlas of Palliative Care in Europe 2013 mapped Programs of Official Specialization in Palliative Medicine (POS-PM).

**Aim:** The study on POS-PM aims to do a comparative analysis of main features of European programs.

**Methods:** A questionnaire was designed to explore the 15 countries: Czek Republic, Finland, France, Georgia, Germany, Ireland, Israel, Italy, Latvia, Malta, Norway, Poland, Romania, Slovakia, UK. Questions included historical background, denomination, requirements, length, characteristic
and content, official body that certified, utility and 2013 workforce capacity. We build up a EAPC Task Force with national experts. The online survey was follow by a meeting in the EAPC Congress 2013 and further fine-tuning of results.

**Results:** All 15 countries answered, 13 attended the meeting. Countries spent almost 10 years dealing with the business. 6 countries has specialty in palliative medicine, 5 sub-specialty and 4 other denomination (i.e. field of competence). Specialty is a direct way from medical graduation. For other POS-PM, a previous specialty (previously determined or any clinical one), years of training in other specialty or of clinical practice as physician are required. To be specialist last 8 year in UK and 7 years in Ireland. Full time training process in PM in other countries are: 2 years (n=6), 1 year (n=2). Part time (n=4) less than 1 year of training-time in a period of about 2 years. Ministry of Education and/or Health certified in 8 countries. The trend is to have a mandatory certification to work as specialist, but now only in 10.

**Conclusion:** Despite a great heterogeneity of POS-PM, the trend in Europe is to have official POS-PM with 2-3 years of training after previous clinical practice in different clinical specialties.

**Funding:** Accademia delle Scienze di Medicina Palliativa (Bologna) and ATLANTES Resarch Program, ICS University of Navarra.

**Abstract number:** P140

**Abstract type:** Poster

**Spirituality and Spiritual Care in the Hospice Volunteers Training in Germany**

*Gratz M.1,2, Paal P.1, Roser T.2*

1University of Munich, Department of Palliative Medicine, Munich, Germany, 2University of Muenster, Practical Theology, Muenster, Germany

**Background:** Educating hospice volunteers is directly connected to practise based experiences and increasing expectations towards volunteers’ competences. Little is known how volunteers are prepared to confront spirituality in their work. This study was designed to find out how spirituality and Spiritual Care are integrated in volunteers’ training.

**Methods:** An online questionnaire was launched in July 2012. Altogether 1,332 ambulatory hospices for adults were asked to fill out the questionnaire that contained 4 NRS Scales (1-10), 8 yes/no questions, 1 closed, 3 multiple choice and 3 open questions. By the end of September 332 hospice coordinators (24.9 %) had given their response. The collected data was analysed using the SPSS 21.

**Results:** The value of confronting personal spirituality during trainings is very high (M=8.3). The time for tackling spiritual issues and working with definitions is varied. The study goals in SC are defined by the organisers (N=211; 64.7 %), educators (N=74; 22.7 %) or institution providing the training (N=85; 26.1 %). 52.1 % (N=173) of institutions use external educators, who are not acquainted with overall study goals. Involved SC experts’ are trained or experienced in pastoral care/theology (N=42; 12.7 %), hospice/palliative care (N=62; 18.7 %) or in both disciplines (N=152; 45.8 %). Results demonstrate that the importance of SC is discussed (N=207; 62.4 %), but there is no clarity in terms of specific tasks or competences (N=192; 57.8 %).

**Conclusions:** Results indicate the need for conceptually integrated curriculum that contains pre defined goals, themes and methods for teaching SC to hospice volunteers. It is a complex task to generate an educational agenda that at the same time prepares volunteers for their duty and is sensitive towards their individual perception of spirituality. Besides understanding the complexity of spirituality it is necessary to work on SC training standards. Equally important is to discuss the competences of trainers.

**Abstract number:** P141

**Abstract type:** Poster

**Interventions in the Last Year of Life: Do They Predict Death in Hospital in England?**

*Kaushik S.1,2, Hounsome L.2, Blinman C.1, Glew S.3, Gornall R.1, Verne J.2*

1Cheltenham General Hospital, Division of Gynaecological Oncology, Cheltenham, United Kingdom, 2Public Health Knowledge and Intelligence Team (South West), Bristol, United Kingdom, 3St Michael’s Hospital, Bristol, United Kingdom

**Aims:** This study aims to observe the trends of interventions performed in the last year of life for women with gynaecological cancer and to study the impact on place of death.

**Methods:** Data were extracted from linked Office for National Statistics deaths data and Hospital Episode Statistics for 71,269 patients who died of gynaecological cancer in England from 2000 to 2012. Univariate analysis was used to study the trends of procedures performed in the last month of life. Multivariate analysis was used to identify those interventions that significantly predict death in hospital after adjustment for socio-demographic variables.

**Results:** The ratio of emergency admissions in the last year of life to elective admissions was 2.3. Chemotherapy, imaging and drainage of ascites were the most common interventions following a hospital admission. One in four women had chemotherapy or imaging in the last three months of life and one-fifth had drainage of ascites. In addition, another 3% of women had their first cycle of
chemotherapy in the last three months of life. Interventions that significantly increased over the past decade, for the last month of life, were: chemotherapy (OR 1.04), drainage of ascites (OR 1.03), emergency imaging (OR 1.16), emergency urological procedures (OR 1.02), emergency pleural drainage and emergency CVC insertion (OR 1.05). Procedures undertaken in the last month of life that significantly predicted death in hospital were: elective chemotherapy (OR 1.80), elective imaging (OR 1.37) and elective urological procedures (OR 1.32). Insertion of a CVC line in the last month of life increased the odds of dying in hospital by 3.5 times (p< 0.001).

Conclusion: Better understanding and recognition of the end of life care stage is required to prevent inappropriate interventions, with integrated multi-disciplinary input to ensure proper decision making and advance care planning. Improved services are required in the community to prevent unscheduled admissions.

Abstract number: P142
Abstract type: Poster
Meaning in Life Experience at the End of Life: Validation of the Hindi Version of the Schedule for Meaning in Life Evaluation and a Cross-cultural Comparison between Indian and German Palliative Care Patients

Kudla D.1, Kujur J.2, Tigga S.2, Tirkey P.2, Rai P.2, Fegg M.J.1

1University of Munich, Munich, Germany, 2Jesu Ashram, Matigara, India

Context: The experience of meaning in life (MiL) is a major protective factor against feelings of hopelessness and wishes for hastened death in palliative care (PC) patients. However, most instruments for MiL assessment have only been developed in Western countries so far. Little is known about MiL experience in Asian PC patients.

Objective: This study aimed to develop a Hindi version of the Schedule for Meaning in Life Evaluation (SMiLE), test its’ feasibility and validity in Indian PC patients and compare the results to previous studies in Germany.

Methods: Indian PC patients of a hospice for the destitute were eligible to participate in this cross-sectional study. In the SMiLE, respondents individually listed MiL giving areas before rating their satisfaction and importance of these areas. Overall indices of satisfaction (IoS, range 0-100), weighting (IoW, range 0-100) and weighted satisfaction (IoWS, range 0-100) were calculated.

Results: A Hindi forward-backward translation of the SMiLE was provided. 258 Indian PC patients took part in the study (response rate, 93.5%). Convergent validity of the SMiLE was found with the World Health Organization Quality of Life-BREF (r=0.17; p=.008) and the Idler Index of Religiosity (public religiousness: r=0.25, p<.001, private religiousness: r=0.29, p<.001). Indian PC patients’ IoW was 65.8±22.1, IoS 68.6±17.4 and IoWS 70.2±17.0. In multivariate analyses of covariance, they differed significantly to German PC patients only in the IoW (IoW: 84.8±11.5, p<.001; IoS: 70.2±19.7, IoWS: 72.0±19.4). Compared to Germans, Indians listed more often spirituality (p<0.001) and social commitment (p<0.001), and less often social relations (p=0.008).

Conclusion: Preliminary results indicate good feasibility and validity of the Hindi version of the SMiLE. MiL experience seems also to be a coping resource for Indian PC patients.

Abstract number: P143
Abstract type: Poster
Patients’ Preferences for Participation in Treatment Decision-making at the End of Life: Qualitative Interview with Cancer Patients

Brom L.1, Pasman H.R.W.2, Widdershoven G.A.M.2, van der Vorst M.J.D.L.1, Reijneveld J.C.4, Postma T.J.4, Onwuteaka-Philipsen B.D.1

1VU University Medical Center, EMGO Institute for Health and Care Research, Public and Occupational Health, Amsterdam, Netherlands, 2VU University Medical Center, EMGO Institute for Health and Care Research, Medical Humanities, Amsterdam, Netherlands, 3VU University Medical Center, Medical Oncology, Amsterdam, Netherlands, 4VU University Medical Center, Neurology, Amsterdam, Netherlands

Background: In palliative care, involvement of patients in decision-making is of great importance. The aim was to obtain insight into reasons for patients preferred role in treatment decision-making at the end of life.

Method: Qualitative interview study with advanced cancer patients. The Control of Preferences Scale was used as a start for discussing the extent and type of influence patients want to have in future medical decisions. In-depth interviews were conducted with 28 patients with incurable cancer. Patients were included at the beginning of first line treatment. Age ranged between 27 and 82 years.

Results: All patients wanted their physician to be involved in decision-making because of his knowledge and clinical experience. The extent to which patients wanted to participate themselves depended on how they saw their own role and capabilities for participation. Some patients considered keeping control over their own life or being responsible for their own decisions important. Also the phase of illness was regarded as relevant. Compared to the current phase, in which treatment aimed for life prolongation, patients expected preferring more participation when quality of life would become more at stake. At the time of
the interview several patients considered having no other option than treatment.

**Conclusion:** While all patients consider the role of the physician as essential, patients expect their preferences to change in the course of the illness. Patients expect to actively participate in decisions about whether or not to continue treatment when quality of life becomes at stake, and want to be able to make the decision to stop further treatment themselves. It is not clear whether physicians are sufficiently aware of the preference for future participation and provide room for it. Communication on patients’ expectations and wishes for future treatment decision is thus of great importance.

**Funding:** The Netherlands Organisation for Scientific Research

**Abstract number:** P144  
**Abstract type:** Poster  
**The Use of Trafficked Counterfeit Tramadol by Patients with Advanced Cancer Referred to a Palliative Medicine Unit in Egypt**  
Alsirafy S.A., Farag D.E., Ibrahim N.Y., Hammad A.M.  
Kasr Al-Ainy School of Medicine, Palliative Medicine Unit, Kasr Al-Ainy Center of Clinical Oncology & Nuclear Medicine, Cairo, Egypt

**Introduction:** A major reason behind the largely inadequate cancer pain control in Egypt is the restrictive regulations that limit the availability of and accessibility to opioids. Tramadol is the only registered weak opioid available for pain control in Egypt. There is a rising “tramadol abuse epidemic” in Egypt, mainly due to the trafficked counterfeit tramadol. In an attempt to lessen the burden of tramadol abuse, the Egyptian government imposed restrictive regulations on access to tramadol in 2012. This study was conducted to explore the accessibility of Egyptian cancer patients to tramadol after the new restrictive regulations.

**Methods:** This survey included all patients referred to a cancer center-based palliative medicine unit (PMU) in Egypt during a 2-month period. The severity of pain was assessed using a four item verbal rating scale (no pain, mild, moderate and severe). Detailed history of analgesics use before referral to the PMU was taken including the use of trafficked counterfeit tramadol.

**Results:** During the study period, 75 patients referred to the PMU for the first time were eligible for analysis. The majority (88%) of patients had moderate to severe pain, 7% had mild pain and 5% had no pain. Among the 66 patients with moderate to severe pain, 32 (48.5%) received counterfeit tramadol, 3 (4.5%) legal tramadol, 1 (1.5%) transdermal fentanyl and 35 (54.5%) did not receive any opioids. For the whole group of patients, the only factor associated significantly with the use of counterfeit tramadol was having moderate to severe pain (p=0.006).

**Conclusions:** The new restrictive regulations did not limit access to the trafficked counterfeit tramadol which may harm cancer patients rather than benefiting them. On the other hand, the regulations limited significantly the access of suffering cancer patients to legal tramadol and other opioids. The tramadol restrictive regulations should be revised to improve the accessibility of cancer patients to legal tramadol.

**Abstract number:** P145  
**Abstract type:** Poster  
**Definitions, Assessment Tools and Outcome Measures of Clinical Trials Regarding Opioid-induced Constipation: A Systematic Review**  
Siemens W., Gärtner J., Camilleri M., Drossman D.A., Webster L., Becker G., Jors K.  
1University Clinic Freiburg, Department of Palliative Care, Freiburg, Germany, 2Mayo Clinic, Clinical Enteric Neuroscience Translational and Epidemiological Research, College of Medicine, Rochester, MN, United States, 3University of North Carolina School of Medicine, Center for Functional GI and Motility, Chapel Hill, NC, United States, 4American Academy of Pain Medicine, CRI Lifetree, Salt Lake City, UT, United States, 5University Clinic Freiburg, Freiburg, Germany

**Background:** Opioid-induced constipation (OIC) is a frequent and burdening symptom in patients treated with opioids but consensus recommendations for the conduction of OIC trials are deficient.

**Aim:** To identify definitions and outcome measures for OIC used in clinical trials and Cochrane Reviews to develop a (i) common definition and (ii) recommendations for relevant outcomes.

**Methods:** In a systematic review, five databases (MEDLINE, PubMed, The Cochrane Library, Web of Science and EMBASE) were screened for clinical trials assessing OIC in adult patients or healthy volunteers. Studies published between 1993 and August 2013 were included.

**Results:** Of a total of 1488 studies 47 were included in the analyses. A minority of the publications (n=16, 34%) provided a definition for OIC. The definitions were highly variable and the recent history of opioid therapy was not frequently part of the definition (n=6, 38%). Seventeen (37%) trials relied exclusively on the assessment of objective measures. Another 17 (37%) studies additionally included patient-reported outcomes (PROMs). Few trials (n=7, 15%) assessed the patient-reported burden of OIC.

**Conclusion:**

(i) **Definitions:** A future consensus definition should contain (a) a basic set of objective measures (e.g. stool frequency), (b) ≥1 OIC-relevant PROMs (e.g. ease of defecation), (c) ≥1 burden
measures (e.g. constipation distress) and (d) the change of these measures since initiation of opiod therapy.

**(iii) Outcome measures:** Clinical trials on OIC should (a) always include key elements of the underlying definition, (b) integrate PROMs and (c) assess the patients’ burden of OIC. (d) Surrogate measures (e.g. stool consistency) should be used carefully since they do not capture the patients’ experience or burden.

Such standards are necessary to conduct patient-centered OIC trials and inevitable to compare trial findings by meta-analyses. An OIC definition and a set of suitable outcome measures are suggested in the manuscript.

The authors Siemens, W. and Gärtner, J. contributed equally to this work.

**Abstract number:** P146  
**Abstract type:** Poster  
A Study to Explore which Constipation Symptoms Predict Satisfaction with Management of Constipation and which Exacerbate the Impact of the Problem on the Individual  
*Clark K.¹, Byfieldt N.²*

¹Calvary Mater Newcastle, Palliative Care, Waratah, Australia, ²Calvary Mater Newcastle, Palliative Care, Newcastle, Australia

**Background:** Chronic constipation, a symptom- based disorder, requires 3 or more specific symptoms without laxatives including straining to pass hard, infrequent bowel actions without a sense of complete evacuation. After commencing laxatives, even when regularly passing soft stool with laxatives, some symptoms may persist. This work aims to consider if experiences of palliative care patients are similar and to determine which factors predict satisfaction or the person to be bothered.

**Methods:** A prospective study of constipated palliative care patients was conducted. Participants completed a 14-day bowel diary detailing laxatives, stool frequency and form, straining, sense of complete evacuation, management satisfaction and the degree of bother they had. Data was analysed with descriptive statistics, correlations and regression analysis.

**Results:** 50 people participated taking 1.87 (SD ± 0.87) classes of laxatives daily resulting in 8.22 bowel actions per week (SD +/- 3.71). Strong evidence supported correlations between laxatives and passing bowel actions (χ² = 5.86; p=0.016). No significant relationship between stool form and laxative use (χ² = 3.66; p=0.161) or between laxative use and straining (χ²= 2.10; p=0.147) was noted. The relationship between stool form and straining was significant (χ² = 64.44; p< 0.001). Regression analyses concluded that in the first week regularly experiencing a sense of complete evacuation impacted people’s satisfaction with constipation management (χ² 12.12; p=0.005). The degree to which people felt they had to strain impacted the degree to which people perceived their constipation was bothersome (week 1: χ² =14.38; p=0.001, week 2: χ² =3.75; p=0.053)

**Interpretation:** Like the chronically constipated, constipated palliative care patients continue to experience symptoms despite passing regular, soft bowel actions. In particular, the need to strain to pass bowel actions seems make the problems seem more bothersome.

**Abstract number:** P147  
**Abstract type:** Poster  
Chemotherapy Associated Oral Problems in Non Head and Neck Cancer Patients  
*Wilberg P.¹, Hjermstad M.J.²,³, Ottesen S.¹,², Herlofson B.B.¹*

¹Faculty of Dentistry, University of Oslo, Dept. of Oral Surgery and Oral Medicine, Oslo, Norway, ²Oslo University Hospital, Ullevål, Regional Centre for Excellence in Palliative Care, Department of Oncology, Oslo, Norway, ³Norwegian University of Science and Technology (NTNU), European Palliative Care Research Centre, Faculty of Medicine, Trondheim, Norway

**Context:** Chemotherapy induces a wide array of acute and late oral adverse effects which makes symptom alleviation and information an important part of patient care.

**Aims:** To assess the prevalence and intensity of oral problems in outpatients receiving chemotherapy for cancers outside the head and neck region, and to investigate if information about possible oral adverse effects was received by the patients.

**Methods:** Outpatients coming for scheduled chemotherapy at the Cancer Centre, aged 18 years or above were invited to participate and included if they fulfilled the inclusion criteria. All patients completed the Edmonton Symptom Assessment System (ESAS), underwent a semi-structured interview and an oral examination conducted by a dentist.

**Results:** Of 226 eligible patients 155 (69%) participated. Mean age was 57 yrs (SD 11.8), 34% were males. Breast (45%) and gastro-intestinal cancers (37%) were the most prevalent diagnoses. Xerostomia was reported by 59%, taste changes by 62%, oral discomfort by 41%, and 27% had problems eating. Fatigue (48%) and xerostomia (37%) were the most prevalent bothersome symptoms on the ESAS (score >3). Oral discomfort was not related to the number cycles received prior to the assessment, but with the total number medications (p=0.01). Twenty-seven percent confirmed that they had received information on oral adverse effects of cancer treatment. Patients reporting oral
discomfort were significantly less satisfied with the information received (p=0.01)

**Conclusions:** Oral problems were frequently reported by patients. Less than one-third of the patients remembered receiving information about oral problems associated with chemotherapy. Re-information on oral adverse effects during cancer treatment is needed. Patients should be instructed on how to optimize their oral health during and after chemotherapy.

**Abstract number:** P148
**Abstract type:** Poster

**“Struggling for Normal in an Instable Situation”: Family Caregivers’ Self-management in Palliative Home Care - A Meta-synthesis**

*Kreyer C.¹, Pleschberger S.²*

¹Health and Life Sciences University - UMIT, Department of Nursing Science and Gerontology, Hall in Tyrol, Austria, ²Health and Life Sciences University - UMIT, Department of Nursing Science and Gerontology, Vienna, Austria

**Background:** Family caregivers play a key role in palliative home care for persons with advanced cancer. Although research has shown numerous burdens and strains of family caregiving, there is a lack of family-oriented support strategies in palliative home care. Research in cancer as a chronic illness frequently refers to the concept of self-management and this may also well apply to the context of palliative care. However there is little work on family caregivers’ self-management in palliative home care so far. Qualitative research provides insight into families’ perspectives of the transition to and management of palliative care at home and can be used as a starting point.

**Aim:** The aim of the study was to increase knowledge of family caregivers’ self-management in palliative home care by synthesizing evidence from qualitative research.

**Methods:** Based on a systematic review of literature a meta-synthesis was conducted following the approach of Noblit and Hare. A total of 13 qualitative studies from six countries, published from 2002 onward, formed the basis for an interpretative synthesis.

**Results:** Caring for a person with advanced cancer at the end of life at home is characterized by an instable transition process in which families are “struggling for normal”. Six different family self-management strategies were identified to deal with this: acknowledging the transition, restructuring everyday life, maintaining balance in family relationships, taking responsibility for care, using social support, and acquiring caring-skills.

**Conclusion:** Focusing family self-management strategies allows better referring to resources and problem solving skills of families. Self-management may provide a key for supporting family caregivers in palliative home care.

**Abstract number:** P149
**Abstract type:** Poster

**The Experience of Living with and Caring for Someone with Dementia at the End of their Life**

*Davies N., Maio L., Rait G., Iliffe S.*

University College London, Research Department of Primary Care and Population Health, London, United Kingdom

The demise of the Liverpool Care Pathway in the UK was due to families describing their experiences of poor end of life care in the British national press. Family opinions of care are therefore crucial to the construction of any replacement of the Liverpool Care Pathway. This study aimed to explore the experience of families at the end of life of someone with dementia, and their views of quality end of life care.

Forty six in-depth interviews with bereaved and currently caring family carers of people with dementia were conducted in the UK. Interviews were recorded and transcribed verbatim and analysed using thematic and narrative analysis methods.

Preliminary findings demonstrate management and leadership of care teams is vital and often the lacking of strong leadership in care homes meant quality of care was compromised. Some believed that their relatives were at a disadvantage when they died on the weekend, in particular struggling to reach GPs and unable to access pain medication. Several carers described how professionals depicted them as negligent or criminal. For example when a GP who was called to the family home because the person with dementia had died made accusations against the carers, or when families felt judged by care home staff because they wanted their relatives suffering to be over.

Finally, there appeared to be opacity not transparency about care at the end of life, with families confused by what care should be provided, in particular with the Liverpool Care Pathway.

This rich array of views from families of people with dementia shows that the role professionals’ play is vital either through managing the care team, or working with families to relieve and reduce guilt that they may already be feeling. Our results confirm what the review of the Liverpool Care Pathway. This study aimed to explore the experience of families at the end of life of someone with dementia, and their views of quality end of life care.

**Abstract number:** P150
**Abstract type:** Poster

**Implementation of a National End of Life Care Audit and Review System: Lessons Learned**

*McLoughlin K.E.¹, Lovegrove M.¹, McKeown K.², Ryan K.³*

1Primary Care and Population Health, London, United Kingdom, 2University College London, Research Department of Primary Care and Population Health, London, United Kingdom, 3University of Manchester, Faculty of Medicine, Health and Social Care, Greater Manchester”
Background: A National End of Life Care Audit and Review System has been developed and piloted to review the deaths of more than 140 people in Ireland, in all settings where people die. The system enables staff and bereaved relatives to review and reflect upon end of life care across eight, evidence based domains.

Aim: The aim of the pilot was to test the audit and review system, with a view to documenting the pilot process and experiences and identifying emerging issues to be considered in advance of national implementation.

Method: A mixed methods approach was utilised to enable the system to be tested. This included

1. the comparison of data from 140 staff reviews, 59 bereaved relatives and 23 independent assessments of care;
2. observation of audit and review meetings with staff;
3. questionnaires examining the experience of audit facilitators;
4. cognitive testing of the tools with healthcare staff using the QAS; and
5. focus groups and one-to-one interviews with audit managers and facilitators.

Results: The system appears to be feasible and recognised as useful, particularly by healthcare teams providing end of life care in hospitals and in residential care settings. A modified tool is required to review deaths in the home and hospice. Areas were identified where the validity of the tool could be improved through changes in language and the provision of additional definitions. Internal consistency of the tool could be improved if consideration is given to a separate tool for the review of sudden deaths. The qualitative feedback from bereaved relatives was considered powerful by healthcare staff and is potentially the biggest driver of quality improvement.

Conclusion: The pilot findings have contributed to the development of v19.0 of the National End of Life Care Audit and Review System. This includes a new tool for reviewing sudden deaths and a facilitator training programme. The system is a public good, available for international use.

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Abstract number: P151
Abstract type: Poster
Impact of a Home-based Social Welfare Program on Care for Palliative Patients in the Basque Country (SAIATU Program)
Herrera E.1, Nuño R.2, Cabrera A.3, Librada S.1, Rodriguez-Pereira C.2, Orueta J.F.3, Hasson N.4

Abstract number: P152
Abstract type: Poster
Changes in Sense of Dignity over the Course of Illness: A Longitudinal Study into the Perspectives of Seriously Ill Patients
van Gennip I.E.1, Pasman R.1, Oosterveld-Vlug M.1, Willems D.2, Onwuteaka-Philipsen B.1

1The Irish Hospice Foundation, HFH, Dublin, Ireland, 2C/O The Irish Hospice Foundation, HFH, Dublin, Ireland, 3HSE, Palliative Care Clinical Programme, Dublin, Ireland, 4NewHealth Foundation, Sevilla, Spain, 5O+berri, Basque Institute for Healthcare Innovation, Basque Country, Spain, 6Saiatu Program Coordinator, Guipúzcoa, Spain

SAIATU is a program of specially trained in-home social assistance which provided support to end-of-life patients (Guipúzcoa, Spain).

Objective: To analyse whether a program of social intervention in PC results in a reduction in the consumption of healthcare resources and cost by end-of-life patients and promotes a shift towards a more community-based model of care.

Method:
1. Retrospective study to determine the baseline risk of consumption of resources (population of patients who die from malignant neoplasm) characterised, by primary diagnosis and age, the behaviour of different malignant neoplasms, with regard to resource consumption: number of visits to or consultations with Primary Care, n. of external consultations, n. of visits to hospital emergency departments, n. of hospital admissions, average length of stay, and days in home hospitalisation.
2. Study of Prospective cohorts (April-Sep 2013, results will be presented at the congress). Exposed cohort: patients attended by SAIATU, without prejudice to the care received from the public health system; Control cohort: patients cared for exclusively through the public health system.

Results: 18,024 people dying from malignancy (2008-2011). Mean age: 72.2. 66.4% were men, 65.4 % died in hospital. The average cost per patient was € 12,172 and € 12,377 for the past 3 months and 1 month before death respectively. Hospitalization consumed 94.2% of the cost of all services in the last 3 months, 95.2% 1 month before death.

The use of health services in their last month of life over the past 3 months was 65.6 %. The average days use for income, emergencies and consultations per patient was 24.8 and 13.5 (3 and 1 month before death, respectively).

Discussion: The results of this prospective study will assist in verifying or disproving the hypothesis that the in-home social care offered by SAIATU improves the efficiency of healthcare resource usage by these patients (quality of life, symptom control).
**Background:** Loss of personal dignity in seriously ill patients is associated with psychological suffering and loss of the will to live. Therefore preservation of a sense of dignity in the ill should be a primary concern throughout the whole illness trajectory from diagnosis onward. However, there is limited insight into the dynamics of patients’ sense of dignity during the progression of illness.

**Aim:** This longitudinal qualitative study investigates patients’ experiences with dignity over time in a diverse patient population (cancer, early-stage dementia and severe chronic illnesses).

**Method:** Twenty-four patients were interviewed yearly (max. 4 years). In total, 64 interviews were conducted. Data were analyzed making use of thematic analysis.

**Results:** Patients were remarkably consistent over time in their ideas on what dignity entails, for example the need to remain autonomous. However, the sense of dignity of most patients fluctuated over time. Three dynamics were distinguished: (a) episodic: temporary decline, or increase, in sense of dignity due to certain events (such as feeling drained after chemotherapy, not being treated seriously as a patient or feeling of use to others) followed by a return to a previous level of self-perceived dignity; (b) gradual slope: a gradual more permanent decline or increase in sense of dignity due to for example losses in functional ability or finding new meaning in live; and (c) stability: a stable level of sense of dignity despite a decline in condition due to the ability to accept or adjust to this new condition.

**Conclusion:** Ideas on what dignity encompasses are rather stable over time, but patients’ sense of dignity appears to be prone to fluctuations depending on circumstances in most patients. It is important that caregivers are aware of factors and events that can potentially diminish or enhance patients’ sense of dignity so they can provide dignity sustaining care.

**Major source of founding:** P. van Foreeststichting, NVVE, NPV.

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**Abstract number:** P153
**Abstract type:** Poster

**Dementia Palliative Care: ZULIDAD - Zurich Life and Death with Advanced Dementia Study**

_Spring A., Eicher S., Martin M., Wolf H., Riese F., ZULIDAD Study Group_

University of Zurich, Zurich, Switzerland

Despite growing numbers of people dying with advanced dementia and the need to improve their end-of-life care, important gaps remain in our understanding of the expectations and requirements regarding palliative care for people dying with advanced dementia in Switzerland.

**Aims:** ZULIDAD aims to provide data on the quality of life, the quality of care, the satisfaction with care among family members of nursing home residents with advanced dementia during the last phase of life, as well as on the dying phase of these residents.

**Methods:** ZULIDAD consists of a longitudinal study of nursing home residents with advanced dementia (n=200), gathering observational data in four selected nursing homes in Zurich during three years. Data from extensive questionnaires for family members and primary nurses at baseline, every three months and post-mortem, as well as RAI-MDS (Resident Assessment Instrument Minimum Data Set) data is entered into data analysis, which includes standard descriptive analysis and group comparison techniques; regression models, multilevel models, latent growth models and trajectories analysis (e.g., growth mixture models). A Round Table consisting of three stakeholder groups (family members, experts and researchers), serves as a supervising instrument and provides a participative decision-making basis for strategic and scientific questions.

**Results:** Key scales in dementia palliative care translated and questionnaires extensively piloted. Publications on baseline results expected in 2014.

**Conclusions:** ZULIDAD is the most comprehensive study on quality of life, quality of care, and of satisfaction with care as well as the dying process for nursing home residents with advanced dementia in Switzerland. The results of this longitudinal study will provide families, health care professionals and policy makers with sound data on which to base palliative care decisions.

**Main sponsor:** Swiss National Science Foundation

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**Abstract number:** P154
**Abstract type:** Poster

**Child and Family Caregiver Perceptions of the Symptom Experience for Children with Advanced Cancer: A Qualitative Study**

_Zhukovsky D.S.1,2, Rozmus C.L.3, Robert R.2, Bruera E.1, Wells R.J.2, Guerra G.R.4, Alto J.1, Cohen M.Z.5_

1The University of Texas MD Anderson Cancer Center, Palliative Care and Rehabilitation Medicine, Houston, TX, United States, 2The University of Texas MD Anderson Cancer Center, Pediatrics-Patient Care, Houston, TX, United States, 3The University of Texas Health Science Center, School of Nursing, Houston, TX, United States, 4The University of Texas MD Anderson...
Cancer Center, Breast Medical Oncology, Houston, TX, United States, ²The University of Nebraska Medical Center, College of Nursing, Omaha, NE, United States

Aim: For children living with cancer, symptom (sx) assessment frequently relies upon proxy reports of family caregivers (FCG). This qualitative study was conducted to describe child and FCG perceptions of the sx experience to better understand: 1. the context and meaning of sx for each and 2. factors associated with differences in sx perception.

Study population: 10 dyads of FCG and child with advanced cancer attending an outpatient pediatric oncology clinic of a comprehensive cancer center.

Study design and methods: Children and FCG participating in a larger sx assessment study based on English and Spanish versions of the pediatric Memorial Symptom Assessment Scale were invited to participate, until accrual goal for each age/language group was achieved. Phenomenological, semi-structured interviews were conducted with dyad members separately.

Analysis: Transcripts (N=20) were analyzed hermeneutically by the interdisciplinary research team until consensus on theme labels was reached.

Results: Median child age was 11 years (7-17), with 7 males. Language of interview was Spanish in 3 dyads. All children had at least 1 sx. Four themes were identified from the interviews of the children, adolescents and their parents: 1. life is different, 2. coping strategies, 3. symptoms as a path to diagnosis, and 4. fear and belief that death is not for children. Saturation of themes was achieved. There were no differences in sx perception between children and their FCG.

Interpretation: Children and their FCG spoke more to the disruption of their lives caused by sx, rather than to the physical and psychological manifestations. Understanding these effects may help health care professionals to provide optimal supportive care. Prospective studies providing further clarification of the themes elucidated in this study are indicated to provide a more in-depth understanding of the issues, in order to better tailor support to patient and family need.

PEP 08-272-01-PC1 American Cancer Society

Abstract number: P155
Abstract type: Poster

Hospitalisations at the End of Life: A Cross-national, Population-based Mortality Followback Study via Nationwide Representative Epidemiological Surveillance Networks

Pivodic L.¹, Pardon K.¹,², Miccinesi G.³, Vega Alonso T.⁴, Moreels S.⁵, Donker G.⁶, Arrieta E.³, Onwuteaka-Philipsen B.³, Deliens L.¹,³, Van den Block L.¹,³, EURO IMPACT

¹Vrije Universiteit Brussel & Ghent University, End-of-life Care Research Group, Brussels, Belgium, ²Hasselt University, Department of Behavior, Communication and Linguistics, Diepenbeek, Belgium, ³Cancer Prevention and Research Institute, ISPO, Florence, Italy, ⁴Public Health Directorate, Junta de Castilla y León, Valladolid, Spain, ⁵Scientific Institute of Public Health, Public Health and Surveillance, Brussels, Belgium, ⁶Netherlands Institute for Health Services Research, Dutch Sentinel General Practice Network, Utrecht, Netherlands, ⁷Health Center of Segovia Rural, Segovia, Spain, ⁸VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands

Aims: Hospital admissions towards the end of life may indicate a low quality of dying. Yet population-based data on hospital use at the end of life are scarce. We aimed to describe and compare the frequency, length and timing of acute hospital admissions in the last three months of life in Belgium (BE), the Netherlands (NL), Italy (IT) and Spain (ES).

Method: Cross-national, population-based mortality followback study via nationwide representative epidemiological surveillance networks of general practitioners (GPs). Using a standardised form, GPs recorded the care in the last three months of life of every deceased adult practice patient (01/01/2009-31/12/2011). Nursing home deaths from the NL (6%) were excluded as they are not attended by GPs. Analysis involved descriptive statistics, chi-squared tests and multivariate logistic regression analysis.

Results: We studied 7,209 deaths. In BE, NL, IT and ES, 53%, 48%, 51% and 52% of patients, respectively (p<.001, adjusted for differences in age, sex, cause of death), were hospitalised at least once in the last three months of life, for median 14 days (inter-quartile range (IQR) 6 to 25) in BE and median 10 days in the other countries (IQR 3 to 20 in NL; IQR 5 to 20 in IT and ES). Thirty days before death BE revealed nearly twice as many patients in hospital (13%) as NL (7%), IT and ES (both 6%), but this difference decreased towards the day of death. All countries revealed a steep increase in the percentage of hospitalised patients over the last 10 days of life (21% to 37% in BE, 15% to 29% in NL, 16% to 37% in IT, 14% to 31% in ES).

Conclusions: Across countries, and particularly in Belgium, hospital care in the last three months of life is highly prevalent and increases considerably in the final days of life, suggesting an institutionalised nature of dying. Differences between countries may reflect differences in healthcare policy and end-of-life care practice.

Abstract type: Poster

Mobile Information Technology in Cancer Symptom Assessment

Thomas S.1,2, Aktas A.1,2, Shrotriya S.1,2, Walsh D.1,2, Estfan B.1

1Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Cleveland, OH, United States, 2Cleveland Clinic, The Harry R Horvitz Center for Palliative Medicine, Cleveland, OH, United States

Introduction: Appropriate utilization of tablet computers (TC) may streamline health service provision. The portability, touch interface and resolution of iPads (© 2013 Apple Inc, Cupertino, California) seems attractive for electronic symptom assessment.

Objectives:

1. Assess TC (iPad) acceptability for electronic symptom and quality of life (QOL) self-assessment in Solid Tumor Oncology Outpatients
2. Capture symptom profile at Cancer Center Outpatients

Methods: Eligible participants were given TC electronic symptom assessment instrument at their first visit. The questionnaire (17 symptoms; 17 QOL) was adapted from the European Palliative Care Research Collaborative-Computerized Symptom Assessment (EPCRC-CCA). Responses were simultaneously, wirelessly downloaded to REDCap (Research Electronic Data Capture; REDCap Software - Version 5.1.3 - © 2013 Vanderbilt University) a secure online database. Printed results with concerned items flagged were given to the Oncologist before the participant encounter.

Results:

I. Survey

- Screened 348; Eligible 174; Participants 107
- Completion rate 98% (65% self completed; 68% completed easily)
- Completion time: mean (SD) 10 (2.6) minutes without any clinic time delay

II. Demographics

- Age: median (range) 64 (23-95) yrs
- Males 65%; College education > 4yrs 17%
- Cancer diagnoses:39% digestive; 26% genitourinary; 16% respiratory, 51% metastatic

III. Symptoms

- Pain: 35 % score ≥ 4; 20% ≥ 8
- Depression: 14 % nearly every day; 20% clinically significant; 33% moderate-severe anxiety
- Others: 48% tiredness; 42% decreased food intake; 38% poor appetite; 28% drowsiness; 15% SOB
- QOL 24% poor; 43% wellbeing affected

Conclusions:

1. Electronic symptom assessment instrument in oncology outpatients practical and quick (completion rate 98%; self-completed 65%; mean completion time 10 minutes)
2. TC acceptable in an elderly symptomatic population group (68% done easily)
3. Participants had significant symptom burden even at first Cancer Center visit.

Abstract number: P157

First Steps in Classifying Integrated Palliative Care Approaches - The Criteria for Analysis

Hodiamont F.1, Dybek E.1, van Wijngaarden J.2, Radbruch L.1

1Universitätsklinikum Bonn, Klinik für Palliativmedizin, Bonn, Germany, 2Erasmus Universiteit Rotterdam, Institut Beleid & Management, Rotterdam, Netherlands

Objective: Different models have been advocated to facilitate integration of palliative care (PC) into other medical fields. As part of an EU-funded project a taxonomy on integrated palliative care (IPC) interventions is being developed.

Methods: Existing models, guidelines and pathways are identified in a systematic review, grey literature search, expert interviews and an online survey. A first set of characteristics was identified from an analysis of three established IPC interventions (LCP, PCAD, Amber Care Bundle). The set was tested against six interventions from Germany and six from the UK identified in the grey literature.

Results: The set of characteristics covered: Type of initiative (pathway, model, guideline), aims/key themes, type of intervention (clinical care, education, etc.), coordination strategy, setting (hospital, hospice, nursing home, community), urban/priurban/rural context, integrational structure of model, target group, disease, prognosis on which intervention starts, referral pathway, inclusion of quality assessment, guidelines/best practice used, covered PC key domains, stakeholders involved, interface of integration, resources needed for implementation, Intervention is tested/piloted, implementation Strategy, funding.

No additional criteria were identified in the analysis of the 12 interventions (7 models, 3 pathways, 2 guidelines). The sources did not provide information on all characteristics. Information was particularly lacking for coordination strategy, referral pathway, quality assessment included, and guidelines/best practices underlying intervention.

Conclusions: The set is considered to be sufficiently detailed as no additional characteristics emerged in the analysis of the IPC interventions. Lacking information details
Use of Quality Indicators across Settings and Countries (Results from Pretest, Quantitative)

Jaspers B.¹, Radbruch L.¹, Grammatico D.¹, Davies N.¹, Iliffe S.², Sommerbakk R.³, Kaasa S.⁴, van Riet Paap J.⁵, Vernooij-Dassen M.⁶, Engul Y.⁷, Mariani E.⁷, Chattat R.⁷, on behalf of the IMPACT Study Group

¹University of Bonn, University Hospital, Department of Palliative Medicine, Bonn, Germany, ²Malteser Hospital Bonn/Rhein-Sieg Germany, Centre for Palliative Medicine, Bonn, Germany, ³University College London, Department of Primary Care for Older People, London, United Kingdom, ⁴Norwegian University of Science and Technology (NTNU), Faculty of Medicine, Trondheim, Norway, ⁵Radboud University Nijmegen Medical Centre (RUNMC), Scientific Institute for Quality of Healthcare, Nijmegen, Netherlands, ⁶Radboud University Nijmegen Medical Centre (RUNMC), Department of Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands, ⁷University of Bologna, Department of Psychology, Bologna, Italy

Background and aim: The overall aim of the IMPACT study is to develop strategies for the implementation of quality indicators (QI) to improve the organization of palliative cancer and dementia care in Europe. For this purpose, the literature was systematically searched for organizational QI in palliative care (PC). A set of QI was derived using a RAND Delphi. This abstract presents quantitative results from a pretest on the use of the selected set of 25 QI among services across 5 European countries (England, Germany, Italy, the Netherlands and Norway).

Methods: A questionnaire covering the consented and operationalised QI was developed by the 5 national researchers and translated in the resp. languages. Purposefully selected participating services (nursing homes, hospital services, hospices and primary care services) were given access to an online questionnaire (limesurvey). The questionnaire was introduced to the participating teams by experienced consultants. After feedback of the results, data sets were cleaned for errors/wrong entries.

Results: The pretest was completed by 37 services. For most a specialised PC team is accessible (25); only 3 didn’t have access to expert advice in PC. Even though many services offered bereavement support to patient families and team members, standardised procedures were often lacking. 24/7 availability of opioids and coanalgesics was given in most services (30/29). 27 services timely provided intense information in case of patient transfers or offered their patients assigned contact persons (key worker etc.) (23). Only few (6) didn’t have single bedrooms for dying persons. All services had unrestricted visiting hours and facilities for relatives to stay overnight.

Conclusion: The QI indicators instigated lively discussions of organisational improvement needs and on the applicability of the QI set in the surveyed services. Most indicators were found useful.

Abstract number: P158
Abstract type: Poster

Description of a Teaching Method for Research Education for Palliative Care Health Care Professionals

Rhondali W.¹,², Nguyen L.³, Peck M.³, Vallet F.⁴, Daneault S.⁵, Filbet M.⁶

¹Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, ²MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, ³Cancer Center at Memorial Hermann Hospital, Hospices and Palliative Care, Houston, TX, United States, ⁴Centre Hospitalier William-Morey, Palliative Care, Chalon-sur-Saône, France, ⁵Centre Hospitalier de l’Université de Montréal, Palliative Care, Montreal, QC, Canada

Background: Although the availability of palliative care services is growing rapidly there is still much to do to better support clinicians who are starting a research program. Among the barriers identified in the literature, methodological issues and lack of research training programs are often reported. Our aim is to describe an educational research method to for healthcare professionals working in palliative care and to report the result of a survey conducted among a three-year sample of students.

Methods: The course was provided for a multidisciplinary group, open to all healthcare professionals involved in palliative care. It took place over a single session during a full day. We used a 20-question e-survey to assess students’ outcomes (e.g. satisfaction, current status of their project).

Results: We received 83 answers out of 119 (70%) students that took the course. The majority were physicians (n=62, 75%) followed by nurses (n=17, 21%). During the class the students assessed the role of the teacher as information provider (n=51, 61%), role model (n=36, 43%) and facilitator (n=33, 40%) and considered all of these roles as suitable with a score of 3.9 to 4.7 out of 5. Participants reported a high level of support from the teacher with a mean score of 8.2 (SD, 1.7) out of 10 and good overall satisfaction with a mean score of 7.6 (1.8). Finally, 51 (77%) participants were able to start their research project.
after the class, 27 (41%) to complete it and eight (12%) to submit their research to a journal or to a conference.

**Conclusion:** Our results suggest that newer teaching methods such as role-play, group work, and target acquisition are feasible and effective in a palliative research curriculum. Additional studies are needed to confirm the objective outputs of educational interventions including research outputs.

**Abstract number:** P160
**Abstract type:** Poster

**Workplace Learning: Doctors Learning from Nurses**

Pype P.F., Mertens F., Deveugele M.

Ghent University, Ghent, Belgium

**Aims:** In Belgium, general practitioners (GPs) collaborate with nurses from specialized palliative home care teams (PHCTs) in caring for their palliative patients. Previous research indicates GPs’ learning from these nurses during collaboration (workplace learning). It is not known how GPs experience the ‘identity of a learner’ during this collaboration. We aimed to explore the experiences and preferences of GPs in learning from nurses.

**Methods:** 20 semi-structured interviews with GPs. Content analysis was done by two researchers.

**Results:** Main facilitators for GPs’ learning from nurses were the trust in the nurses’ expertise, the realization of one’s own limitations as a GP, and the possibility to put theory into practice in a supervised way. Main barriers to take up the identity of a learner were lack of clarity on roles and responsibilities (e.g. hesitation from GP on whether he has to learn about emotional support of the family or whether he should delegate this task to the nurses) and the GPs perception that patients and families expect GPs to be an expert.

**Conclusion:** General practitioners are mostly willing to accept the ‘identity of a learner’ during collaboration with PHCT nurses. Good working relationships and role clarity need to be established. Both nurses and GPs should pay attention to the teaching/learning aspect of collaboration to turn the ‘implicit learning’ more explicit and efficient.

**Abstract number:** P161
**Abstract type:** Poster

**How to Ask Terminally Ill Patients about their End-of-Life Preferences?**

Schou-Andersen M.¹, Ullersted M.P.¹, Brogaard T.², Jensen A.B.³, Neergaard M.A.⁴

¹Aarhus University, Aarhus, Denmark, ²Aarhus University, Research Unit for General Practice, Aarhus, Denmark, ³Aarhus University Hospital, Department of Onkology, Aarhus, Denmark, ⁴Aarhus University Hospital, Palliative Team, Aarhus, Denmark

**Introduction:** Meeting patients’ end-of-life preferences in relation to place of care (POC) and place of death (POD) is a main goal in palliative care. Studies have shown that patients’ preferences are likely to change when death approaches and can be influenced by practical issues and concerns for relatives. Therefore, discrepancies between the ideal situation and preferences influenced by other factors must be common.

**Aim:** The aim of this study was to investigate whether the way of asking changes the answer in relation to patients’ preferred POC and POD.

**Method:** Structured interviews among 96 terminal cancer patients were performed in 2008-2009 where terminally ill patients were asked two types of questions: Patients were asked about their preferences for POC and POD. Subsequently, they there asked about their preferences imagining an ideal situation where all patients’ and families needs were met. Descriptive statistics, agreement and kappa statistics were calculated.

**Results:** When asked about an ideal situation less patients preferred POC and POD to be at home and at hospice, respectively, compared to when they were asked about a situation reflecting reality. Also more patients were undecided when asked about the ideal compared to the actual situation. When comparing preferences for POC in the actual and ideal situation the congruence between answers was 77%, but kappa coefficients showed only moderate agreement (kappa: 0.54 (Confidence interval(CI):0.40;0.68)). Comparing preferences for POD the congruence between answers was 66% while the kappa coefficients again only showed a moderate agreement (kappa: 0.49 (CI:0.36;0.62)).

**Conclusion:** The study shows that wording of the question is essential when studying patients’ preferences for POC and POD. Asking two nearly identical questions after each other may also influence the answers. There is a need for further research on how to approach these crucial issues, both in a clinical and in a research setting.

**Abstract number:** P162
**Abstract type:** Poster

**Hospitalization or Home Care at the End of Life. The Experience in a Greek Home Palliative Care Service**


Palliative Care Unit Galilee of Holy Metropolis Mesogaia and Lavreotiki, Spata, Greece
Aim: The aim of the study is to explore factors associated with the cancer patients’ place of death.

Methods: The sample consisted of cancer patients receiving home palliative care from an interdisciplinary team from March 2010 to July 2013. Retrospective data collection included: demographic and clinical characteristics, patients’ ESAS-r (Edmond Symptom Assessment System Revised) evaluation of symptoms (Likert type 0-10 scale) at the time of referral to the service, 1 and 2 months later. SPSS 17.0 was used for statistical analysis.

Results: A total number of 237 cancer patients mostly female (51.5%) analyzed. Patients’ mean age was 67.3 years and ECOG performance status 2.8. The prevalent diagnosis was lung (19.8%) followed by gastrointestinal (19.0%) and breast cancer (18.1%). Almost half of them (48.9%) received antineoplasmatic treatment during home care. The husband/wife (39.7%) was the most frequent primary caregiver. The median patients’ length of care was 58 days and the median number of home visits was 13.5. Just 39.2% of patients were hospitalized during home care. The majority of patients (66.7%) died and 43.0% and 19.6% of them within the first and the second month respectively after referral to the service. Most of the patients (65.8%) chose to die at home and were supported to do so. Older patients ($\chi^2(2)=9.67, p=0.008$) and those with a family member primary caregiver ($\chi^2(12)=33.4, p=0.001$) preferred to die at home. On the other hand patients that died in hospital had more hospital admissions ($\chi^2(12)=33.4, p=0.001$). This proved to be true, regardless of the reasons of hospitalization ($p=0.496$). Finally none of patients’ symptoms during the two months of home care were associated with the place of death ($p=0.050$).

Conclusions: Study results highlight that regardless of late referral, a great number of patients were supported to die at home. Further research is needed to clarify reasons of hospitalization at the end of life. Study was funded by FP 8.

Abstract number: P163
Abstract type: Poster
Agitation, Interaction, Calmness, Consciousness or Motor Activity: What Are we Monitoring during Palliative Sedation?
Arevalo J.J., Zuurmond W.W.A., Perez R.S.G.M.
VU University Medical Center, Department of Anesthesiology, Amsterdam, Netherlands

Context: Comfort is the ultimate goal of palliative sedation but no observational scale has been designed to monitor this outcome. Existing instruments focus on different theoretical constructs of sedation and there is a lack of knowledge as to what they are actually measuring.

Aims: To investigate the factor structure of observational scales used to monitor palliative sedation.

Methods: We performed a confirmatory factor analysis using 311 concurrent measures using four scales designed to monitor agitation, interaction, calmness, consciousness and motor activity during sedation. Patients were monitored with these scales in the hospice setting during intermittent and continuous palliative sedation. The hypothesis that any scale used during palliative sedation would provide information on a factor called patient comfort was tested.

Results: The factors with largest correlations with the intention to achieve comfort in palliative sedation were consciousness (0.92, 95% CI 0.89-0.95), arousal (0.87, 95% CI 0.84-0.91) and interaction (0.76, IC 95% 0.70-0.81). Calmness, agitation and motor activity showed covariance and contributed little to patient comfort during palliative sedation.

Conclusion: Patient comfort seems to be a multifactorial outcome that can be monitored during palliative sedation but currently available scales focus only partially on its theoretical constructs. A scale designed to specifically monitor comfort should be developed with integration of the factors consciousness, arousal and interaction.

Abstract number: P164
Abstract type: Poster
Reversal of English Trend towards Hospital Death in Dementia. A Population-based Study of Place of Death and Associated Individual and Regional Factors, 2001-2010
Sleeman K.E., Ho Y.K., Verne J., Gao W., Higginson I.J., GUIDE_Care Project
1King’s College London, Dept of Palliative Care Policy and Rehabilitation, London, United Kingdom, 2Public Health England, Knowledge and Intelligence Team (South West), Bristol, United Kingdom

Background: England has one of the highest rates of hospital death, and lowest rates of home death, in dementia in Europe. How this has changed, particularly in response to national strategies, is unknown.

Aim: To analyse trends in place of death in dementia over a recent ten year period.


Population: Adults aged over 60 with a death certificate mention of dementia (n=388,899).

Measurements: Multivariable Poisson regression determined the proportion ratio (PR) for death in care home and home/hospice compared to hospital. Explanatory variables included individual (age, gender, marital status, underlying cause of death) and regional variables (deprivation, care home bed provision, urbanisation).

Abstract type: Poster
Agitation, Interaction, Calmness, Consciousness or Motor Activity: What Are we Monitoring during Palliative Sedation?
Arevalo J.J., Zuurmond W.W.A., Perez R.S.G.M.
VU University Medical Center, Department of Anesthesiology, Amsterdam, Netherlands

Context: Comfort is the ultimate goal of palliative sedation but no observational scale has been designed to monitor this outcome. Existing instruments focus on different theoretical constructs of sedation and there is a lack of knowledge as to what they are actually measuring.

Aims: To investigate the factor structure of observational scales used to monitor palliative sedation.
Results: Most people died in care homes (55.3%) or hospitals (39.6%). A pattern of increasing hospital deaths reversed in 2006, with a subsequent decrease in hospital deaths (-0.93% per year, 95% CI -1.08 to -0.79 p< 0.001), and an increase in care home deaths (0.60% per year, 95% CI 0.45 to 0.75 p< 0.001). Care home death was more likely with older age (PR 1.11, 1.10 to 1.13), in women (PR 1.16, 1.16 to 1.17), and in areas with greater care home bed provision (PR 1.82, 1.79 to 1.85) and affluence (PR 1.29, 1.26 to 1.31). Few patients died at home (4.8%) or hospice (0.3%). Home/hospice death was more likely in affluent areas (PR 1.23, 1.18 to 1.29), for women (PR 1.61, 1.56 to 1.65), and for those with cancer as underlying cause of death (PR 1.84, 1.77 to 1.91).

Conclusions: Two in five people with dementia die in hospital. However, the trend towards increasing hospital deaths has reversed, and care home bed provision is key to sustain this. Home/hospice deaths are rare. Patients without cancer diagnoses should be a focus for support.

Funding: NIHR HS&DR programme (project number 09/2000/58).

Abstract number: P165
Abstract type: Poster

Handing over the Baton? Near Misses/Errors in Patient Medication on Point of Admission to Hospice
O'Reilly V., Wright M.
Milford Care Centre, Limerick, Ireland

Medication errors are common & frequently underreported although limited research exists within hospice setting. Transition of patient care between community/acute interfaces is identified as a flashpoint.

To identify discrepancies in patients drug history on admission from community/acute hospital settings by reconciliation.

Review current practices relating to information transfer between interfaces with view to informing processes to ensure safe practice.

Patients were consecutively recruited on hospice admission over 19 day period. Medication reconciliation performed using 1 additional source identified variances in drug history or incidents of transcribing error. All variances underwent evaluation by applying an internationally recognized medication error index to quantify patient risk.

34 patients admitted within timeframe with 70.5%(n=24) originating from community setting. Reconciliation performed using patient own drugs (58.8%n=20) patient self-report (11.7%n=4) or available hospital prescription (17.6%n=6) identified variances in prescription history in 44.1% (n=15). Further transcribing errors occurred in 17.6% (n=6) 28 variances identified amongst 20 patients encompassed incorrect medication dose (n=12) medication omission (n=10) or inappropriate inclusion (n=6). Evaluation of variances using National Coordinating Council Medication Error Reporting & Prevention (NCC MERP) index categorized the majority under B-C or D (error no harm) with a minority (10.7%n=3) categorized as E (Errorharm). Inaccuracies involving high alert medication were identified in 7 cases. Suboptimal documentation between interfaces was evident.

Near misses and errors in drug history or initial prescribing occur frequently within studied cohort with higher than anticipated rates. Absent, incomplete or non-contemporaneous transfer documentation may be a factor although erroneous prescribing contributes. Ongoing clinical governance activity to implement robust systems to minimize potential error are under development.

Abstract number: P166
Abstract type: Poster

Kia Ngawari Study: An Indigenous Perspective of Palliative Care
Moeke-Maxwell T.H.
University of Auckland, School of Nursing, Auckland, New Zealand

Research aims: To explore the palliative care needs of New Zealand Māori adults and their whānau (family) carers during the illness trajectory, dying and bereavement period from a cultural perspective.

Study population: 26 whānau groups.

Study design and methods: Ethnographic methods using a kaupapa (indigenous) Māori research design provided the frame for the study. Face to face interviews investigated 26 Māori adults’ end of life experiences with a particular focus on their cultural needs and the needs of their whānau carers. A further six case studies spanned up to two years and included bi-weekly interviews and written/photo journaling.

Analysis: Kaupapa Māori (indigenous) research methods informed the analysis supported by a social constructivist analytical approach.

Results and interpretation: Māori whānau carers drew on cultural beliefs associated with tribal practices of aroha (love and concern), manaakitanga (protection of mana (dignity/respect) and whanaungatanga (relationships and connections) to provide quality care to the ill and dying. Cultural and spiritual beliefs and practices influence bereavement recovery. Smaller family compositions, geographical displacement from tribal homes and whānau dependant on low incomes or state assisted benefits contributed to changes in traditional whānau community care approaches. Unless whānau had prior positive experience of using palliative care services these were underutilised. Whānau often struggled to manage caregiving demands.
Low health and palliative care literacy must be considered within a framework of colonialism. New Zealand’s health and palliative care sectors could increase their capacity to inform and support whānau to access and navigate palliative care and psychosocial support within their communities to support quality end of life care. **Funding:** Health Research Council of New Zealand, contract 10/037 ($340,000).

**Abstract number:** P167  
**Abstract type:** Poster  
**To Explore Nurses’ Attitudes to and Knowledge of Palliative Care for Patients with Chronic Obstructive Pulmonary Disease**  
*Cronin A.M.*, Landers M.*

1University Collage Cork and Bons Secours Hospital Cork, Co. Cork, Ireland, 2University Collage Cork, Nursing, Cork, Ireland

**Aim:** To explore nurses’ attitudes to and nurses’ knowledge of palliative care for patients with COPD.

A qualitative descriptive research approach with a purposive sample of ten acute medical nurses was used. Semi-structured interview questioning was adopted. Data were organised according to pre-determined categories, these were then sorted into themes.

The chronic, unpredictable nature of COPD and the ‘stress’ of nursing a patient with COPD was noted. Disease staging could guide care but could also ‘label’ patients. Nurses’ attitudes supported more individualised care. Palliative care was emotionally difficult. Nurses felt more specialised education regarding COPD and palliative care was needed. Multidisciplinary team (MDT) co-operation was beneficial.

Palliative care for COPD is internationally supported by the EAPC, The American Thoracic Society and The European Respiratory Society (2004) and the Global Initiative for COPD (2013). However, only 65.4% of inpatients with COPD in Ireland use palliative care services (Irish Thoracic Society, Health Service Executive and Irish College of General Practitioners 2008). Findings of this research will aid the development of a holistic individualised patient care delivery system. Areas of nursing practice that need to be addressed include support for the ‘stress’ of nursing chronic illnesses and the emotional difficulty of providing palliative care. Specialised in-service education also needs to be addressed to support care delivery systems. The benefits of MDT co-operation and the impact of disease grading should be explored further. These will aid nurses implement international and national recommendations in support of palliative care for patients with COPD (Irish Hospice Foundation, 2008; GOLD 2013).

**Abstract number:** P168  
**Abstract type:** Poster  
**Pharmacological Treatment for Cancer Pain in Catalonia: Adequacy of Treatment and Patient Satisfaction**  

1Institut Català d’Oncologia, IDIBELL, Palliative Care Service, L’Hospitalet de Llobregat, Spain, 2Hospital Universitari de Bellvitge, Barcelona, Spain, 3Hospital Universitario Arnau de Vilanova, Lleida, Spain, 4Institut Català d’Oncologia, IDIBELL, Quany, Barcelona, Spain, 5Hospital del Mar, Barcelona, Spain, 4Hospital Clinic, Barcelona, Spain, 7Institut Català d’Oncologia, Badalona, Spain, 8Hospital Universitari de la Vall d’Ebron, Barcelona, Spain, 9Hospital de la Santa Creu i Sant Pau, Barcelona, Spain, 10Hospital Universitari Sant Joan de Reus, Tarragona, Spain, 11Corporació Sanitària Parc Taulí, Sabadell, Spain, 12Hospital Asil de Granollers, Granollers, Spain, 13Consorci Sanitari de Terrassa, Terrassa, Spain, 14Institut Català d’Oncologia, IDIBELL, L’Hospitalet de Llobregat, Spain, 15Departament de Ciències Clínikes, IDIBELL, Universitat de Barcelona, Barcelona, Spain, 16Institut Català d’Oncologia, IDIBELL, Quany, L’Hospitalet de Llobregat, Spain

**Objective:** To assess patient (pt) Satisfaction (‘S’) and the Adequacy (‘A’) of pain treatment in inpatient (IP) and outpatient (OP) cancer pts.

**Material and methods:** Multicentric transversal descriptive study in cancer pts ≥18 y-old. The *Brief Pain Inventory* (BPI) was used to assess pain intensity, relief, & interference. Pharmacological treatment was recorded. Adequacy was assessed with *Pain Management Index* (PMI) & ‘S’ with the *Patient Perception with Pain Management Questionnaire* (PPPM). Categorical data were compared using Pearson’s χ² & Fisher’s exact test. Means of continuous variables were compared using Student’s t-test (for normal distributions), and Mann-Whitney and Kruskal-Wallis test, when not.

**Results:** Of 1064 candidate pts from 44 centres, 332 pts were evaluable. Mean age was 64 &53% were men. Median KPS was 70, & M1 65%. Rescue analgesia was prescribed in 63% of pts. DDEMO=183.6mg. Moderate-Severe ‘Worst pain’ (ENV≥7) was present in 77.1% of the sample (80.6% & 71.5% of OP and IP pts, respectively). ‘A’ was 70.2%, 54.1%, and 42.9%, respectively, in Palliative Care, Oncology, and Hematology (P=0.003). Pts ≥65 y-old with better KPS, OP, & no M1 showed indications of...
Abstract number: P169
Abstract type: Poster

Effectiveness of Mirtazapine on Cancer-related Anorexia: A Systematic Review

Canario R.1,2, Soares D.S.1,3, Gomes Da Silva B.4, Higginson I.J.1

1King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Instituto Portugues de Oncologia de Coimbra Francisco Gentil E.P.E., Departamento de Oncologia Medica, Coimbra, Portugal, 3Unidade Local de Saude do Nordeste, Departamento de Medicina Interna, Bragança, Portugal

Background: Anorexia is a common symptom in cancer patients, contributing to unintentional weight loss and distress among patients and caregivers. Currently there is no standard treatment. Mirtazapine may be an option as weight gain and increased appetite have been reported as side effects.

Research aims: To evaluate the effectiveness of mirtazapine as an appetite enhancer in adult cancer patients, by identifying and appraising studies that evaluated mirtazapine effects on appetite (primary outcome), weight and health-related quality of life (HrQoL).

Methods: Systematic review using electronic databases (MEDLINE, EMBASE and CENTRAL until March 2013). Eligibility criteria: adult cancer patients, experimental and quasi-experimental studies, interventions including mirtazapine and evaluating outcomes in terms of appetite, weight and HrQoL. Risk of bias was evaluated using a standardized tool. Results were narratively synthesised.

Results: Four studies were included (1 patient choice randomised trial, 1 randomised cross-over trial, 2 before-and-after studies) including 148 patients. The majority had advanced cancer and ages ranged 22-86. Risk of bias was high mainly due to attrition and performance bias. The drop-out rate was 51.3%. Doses of mirtazapine varied from 5-45mg. Appetite was improved in 3 studies but only 1 demonstrated differences between groups (before-and-after study, n=42, 1.3-point mean difference on 6-item scale, mirtazapine dose titrated from 15-45mg based on physician’s choice, p< 0.001). Two studies reported improved weight and HrQoL but only 1 reported statistical significance (cross-over trial, n=36, mirtazapine 15mg vs 30mg, improvement in both arms, p< 0.05).

Conclusions: Due to the paucity of data and the methodological quality of the reviewed studies, mirtazapine cannot be recommended as an appetite enhancer in cancer anorexia. Powered RCTs with more homogeneous populations and measures sensitive to change are needed.

Abstract number: P170
Abstract type: Poster

Quality of Life and Coping Styles in Italian Advanced Cancer Patients

Serpentini S.1,2, Del Bianco P.3, Odorico G.C.4, De Martino R.3, Chirico A.3, Berti C.1, Busa F.1, Biasco G.4, Trentin L.1, Merluzzi T.V.2, Capovilla E.2

1Az. ULSS 3, Bassano del Grappa, Italy, 2Veneto Institute of Oncology IOV-IRCSS, Psychoncology Unit, Padova, Italy, 3Veneto Institute of Oncology IOV-IRCSS, Padova, Italy, 4Fondazione Hospice Seràgnoli, Bentivoglio, Italy, 5Istituto Nazionale Tumori Fondazione Pascale-IRCCS, Napoli, Italy, 6Academy of Science of Palliative Medicine, Bentivoglio, Italy, 7University of Notre Dame, Notre Dame, IN, United States

Background and aims: The psycho-social and physical condition related to advanced cancer results to be serious and critical. Considering the paucity of specific studies in the Italian reality, the aim of the present research is to explore the quality of life and the coping styles toward the illness in Italian advanced cancer patients.

Methods: The present study represents a part of a major ongoing research. In this context, preliminary results of the EORTC QLQ-C30, evaluating the quality of life, and the Mini-MAC, evaluating the coping styles, will be presented.

Results: Currently 106 advanced cancer patients (mean age: 59.6 yrs, range age: 35-86 yrs) from 3 Italian centers took part. 60 (56.6%) are female, 46 (43.4%) male; 81 (78.6%) are married, 65 (65.6%) with medium education, 85 (85%) religious. The prevalent diagnosis is breast cancer (32.1%), the time from diagnosis is < 1 year for 36 pts (35%), between 1-5 years for 41 pts (40%), >5 years for 26 pts (25%); mostly (98 pts, 93.3%) the ECOG-Performance Status is grade 0-2.

Regarding the EORTC QLQ-C30, Global Health State (p=0.0195), Physical Functioning (p< 0.0001)
and Emotional Functioning \( (p=0.0264) \) result significantly lower than normative sample; significantly more critical appears to be the emotional state of the females \( (p=0.0338) \). Regarding Mini-MAC, the prevalent coping style is the fighting spirit: females have significant higher scores than male \( (p=0.0069) \), in particular patients with breast cancer and gynecological tumors.

**Conclusions:** The current results, even if partial, provide an interesting picture of an Italian sample of advanced cancer patients: adults, with newly diagnosis, religious, medium educated, capable of self-care, our patients present a critical psycho-physical condition but they cope with a fighting spirit style. The end of the study, scheduled for May 2014, is needed in order to have the final data and to achieve an overall view of the results.

**Abstract number:** P171  
**Abstract type:** Poster  

**Quality Perceived by Deceased Patient’s Relatives Treated of Complicated Grief in a Palliative Care Unit**  
Lacasta-Reverte M.A.\(^1\), Vilches Y.\(^2\), Alonso A.\(^2\), Diez E.\(^2\), Manrique T.\(^2\), Ybarra C.\(^2\), De la Torre M.I.\(^2\), Feliu M.\(^2\)

\(^1\)Hospital Universitario La Paz, Cuidados Paliativos, Madrid, Spain, \(^2\)Unidad de Cuidados Paliativos, Hospital Universitario La Paz, Madrid, Spain

**Background:** Studies that measure quality have been developed assessing the satisfaction’s level of the users. Satisfaction is the result of a comparison process, so when the service is perceived as it was expected or better than expected, the service is considered as satisfactory.

**Objective:** To assess the satisfaction of the users treated by a psychological intervention group programme of complicated grief.

**Methods:** Descriptive and observational study. The measures were collected by anonymous telephone interviews to the relatives. Data were analysed statistically by SPSS 9, descriptive index were estimated.

**Results:** In total, 106 relatives of cancer deceased patients derived because complicated grief took part in the study. The average age was 58 (SD=15), M/F: 19/87. The intervention groups were homogenous with respect to age and relative lost (74% spouses, 15% parents and 11% sons). The 42% of them were derivate to Palliative Care, 40% to Primary Care, 18% to different Hospital services. The patients’ expectations were: to obtain psychological help to cope with their life (78%), to have the chance to express their feeling without been coerced (64%), to learn how to deal with the bereavement (62%), to share their situation with people in their same situation (58%). The 82% of the patients did refer to be “very satisfied” with the received service. The 96% would recommend this program to other people. The 99% admit that the program have reached their expectations, the 72% affirm that the program have reached their needs and it have helped them to deal with their situation in an effectively way (72%).

**Conclusions:** The relatives of deceased patients that participate in a psychological intervention group programme of complicated grief show a high global satisfaction in the perceived quality in comparison with they had expected.

**Abstract number:** P172  
**Abstract type:** Poster  

**Basic Palliative Care in a Large Teaching Hospital – Under Pressure?**  
Vinnem L.I.H.\(^1\), De Vreede I.\(^1\), Haugen D.F.\(^2\)

\(^1\)University of Bergen, Bergen, Norway, \(^2\)Haukeland University Hospital, Regional Centre of Excellence for Palliative Care, Western Norway, Bergen, Norway

**Background and aim:** Hospital departments should provide palliative care at the end of life. In 2006 an audit of the care for terminally ill cancer patients (pts) was performed in our large teaching hospital, showing needs for improvement in symptom control. In 2008 a specialist palliative care consult team (SPCT) was established in the hospital. The aim of the present study was to see if the care offered to inpatients at the end of life had changed between 2006 and 2010.

**Method:** Retrospective review of the medical records for the last three months of life for all cancer pts who died Jan-June 2010 at the Departments of Surgery and Oncology. Like in 2006, we recorded data on demographics and several quality indicators for palliative care, based on national recommendations, 25 variables in all.

**Results:** 73 pts were included (8 <55 years; 34 between 55 and 75; 31 >75; 49 males). They had on average 2.4 admissions and length of the last admission 14 days. 25 pts were referred to the SPCT. A long-term plan for symptom management was documented in 24/73 records (3/78 in 2006); 19/24 plans were written by the SPCT. Symptom assessment by ESAS was completed in 45% of the pts (31% in 2006). A family meeting was held in 15% of the cases (49% in 2006). In 26% of all cases the record held information that the patient was dying without the patient being informed about it (10% in 2006). Blood samples were drawn from 56% of the pts during the last 48 h of life (42% in 2006). 14/73 pts died alone (6/78 in 2006).

**Conclusion:** Our data show a considerable decrease in the number of family meetings, more pts who were not informed that they were dying, and more pts who died alone. Even though data showed influence by the SPCT on symptom management, several aspects of basic palliative care were less satisfactory than in 2006. We hypothesize that decreased staffing levels, increased demands for productivity, and time pressure may divert attention from dying patients.
Abstract number: P173
Abstract type: Poster

Impact of Outpatient Palliative Care on Quality of End-of-Life Care in Patients with Advanced Cancer

Hui D.¹, Kim S.-H.², Roquemore J.³, Dev R.³, Chisholm G.³, Bruera E.¹

¹MD Anderson Cancer Center, Houston, TX, United States, ²Kwandong University, College of Medicine, Seoul, Korea, Republic of, ³University of Texas MD Anderson Cancer Center, Houston, TX, United States

Aims: Limited data is available on how the setting and timing of palliative care referral can affect end-of-life care. In this retrospective cohort study, we compared the quality of end-of-life care between patients referred to outpatient and inpatient palliative care.

Methods: All adult patients residing in the Houston area who died of advanced cancer between 9/1/2009 and 2/28/2010 and had a palliative care consultation were included. We retrieved data on palliative care referral and quality of end-of-life care indicators. We analyzed the data using descriptive statistics, Chi-square tests, Mann-Whitney tests, and multivariate logistic regression with backward selection.

Results: Among 366 decedents, 169 (46%) had their first palliative care consultation in the outpatient setting and 197 (54%) in the inpatient setting. Outpatient palliative care referral was associated with a significant decrease in emergency room visits (48% vs. 68%, P< 0.001), hospital admissions (52% vs. 86%, P< 0.001), prolonged hospital stays (10% vs. 24%, P=0.002), hospital death (18% vs. 34%, P=0.001) and intensive care unit admissions (4% vs. 14%, P=0.001) in the last 30 days of life. The outpatient cohort had a lower aggressive end-of-life care score (median 0 vs. 1 for inpatient referrals, P< 0.001, where 0=best and 6=worst). In multivariate analysis, palliative care outpatient referral was independently associated with less aggressive end-of-life care (Table).

Conclusion: Patients referred to outpatient palliative care had improved end-of-life care compared to inpatient palliative care. Our findings support the need to increase the availability of palliative care clinics and to streamline the process of early referral.

Funding: Institutional grant

Table. Factors Associated with Aggressive EOL Care.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds ratio (95% confidence interval)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male sex</td>
<td>1.63 (1.06-2.50)</td>
<td>0.027</td>
</tr>
<tr>
<td>Hematologic malignancies</td>
<td>2.57 (1.18-5.59)</td>
<td>0.018</td>
</tr>
<tr>
<td>Palliative care</td>
<td>0.42 (0.28-0.66)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Abstract number: P174
Abstract type: Poster

What Happens and what Matters: Understanding Quality of Dying in a Hospital

Witkamp E.¹, van Zuylen L.², van der Rijt C.C.D.³, van der Heide A.³

¹Erasmus MC University Medical Center, Public Health and Medical Oncology, Rotterdam, Netherlands, ²Erasmus MC Cancer Institute, Medical Oncology, Rotterdam, Netherlands, ³Erasmus MC University Medical Center, Public Health, Rotterdam, Netherlands

Background: Though the majority of deaths in western countries occur in hospital, little is known about the quality of dying (QOD) and determining factors. We aimed to assess QOD in a hospital as experienced by relatives, and to identify related factors.

Methods: Between June 2009 and March 2011 each adult death at non-IC units in a university hospital was followed by an invitation to relatives, sent 10-13 weeks later, to answer a questionnaire. Relatives were asked to rate QOD overall on a 0-10 numeric rating scale, and to evaluate their experiences in different domains, on verbal scales. The association between QOD scores and these experiences was analyzed with regression and component analyses.

Results: In the study period, 524 patients died; of 490 patients (94 %) relatives could be traced, and 249 participated ( 51%). Of patients, 57% was male, mean age was 69 years (sd 14), and mean duration of final hospital stay was 15 days (sd 21). On average, relatives rated QOD at 6.3 (sd 2.7). Patients had suffered from 7 (sd 5.8) out of 22 symptoms; 21% had not been in peace with imminent death. Half of the patients and relatives had not said goodbye, and in 23% no relative had been present at the moment of death. Symptom alleviation was judged as insufficient in 24%, and efforts to relieve symptoms in 16%. Relatives were not satisfied about social and spiritual support in 28%. Factors most strongly associated to the QOD scores could be summarized in 9 domains. Domains regarding experiences with care, i.e. medical and symptom care (R2 0.22), and personalized care (R2 0.16), and regarding life closure/ death preparation (R2 0.11), were most strongly associated to QOD. Overall 34% of the variation in QOD scores could be explained.

Conclusions: On average, relatives rated QOD in hospital as moderate. Experiences of care were most important in explaining variation in QOD. Better QOD can be achieved by clinical staff being present, providing information and listening.

Abstract number: P175
Abstract type: Poster

How Dementia Affects Patients’ Sense of Dignity: A Qualitative Study into their Perspective
Background: It is stated that the maintenance of dignity amongst patients with dementia should be a guiding principle in the ethics of dementia care. However, knowledge is lacking on how individuals suffering from dementia experience their sense of dignity and what they think is important in maintaining their sense of dignity.

Aim: Our study explores the factors and circumstances that may influence the sense of dignity as seen from the perspective of patients suffering from mild to moderate dementia.

Method: To gain insight in the personal experiences of patients with dementia, we used a qualitative approach. We carried out 14 in-depth interviews with 8 men and 6 women, aged 53-90, with mild to moderate dementia. Data was analyzed making use of the principles of thematic analysis.

Results: Although mild to moderate dementia resulted in a diminished sense of personal dignity, in general participants still felt reasonably dignified. The decline in dignity was generally caused by impairments in personal qualities resulting in diminished autonomy and changes to the patient’s former identity. However, the intensity with which the decline in dignity was experienced depended to a large degree on the social context of the patient, with a marked difference between the private sphere and the external environment.

Interpretation: Both the care provided by the spouse and continuing to live at home play a crucial role in the maintenance of dignity in patients with dementia as viewed from their own perspective. Given the social vulnerability of patients with dementia and the considerable impact the social environment has upon their sense of dignity, it is important not to limit attention to neurophysiological or individual patient aspects alone, but also to understand dementia as a socially embedded phenomenon.

Abstract number: P176
Abstract type: Poster

Perceptions of Spirituality, Religiosity, and Spiritual Caregiving at the End of Life: A Nationally Representative Survey of Physicians Practicing in Long-term Care in the Netherlands

Gijsberts M.-J.H.E., van der Steen J.T., Hertogh C.M.P.M., Deliens L., Wagner L.

1VU University Medical Centre, General Practice and Elderly Care Medicine, Public and Occupational Health, Amsterdam, Netherlands. 2VU University Medical Centre, Public and Occupational Health, Amsterdam, Netherlands. 3Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium

Aims: To examine physicians’ perceptions of spirituality, and how these and their religiosity, relate to their reports of providing spiritual end-of-life care.

Methods and design: Cross-sectional survey with 642 postal questionnaires (October 2012-February 2013).

Participants: A representative sample of Dutch elderly care physicians practicing in long-term care.

Measurements: Perceptions of spirituality were measured with a scale that, when endorsed, sums 15 items from published validated instruments that measure spirituality, and subtracts 15 not included (sum score -15 to +15). The Religious and Spiritual Beliefs and Practices Scale (range 5-22) measured religiosity. Spiritual end-of-life care referred to the last resident the physician attended.

Results: The response rate was 47.2%. Almost half (48.4%) of the physicians felt they provided spiritual end-of-life care. The mean religiosity score was 11.5 (SD 4.4), and the perception in accordance with the literature mean score was 5.5 (SD 3.9). Items referring to religion or religious activities were more frequently endorsed than spiritual wellbeing items (e.g., connectedness, closure). The physicians who felt to have provided spiritual end-of-life care scored lower on perception: 4.4 SD 4.0 versus 6.7 SD 3.6; p< 0.001) due to endorsing a larger number of items (mean 24 SD 5 versus 21 SD 5; p< 0.001) including non-spiritual items, and were more religious (12.4 SD 4.3 versus 10.5 SD 4.4; p< 0.001; no correlation).

Conclusion: More religious physicians and physicians with an inclusive perception of spirituality more frequently feel they provide spiritual end-of-life care. Training should include the examining of physician’s own perceptions of spirituality.

Abstract number: P177
Abstract type: Poster

Some Factors Significant to Continuity in Basic Palliative Hospital Care - From the Perspective of Advanced Cancer Patient

Soelver L., Rydahl-Hansen S., Oestergaard B., Wagner L.

1Research Unit of Nursing, Institute of Clinical Research, University of Southern Denmark, Bispebjerg and Frederiksberg Hospital, Surgery K, Copenhagen, Denmark. 2Bispebjerg and Frederiksberg Hospital, Research Unit of Clinical Nursing, Copenhagen, Denmark.
Aim: Most cancer patients receiving palliative or life-prolonging treatment are not in specialist palliative care and little is known about continuity in basic palliative hospital care. We aimed to identify and describe the factors that, from the perspective of advanced cancer patients, are importance to continuity, focusing on the identification and alleviation of physical and emotional problems in a hospital context.

Methods: Patients hospitalised with advanced cancer, in medical and surgical wards, were included. Data generation and analysis were based on the research method ‘Grounded Theory’, as described by Strauss and Corbin. Patients responded to the questionnaire EORTC QLQ-C15-PAL, and selected one and three problem areas to the subject of the qualitative interview, conducted in patients’ own homes 4-5 days after discharge from hospital.

Results: Eleven patients aged 54-86 (mean 71), were interviewed. The factors that were important in the creation and maintenance of continuity could be summarised in the core category of disheartening interactions. The core category was supported by four categories: a) falling outside the professional framework, b) not being regarded as a person, c) unmet need for guidance and involvement and d) patient strategy - minimizing conflicts. The categories referred to interactions that patients felt were narrowly focused and restricted the identification and alleviation of their problems and limited their ability to participate proactively.

Conclusion: Hospitals’ organisational framework, professional routines and inadequate competence and patients’ concealment of problems seem to be restrictive to continuity in basic palliative care. One can consider the systematic use of a questionnaire to identification of patients’ problems and needs as a basis for developing individual action plans and follow-up. In the palliative phase of the disease, however, a screening instrument with a broader scope than the QLQ-C15-PAL should be used.

Abstract number: P178
Abstract type: Poster

Satisfaction with Medical Interventions and Overall Care in Outpatient Clinic of a Palliative Care Department

Porta-Sales J.1, Garzón-Rodriguez C.1, Llorens-Torromé S.1, Villavicencio-Chávez C.1, Artigas Lage R.1, Sala-Suñe S.1, Barbero-Biedma E.1, González-Barboteo J.1, López-Rómboli E.1, Casals-Merchán M.2, Mate-Méndez J.1, Serrano-Bermúdez G.1, Trelis Navarro J.1

1Institut Català d’Oncologia, IDIBELL, Palliative Care Service, L’Hospitalet de Llobregat, Spain, 2Hospital Universitari de Bellvitge, Barcelona, Spain

Objectives: To assess ambulatory cancer patient (pt) satisfaction (S) with the palliative care department (PC) in terms of overall and staff-specific (physicians and other professionals) satisfaction.

Material and methods: Longitudinal opinion study assessed by a self-administered questionnaire in consecutive pts referred to PC who completed 3 consecutive visits. ENV (range, 0-10) was used for item assessment. Pts’ opinion of the physician, assessed after the 2nd consultation, included: Reception (R), Understanding of problems & concerns (U), Explanation of causes of problems and concerns (E), Explanation of Treatment (ET), commitment to Follow up (F) the prior consultation (i.e., from the 1st to the 2nd & from the 2nd to 3rd visit). In the 3rd consultation, additional items were assessed: Pts’ S with other professionals, punctuality, furniture & equipment, personal treatment, follow-up, & overall care. Analysis of differences was assessed with the Wilcoxon Sign Rank test. All pts provided informed consent.

Results: Of the 274 pts enrolled, 106 pts were assessable. Mean age was 67 & 67% were male. Most pts (80%) were referred from Medical Oncology. M1 was 78%, median PPS 70%, & 53% received anticancer treatment. Time from diagnosis (median) was 1.4 yrs. Mean time between the 1st & 3rd consultation was 70 days (range, 28-120). The mean results after 1st consultation were as follows: R 9.1 v. 8.9 (P=0.1); U 9.2 v. 8.7 (P=0.001); E 8.7 v. 8.6 (P=0.2); ET 8.9 v. 8.7 (P=0.1); and F 8.6 vs. 8.7 (P=0.4). Overall S with staff: physician 9; nurse 8.9; social worker 8.9; psychologist 8.7; anesthesiologist 9; secretary 8.8. Pts S with other items were: punctuality, 8.3; furniture & equipment, 8.1; personal treatment, 9; follow up, 8.8; & overall care, 8.8.

Conclusions: In our sample of advanced cancer pts with early intervention, patient S with medical care and staff in the PC was very high. We stress the importance of periodic assessment of satisfaction as a quality parameter of care.

Abstract number: P179
Abstract type: Poster

Awareness of Dementia by Family Carers of Nursing Home Residents Dying with Dementia

Penders Y.W.H.1, Albers G.1, Deliens L.1, Vander Stichele R.2, Van den Block L.1, on behalf of EURO IMPACT

1Vrije Universiteit Brussel, Faculty of Medicine and Pharmaceutical Science, Brussels, Belgium, 2Ghent University, Ghent, Belgium

Background: People in later stages of dementia are often not capable of decision-making. Therefore, family carers play an important role in making decisions about end-of-life treatments and care.

Aim: To describe the prevalence of awareness of dementia by family carers of nursing home residents who died with
dementia, and the associations between family carer awareness, clinical judgments of dementia by GPs/nurses and patient and care related factors.

**Methods:** Using random cluster sampling, a representative nationwide post-mortem study was conducted in nursing homes in Flanders, Belgium (2010). Structured questionnaires were completed by family carers, nursing staff and GPs of deceased nursing home residents identified by nursing staff or GP as having dementia. Data were analyzed using pairwise comparison and bivariate or multivariate logistic analysis.

**Results:** Of 190 residents who died with dementia, 53.2% of family carers responded. In 27.5% of cases family carers indicated they were not aware their relative had dementia. Awareness among family carers was positively related to more advanced stages of dementia one month before death (p=.02), although 20% of family carers was unaware when dementia was advanced. Awareness was also positively related to hours the family carer provided care per week before admission (p< .01) and the longer the onset of dementia before admission to the nursing home, the more likely family carers were aware (p<.001).

**Conclusion:** Appropriate end-of-life decision-making is only possible when optimally informed about the diagnoses. Our data show that too many relatives of deceased nursing home residents with dementia were unaware i.e. one fourth of cases with dementia and one fifth of cases with advanced dementia. Relatives of people who developed dementia at home appeared more likely to be aware then people developing dementia in the nursing home, showing room for improvement in communication with family for nursing home residents.

**Abstract number:** P180

**Abstract type:** Poster

**Perceptions of- and Attitudes towards End-of-Life Needs and Demands of Elders over 80 Years Continuing Intellectual Work in Georgia**

**Chikhladze N.1, Velijanashvili M.1,2, Kordzaia D.1,2**

1Iv. Javakhishvili Tbilisi State University (TSU), Tbilisi, Georgia
2Georgian National Association for Palliative Care, Tbilisi, Georgia

The study is the component of multifocal program dedicated to the development of optimal model for geriatric palliative care in Georgia. Such model logically requires consideration of perceptions of- and attitudes to end-of-life needs and demands of elders themselves. Presumably, these perceptions and attitudes are highly conditioned by recognition of limited lifespan in the respective group.

**Aim:** Study aim was to map and analyze the perceptions of- and attitudes to the needs and demands of individuals recognizing their limited lifespan.

**Methods:** 10 elders (aged over 80 years) still pursuing intellectual work though recognizing their limited terms of life were inquired by semi-structural interviews with 2 questions - “tell me about your life” and “what do you plan for future?”. The interviews were transcribed from audiotapes and coded. More or less independent fragments from each interview were assessed according to A. Maslow “Hierarchy of Needs” and placed at the respective level of Maslow’s pyramid. Results were analyzed by methods of comparative statistics.

**Results and discussion:** 89 fragments were outlined for evaluation (from 2 to 13 fragments in every interview). Every fragment was placed at the respective levels of Maslow’s pyramid: 3 fragments (3.37%) at I (physiological needs and survival), 15 (16.8%) - at the II (safety needs), 36 (40.4%) - at the III (social needs), 30 (33.7%) - at the IV (esteem, respect) and 5 fragments (5.6%) - at the V (self-actualization). Comparison of distribution of these data with the respective data for every respondent shows that difference does not exceed the permissible limit of deviation and confirms the validity of averaged data.

**Conclusion:** The needs on social affiliation and respect obviously predominate in elders aged over 80 years recognizing their limited life span. The options of these demands varied between 1-5 and 1-4 - at the III and IV levels of Maslow’s pyramid, correspondingly. The study was funded by TSU Budget.

**Abstract number:** P181

**Abstract type:** Poster

**ALS Patients in Locked-in Syndrome: A Systematic Review of the Literature**

**Reigada C., Mendes O., Paiva C., Tavares M., Gonçalves E.**

São João Hospital Center, Palliative Care Service, Porto, Portugal

**Aim:** To analyze the strategies used to communicate with amyotrophic lateral sclerosis (ALS) patients in locked-in syndrome (LIS), the decision-making process used for therapeutic interventions and the holistic process of care in general.

**Method:** Complying the research question “how to communicate and deal with ALS patients in locked-in syndrome”, we conducted a systematic review of the literature published in English using the PubMed and Scopus databases. The research keywords were (amyotrophic lateral sclerosis) [Title/Abstract] OR (motor neuron disease) [Title/Abstract] AND Locked-in [Title/Abstract]. The inclusion criteria were: scientific periodicals articles; unlimited years; age >18 years; written in English. All articles were selected and analyzed by three independent groups of reviewers.
Results: Ninety one articles were identified, 17 of which fulfilled the review criteria (94% concordance between reviewers). Most of them were experimental and the number of ALS patients included varied between 1 and 21. All of the considered articles deal with the field of communication by exploring alternative communication techniques; three reported issues about the decision-making process and four described team interventions.

Conclusion: The literature published is focused predominantly in alternative communication systems, all experimental, with few critically examining the holistic care needed to deal with ALS patients in LIS. In the meantime the palliative care teams are challenged to look after these patients with intense suffering and difficult ethical issues, particularly with regards to the meaning of life and medical decisions.

Keywords: Amyotrophic lateral sclerosis; Neuron motor disease; Locked-in

Abstract number: P182
Abstract type: Poster

Dignity of the Person with Advanced Disease: Perception of the Medical Residents (MR)

Pons Rodriguez A.1, Roca Monso M.2, Balcells Teres A.2, Viladot Pachón R.1, Rodriguez-Rosich A.1

1ABS Eixample, Lleida, Spain, 2ABS Mollerussa, Mollerussa, Spain

Introduction: The person who has an incurable, progressive disease undergoes a series of physical and psychic changes that may cause a change in the concept of dignity of the individual. It is essential that already during its formative process, doctors keep in mind these changes to improve the quality of care of these patients.

Objective: To know the opinion of the MR on the values that make up the concept of palliative patient’s dignity.

Identify the experiential impact on palliative care in the formation of the MR.

Material and methods: Cross-sectional study. Study population: MR of a university hospital during the period January to July 2013. It also reflected a view of the MR (141) through a questionnaire Patient Dignity Inventory (PDI), which evaluates the opinion and the application in their clinical practice. The questionnaire has 25 items divided into five sub-themes.

Results: 141 MR of a total of 163 were interviewed. Average age 29.18 years ± 5.33; 78.7 % women; 24.1 % foreign nationality; 80.9 percent have been studied at Spanish universities. 22.7 % are MR of first year, 24.8 % of second year, 28.4 % of third year and 24.1 percent from the fourth and fifth year of specialty. Most (70.95%) corresponded to MR of medical specialties. A 95.7% received training in bioethics during the university education, but only a 22.1% have received it on a voluntary basis. Within the parameters evaluated at PDI. The most highly valued in the PDI was the dependence and the least valued spirituality (put percentages). Among the aspects of the daily clinical practice the most outstanding items were distress and the less spirituality. No significant differences were found between opinion and clinical application.

Conclusion: The results obtained show that the MR of our center identified as items associated with the dignity of palliative patients mainly physical aspects rather than spiritual aspects.

Abstract number: P183
Abstract type: Poster

An Invisible End-of-Life: Palliative Care in Care Homes for Adults with Disabilities. First Results from a Nationwide Study in France

Morin L., Rotelli-Bihet L., Aubry R.

French National Observatory on End of Life Care, Paris, France

Aims: The life expectancy of adults with physical and/or intellectual disabilities is growing faster than in the general population, leading to the ageing of heavily disabled people and therefore to very complex end-of-life situations. Yet, this reality remains “invisible” in both the public opinion and the healthcare policies. Therefore, this study aims to make an inventory of the needs related to palliative care in care homes for adults with disabilities.

Methods: A paper-based questionnaire was sent to all care homes for adults with physical and/or intellectual disabilities in France. Attending physicians and directors were asked to describe the organization of end-of-life care in their facility, and also to report detailed informations about the circumstances of death of the residents who died in 2012.

Results: 778 care homes participated in this study (response rate: 52%), representative of all facilities in the country. 60% of these facilities are in contact with a Palliative Care Support Team, but in almost one half (49%) of them neither the attending physician nor the nurses received a palliative care training, and only 16% of them have a night-shift nurse. On 933 death cases reported by the respondents, 46.7% occurred in a hospital, 16% were preceded by a decision to withhold or withdraw life-sustaining treatments. In addition, 32% of all deceased residents received artificial nutrition or hydration during the last month of life, and 31% received opioids.

Conclusion: The presence of a nurse at night, the palliative care training of the attending staff and the existence of regular contacts with a Palliative Care Support Team have a great influence on the circumstances of deaths in care homes for adults with heavy disabilities. This study also
shows major discrepancies between regions regarding the provision of end-of-life care and the place of death.

**Abstract number:** P184  
**Abstract type:** Poster  
**High Grade Gliomas: A Challenge for Palliative Care Teams**  
*Capela A.*, *Moreira C.*, *Almeida D.*, *Pires C.*, *Gonçalves E.*

1Centro Hospitalar de São João, Serviço de Oncologia Médica, Porto, Portugal, 2Centro Hospitalar de São João, Serviço de Cuidados Paliativos, Porto, Portugal

**Background:** High grade gliomas (HGG) normally have an aggressive course. Patients with HGG experience a range of symptoms that impacts themselves and their families, representing a challenge to palliative care teams (PCT). In order to improve the management of these patients and families it is mandatory to identify their needs.

**Aim:** To characterize the HGG adult population followed by a PCT and to identify the main interventions implemented.

**Methods:** Descriptive retrospective study based on the clinical records of HGG patients followed by the PCT between November 2008 and September 2013.

**Results:** One hundred fifty-one patients were observed (56.3% male), with a median age of 61 years old (22-88). The main reasons for PCT request were symptom control (57.0%) and care organization (42.4%). Ninety percent of patients had a low performance status (ECOG 3-4) and 12.6% were on chemotherapy. The most prevalent problems were motor impairment (99.3%), speech disability (73.5%), dysphagia (57.0%), pain (33.8%), seizures (28.5%) and depression (20.5%). One hundred thirty-two patients died (87.4%), 18.2% at home. Pharmacologic intervention included: prescription of medication when required (61.6%); therapeutic simplification (34.4%); adjustments in the drug administration route (21.2% and analgesia (39.7%), corticoid therapy (28.5%), anticonvulsants (26.5%), anxiolytics (15.9%). The social worker was required in 57.0% and psychology in 31.1%.

**Conclusion:** HGG patients were referred to PCT in quite advanced disease stages, making it difficult to deal with the psychosocial and spiritual problems. In the future, it is important to assess the potential benefits of a shared care model with the PCT intervention almost at diagnosis.

**Abstract number:** P185  
**Abstract type:** Poster  
**Effects of Long Term Bisphosphonates Administration Beyond 24 Months in Metastatic Breast Cancer**  
*Zecca E.*, *Ferrari L.*, *Pigni A.*, *Brunelli C.*, *Caraceni A.*

1Centro Hospitalar de São João, Serviço de Oncologia Médica, Porto, Portugal, 2Centro Hospitalar de São João, Serviço de Cuidados Paliativos, Porto, Portugal

**Aim:** To evaluate the effects of BP administered for more than 24 months on pain control, osteonecrosis of the jaw (ONJ) and skeletal related events (SRE) incidences.

**Methods:** We retrospectively screened patients with MBD due to breast cancer who received BPs for at least 20–24 monthly administrations (first cycle). The following variables were collected at the end of first cycle and monthly for the first 12-months follow-up (FWUP): BPs administration (yes/no), reasons for continuing or not the treatment, pain intensity (PI) (0-10 numerical rating scale) and occurrence of SRE and of ONJ. Patients with at least 1 FWUP evaluation were eligible. Multivariate regression models were used to estimate the effect of the number of additional BPs’ administrations on the outcomes selected.

**Results:** Out of 123 patients screened, 113 were eligible and had an average FWUP time of 10 months. 54 patients (48%) received at least 1 BP dose during the FWUP (average 4.5 administrations). Reasons for continuing the treatment ranged from patient request to progression of MBD and hypercalcemia. Average PI in the last 3 months of the FWUP resulted significantly associated to PI at the end of first cycle (p=0.025) but not to the number of additional BPs’ administered (p=0.69). Only 1 patient developed ONJ at the 2nd FWUP month but she continued BPs administration due to hypercalcemia. 12 pts experienced at least one SRE: 2 spinal cord compression, 5 hypercalcemia, 5 pathological fracture; the number of BP doses received was not significantly associated to time to first SRE occurrence (p=0.47).

**Conclusion:** In the first year of follow-up no, evidence of benefits of prolonging BP administration beyond 24 months was found.
Division of Palliative Care, Dept of Medicine, Dept of Epidemiology and Community Medicine, University of Ottawa, Bruyere and Ottawa Hospital Research Institutes, Ottawa, ON, Canada

**Background:** There are few literature data on CP characteristics in Portugal.

**Aims:** To determine the correlates and predictors of Pi at initial CP clinic referral.

**Methods:** Consecutive patient referrals to a specialist CP clinic had standard assessments and documentation: Brief Pain Intensity ratings (worst and average in last 7 days; and pain now as the outcome variable, labelled Pi) on a 0-10 scale; pain mechanism (using the DN4 tool to assess neuropathic pain, NeuCP); episodic pain; Eastern Cooperative Oncology Group (ECOG) rating of functional status; oral morphine equivalent daily dose (MEDD); Hospital Anxiety Depression and Emotional Thermometer scores; demographics; cancer diagnosis, metastases, treatment and pain duration. With Pi as outcome, univariate analyses were conducted using the t-test, one-way ANOVA and Pearson correlation (r), as appropriate for predictor variables. Variables with p < 0.1 were entered into a multivariate regression model, using backward elimination and a cut-point of p=0.2 for final model selection.

**Results:** The means ± SD of Pi, pain worst and average for the study sample (N=371) were 5.4±2.6, 7.4±2.6, 4.9±1.9, respectively, and all were highly correlated (r>0.8, p<0.0001). Higher income and socioeconomic group; drug or alcohol abuse; more functional dependency; “palliative” status designation; cancer type; radiotherapy treatment; NeuCP or mixed pain; presence of metastases; ≥1 adjuvants and initial MEDD were associated with Pi at univariate level (p<0.05). In the final multivariate model, 9 variables were retained and 5 were positively correlated with Pi: higher income, ECOG 3-4, cancer type (head & neck, genitourinary and gastrointestinal); adjuvant use and initial MEDD (p<0.05). Adjusted R²=18.6, and thus the model explained <20% of Pi variance.

**Conclusions:** Our study underscores the biopsychosocial complexity of CP, and the limited explanation of Pi variance. Adequacy of CP treatment warrants further exploration.

**Abstract number:** P187

**Abstract type:** Poster

**Weight Loss in Solid Tumors: A Population Based Study**

_Shorotiya S.1, Walsh D.1, Estfan B.1, Aktas A.1, Rybicki L.2_  
1Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Harry R. Horvitz Center for Palliative Medicine and Supportive Oncology, Cleveland, OH, United States, 2Cleveland Clinic Taussig Cancer Institute, Cleveland, OH, United States

**Aims:** Large cancer databases provide valuable information on weight change and different clinical parameters. Body weight change in adults with solid tumors was examined in outpatients. The objective was to determine if demographics, clinical and biochemical indices predicted weight loss (WL). The effect of WL and other parameters on survival were also assessed.

**Methods:** Electronic medical records (EMR) for outpatients visits from a tertiary cancer center were retrospectively reviewed. Body weight and other clinical parameters on visit 1: within a year post diagnosis - visit 2: ≥3 weeks after visit 1. WL at visit 2 from visit 1 categorized as: ≤5%, 5.01-10%, >10%. Results summarized by descriptive statistics, logistic regression and Cox proportional hazards analysis.

**Results:** N = 5901; 58% Male; Mean age (±SD): 61±12 years; 82% were Caucasians; 16% African Americans. Common cancers: genitourinary (GU) 31%; gastrointestinal (GI) 16%; breast 15%; lung 15%; head and neck 6%; brain 5% and others 12%. Metastatic disease in 18%. Bone, brain, lymph nodes - common metastatic sites. 45% had radiotherapy and 41% chemotherapy. Median (range) weight, kgs: visit 1=81(32.0-223), visit 2=79(34-221). Median duration (range) days visit 1→visit 2: 195 (22-1080). WL visit 1→visit 2: ≤5% (73%), 5.01-10%(13%) and >10%(14%). Median change in BMI visit 1→visit 2: -0.2(-19, 13). Median survival for 5.01-10.0% WL= 9.4 months, >10.0% = 5.3 months and not observed for ≤5%. Risk factors for WL (multivariable analysis) were primary site, metastatic sites, treatment-related variables, BMI category. WL was prognostic in multivariable analysis (p<0.001).

**Conclusions:**

1. Majority lost ≤5% of body weight by visit 2  
2. Head and Neck and GI cancers (primary): the greatest risk of WL; breast - lowest  
3. Overweight and obese = High WL; underweight = low WL  
4. ≤5% WL had survival advantage compared to other WL groups; 5.01-10% and >10%  
5. WL remained prognostic for survival even after adjusted for other factors

**Abstract number:** P188

**Abstract type:** Poster

**A Study to Define the Physical Symptoms Experienced by Constipated Palliative Care Patients and the Impact of these Symptoms on Quality of Life**

_Clark K.1,2, Lam L.3, Currow D.C.4_  
1Calvary Mater Newcastle, Palliative Care, Waratah, Australia, 2The University of Newcastle, Newcastle, Australia, 3University of Sydney, Medicine, Sydney,
Objectives: Despite the numbers of people with disturbed bowel habits in palliative care, little detail describes people’s self-reported symptoms and how this impacts quality of life. Numerous risk factors are quoted, but opioids are best defined. The primary aim of this work was to document people’s symptoms and explore the impact of symptoms on quality of life. The secondary aim was to examine whether demographic variables may impact the experience of constipation in palliative care.

Methods: A prospective study of 69 people was conducted. Questionnaires were used to document current symptoms (the Patient-Assessment of Constipation symptoms), constipation symptoms experienced over the previous 12 months and quality of life (Patient Assessment of Constipation quality of life).

Results: Most of the group had cancer but were mobile and well-nourished [mean BMI 25 (SD +/-6.11)]. Numerous physical symptoms were reported and attributed to constipation similar to the general populations’ chronically constipated. A moderately strong and positive correlation between the global PAC-SYM score and the global PAC-QOL score (r=0.50) was noted. This was highly significant (p<0.001). Four items examined constipation symptoms over the previous 12 months highlighting that half the cohort reported lumpy stools (47%), infrequent stools (48%) and dissatisfaction with bowel actions (54%). Furthermore, 2/3 reported the need to strain to pass bowel actions. Regression analyses did not suggest an association between gender, age, performance status or BMI but a 12-month history of straining to have a bowel movement was significantly associated with higher global PAC-SYM (162=3.97, p<0.001).

Conclusions: This study highlights that people with disturbed bowel function in palliative care are highly symptomatic with the severity of symptoms negatively impacting quality of life. Further work is needed to understand the physiology of these symptoms with the aim of optimising palliation.

Abstract number: P189
Abstract type: Poster

Dignity through Integrated Symptom Management: Lessons from the Breathlessness Support Service

Gysels M.1, Reilly C.2, Jolley C.3, Pannell C.2, Spoorendonk F.4, Bellas H.1, Madan P.3, Debiase C.4, Moxham J.3, Higginson I.J.2, Bausewein C.5

1University of Amsterdam, Amsterdam, Netherlands
2King’s College London, London, United Kingdom
3University Hospital Munich, Munich, Germany
4University Hospital Berne, Center of Palliative Care, Berne, Switzerland
5Cantonal Hospital, Centre of Palliative Care, St.Gallen, Switzerland

Aim: Dignity is poorly conceptualized in end of life care and it is little empirically explored. A qualitative evaluation of a specialist palliative care intervention - the Breathlessness Support Service - uncovered an unexpected outcome, it enhanced patients’ dignity. We aimed to analyse what constitutes dignity for people suffering from breathlessness with an advanced illness, and its implications for the concept of dignity.

Methods: Qualitative study of face-to-face cross-sectional interviews. The interviews are part of a phase III evaluation with a randomized controlled fast-track trial (RCT), following the MRC Framework for Complex Interventions. A subsample of patients were invited to take part in semi-structured, in-depth interviews, which were transcribed verbatim and imported into NVivo. The interviews were analysed through constant comparison. The findings were compared with the dignity model developed by Chochinov et al. The model was adapted with the themes and sub-themes specific to patients suffering from breathlessness.

Results: The findings of this study underscore the applicability of the conceptual model of dignity for patients with breathlessness. There were many similarities in themes and sub-themes and also differences that were specifically relevant for patients suffering from severe breathlessness: a. Physical distress and psychological mechanisms are interlinked with the disability and dependence breathlessness causes, in the illness-related concerns; b. Stigma is an important component of the social dignity inventory; c. Conditions and perspectives need to be present to practice self-care in the dignity conserving repertoire.

Conclusions: Dignity is an integrated concept and can be affected by influences from other areas such as the illness-related concerns. The intervention shows that targeting the symptom holistically, by equipping patients with the means for self-care, realized the outcome of dignity.

Abstract number: P190
Abstract type: Poster

Diagnosing Dying - Development of a Clinical Tool for Identifying the Last Days of Life

Domeisen Benedetti F.1, Eychmüller S.2, Forster M.1, Haile S.R.3

1Cantonal Hospital, Centre of Palliative Care, St.Gallen, Switzerland
2University Hospital Berne, Center of Palliative Care, Berne, Switzerland
3Cantonal Hospital, Clinical Trials Unit (CTU), St.Gallen, Switzerland

Aim and objective: Recognition of the dying process is a key area to address. But clinical assessment of time and condition at which a patient enters the last days of life is
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a challenge and not much research has been done on this topic. Based on results from a literature review and an international Delphi process (OPCARE9), the aim of this study is to construct a clinical tool to recognize imminent death.

**Study design and methods:** prospective, observational, longitudinal, multicentre study. A population of patients included by surprise question (estimated survival < 1 week) in various care settings has been observed every second day during max. 7 days (4 times) by the responsible nurse/physician (by structured questionnaire and written specification for each observational category).

**Statistical analysis:** Sensitivity and specificity of each criterion has been estimated and summarized using AUC of the corresponding ROC curve. Best fit models are chosen. Written specifications are analysed by content analyses.

**Results:** 521 observations (246 patients) were collected and included for analyses. 77% of patients died during observation time. Main care setting: hospital; main diagnosis: cancer; mean age: 72. After multiple logistic regression “best models” were analysed. 2 out of initial 10 categories (“change in breathing”, “gut feeling/ intuition”) were included in all best models. In cancer patients (hospital) “changed cognition” and “reduced intake” are significantly indicating dying.

**Conclusion:** 2 clinical criteria, well known as items of other prognostic tools (e.g. PaP Score), appeared as essential for recognizing the dying phase. A clinical tool will be tested prospectively in the next phase of this project. Discussions within the care team and with the family should accompany the clinical process of diagnosing dying for improving sensitiveness of this approach as well as to avoid potential harm/ misdiagnosis.

**Funding:** The project is funded by Swiss Cancer Research.

**Abstract number:** P191

**Abstract type:** Poster

“Trauma, Protection, Integration and Growth - Bereavement Questionnaire” (TPIG-BQ): Development and Initial Validation

García J.1, Pavás A.2, Vivo J.-M.3, Camacho D.4, Andonegui I.5

1Basque Health Service, Centro de Salud de Kueto, Sestao, Spain, 2Instituto de Psicoterapia Integrativa-Relacional en Pérvida, Dueto y Trauma, Barcelona, Spain, 3Universidad de Murcia, Murcia, Spain, 4Alalia - Centro de Atención al Dueto, Madrid, Spain, 5Bidegin - Servicio de Apoyo al Dueto, Donostia, Spain

Trauma, Protection, Integration, and Growth - Bereavement Questionnaire (TPIG-BQ) is a new instrument designed to assess the presence of these four dimensions in bereaved adults, proposed elsewhere by one of the authors (AP). TPIG-BQ focuses on the trauma level of the experience, the balance between avoidance and connexion responses, and the meaning making and growth experienced by the bereaved. The specific object of this project was to develop and validate the TPIG-BQ.

**Study design and methods:** A questionnaire validation pilot study with a mixed design, transversal and longitudinal, was implemented. Thirty-five bereaved people (21 female, mean 49.63 y/o, range 29-70 y/o) were recruited: 22 had lost a child, 9 a partner, and 4 a parent; all of them were asked for verbal informed consent before their participation. TPIG-BQ is a paper-pencil and self-administered questionnaire. TPIG-BQ was initially designed with 78 five-point Likert items, and after a qualitative and quantitative item selection process it was finally reduced to 40. The items were specifically created by the researchers or extracted from different validated questionnaires on death, grief, bereavement and terminal illness. TPIG-BQ psychometric properties were evaluated through the internal consistency reliability (Cronbach’s alpha), test-retest reliability, construct validity (factorial analysis), and concurrent validity.

**Results:** TPIG-BQ Cronbach’s alpha was 0.64. TPIG-BQ factorial analysis (Varimax rotation) produced four factors that explained the 60.15% of the variance in the data and corresponded with the four dimensions TPIG. Agreement between TPIG clinical evaluation and TPIG-BQ was 65%.

**Conclusions:** TPIG-BQ seems to capture the four TPIG dimensions of the bereavement experience. TPIG-BQ can be very useful to clinicians as a tool for selecting intervention strategies. These preliminary results need to be confirmed in a suitable sample of bereaved people.

**Abstract number:** P192

**Abstract type:** Poster

The Caregiver’s Role in Palliative Care: A Systematic Review

Reigada C.1, Pais Ribeiro J.L.2, Novellas A.3, Tavares M.4, Gonçalves E.4, Pereira J.L.5

1Faculty of Psychology and Educational Sciences, University of Porto, São João Hospital Center, Palliative Care Service, Porto, Portugal, 2Faculty of Psychology and Educational Sciences, University of Porto, Porto, Portugal, 3University of Barcelona, Catalan Institute of Oncology, Barcelona, Spain, 4São João Hospital Center, Palliative Care Service, Porto, Portugal, 5Bryuère Continuing Care, Palliative Care Unit, University of Ottawa, Ottawa, ON, Canada

The presence of family members able and qualified to take care of patients in end-of-life is essential for patients to choose where to be treated. Caregivers are the main collaborators of palliative care (PC) teams. They assume roles
and tasks which ensure the care continuity. The aim of this study is to analyze the existing literature about the role of family caregivers in PC.

**Method:** A systematic review of the literature was conducted and the research question was: Which activities, responsibilities and roles are connected to the family caregivers? We searched in databases PubMed, EBSCO and SciELO, conjoining the keywords “palliative care,” “hospice”, “end-of-life”, “family”, “caregivers” and “role” (in English, Portuguese and Spanish language), from 2006 to 2012. We used the method of Hawker, Payne, Kerr, Hardey and Powell (2002) to evaluate the methodological rigor of the final articles. All articles were selected and analyzed by two independent reviewers.

**Results:** From 650 articles identified, only 7 answered the research question. They describe functions, responsibilities and roles of the family like: be a caregiver, promote welfare; do tasks; support physical and emotional care; encourage the PC teams and the continuity of care; be learners; manage the suffering; deal with therapeutic decisions; supervising and informers.

**Conclusion:** The family caregivers are an important support of patients in the end of their lives and they can be considered a central structure. It would be interesting to know how these caregiving roles are perceived by the caregivers themselves, patients and PC staff.

**Abstract number:** P193

**Abstract type:** Poster

**The Feasibility of Using Goal Attainment Scaling on an Acute Oncology Ward in Patients Advanced Metastatic Disease**

*Panchmatia N.*, *Urch C.*

1Imperial College Healthcare NHS Trust, Therapy Department, London, United Kingdom, 2Imperial College Healthcare NHS Trust, Palliative Care Department, London, United Kingdom

**Background:** Patient-centred goal setting is central to the interdisciplinary rehabilitation process. It yields effective rehabilitation outcomes, patient satisfaction and shorter length of hospital stay. Yet patient involvement in goal setting seems to be elusive in acute care, where the focus on medical treatment and rapid discharge does not allow translation of rehabilitation goal setting methods. The short time for therapy intervention means variance in the assessment and goal setting process which lacks a patient-centred approach.

**Aim:** To assess the feasibility of using the Goal Attainment Scaling (GAS) on acute oncology wards with patients diagnosed with advanced metastatic disease and explore patients’ experience of participation in the process.

**Study design:** A feasibility study.

**Setting and participants:** Patients referred to Occupational Therapy (OT) services during February to April 2012, were assessed for study inclusion. Out of 26 eligible 12 patients were recruited. The Goal Attainment Scaling – light (GAS-l) and Patient Opinion Survey were used to document goals, outcomes and patient experience.

**Results:** The pre and post intervention scores demonstrated a clinically significant change (mean change 12.77, +/- SD (9.03). The average length of time required to set goals was 33 mins (range 20-45 mins). The goal setting process was perceived to be beneficial and satisfactory.

**Conclusion:** The study results and patient experience indicates that the GAS-l was a useful outcome measure for a few selected patients of this population. In addition it helps to define ongoing (community) rehabilitation requirements.

**Abstract number:** P194

**Abstract type:** Poster

**Can Nurses Be Trained as Facilitators for Physicians’ Learning?**

*Pype P.*, *Mertens F.*, *Deveugele M.*

Ghent University, Department of Family Medicine and Primary Health Care, Ghent, Belgium

**Background:** In caring for palliative patients, general practitioners (GP) in Belgium collaborate with palliative home care teams (PHCT). GPs state to learn from this collaboration. Registration and literature seem to indicate that this learning process is indirect, unintentional and probably inefficiently. Training nurses to recognize and address learning opportunities might facilitate GP’s learning. There are no papers found reporting on a training program for nurses to act as a facilitator for GP’s learning. This study aims to fill in this gap.

**Aim:** To describe the development and evaluation of a training program for PHCT nurses, designed to facilitate GPs’ learning.

**Study design and method:** The content was based on literature of preceptor- and mentorship. The program consisted of a full day of training and half a day of a booster session three months later. Between training and booster session, homework assignments and individual feedback by telephone was provided. A summative assessment was done using a videotaped conversation. Semi-structured interviews were done to discuss personal experiences.

**Results:** Thirty-five nurses participated. The training was overall experienced as useful. The homework assignments showed to be fundamental to put theory into practice but interfered with the workload. Some program items were more difficult to practice (e.g. incident analysis), others were done easily (e.g. giving feedback). Practicing some trained items conflicted with workplace procedures.
or personal preferences of professional role. Twenty-five nurses took part in the assessment; fourteen passed (14/25=56%).

Conclusions: Palliative care nurses can be trained as a facilitator to enhance GPs’ learning in the workplace, although some do not prefer this role due to personal characteristics. Protected time is needed to enter the training. To develop such a training program, characteristics of the interprofessional collaboration and workplace organization should be considered.

Abstract number: P195
Abstract type: Poster

Palliative Care Referrals and Associated Outcomes among Advanced Cancer Patients in an Academic Medical Center

Ledoux M.1, Rhondali W.1,2, Teisseire M.1, Piegay C.1, Berthiller J.1, Couray-Targe S.1, Schott A.-M.1, Bruera E.1, Filbet M.1

1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative care, Houston, TX, United States, 3Hospices Civils de Lyon, IMER, Lyon, France

Background: Palliative care (PC) has a recognized role in the care of cancer patients at the end of life. However, referral occurs very late in the illness trajectory.

Aim: Our aim was to examine palliative care referral among advanced cancer patients and associated outcomes during their 2 last weeks of life in an academic medical center.

Design: We reviewed the medical records of 536 cancer inpatients who died in 2010. Our retrospective study compared patients who accessed PC services with those who did not. Nonparametric methods were used for statistical analyses. A multivariate logistic regression model including age, gender, type of cancer and metastatic status was conducted.

Results: 239/536 patients (45%) had PC referral before death. The most common cancer types were respiratory (22%) and gastrointestinal (19%). Patients with breast (OR,23.76; CI,6.12-92.18), and gynaecologic cancers (OR,7.64; CI,2.61-22.35) had significantly greater PC access. The daily cost of care for the last year was significantly lower (p=0.003) for PC patients. Patients referred to PC received less chemotherapy in the last 2 weeks of life (22 vs 59; p< 0.001). We found that nonreferred patients deaths were significantly more frequent in ICU (47 (16%) versus 2 (1%), p < 0.001) and in the Emergency Room (38 (13%) versus 5 (2%), p< 0.001), than referred patient.

Conclusions: There was a large variation in access to palliative care according to the location of death. Referred patients received less aggressive interventions during their 2 last weeks of life and last year cost of care was lower.

Abstract number: P196
Abstract type: Poster

Palliative Sedation in a Tertiary Palliative Care Unit

Castillo M.R., Garrido-Bernet B., Benitez-Rosario M.A.
Hospital Universitario Nuestra Señora de Candelaria, Unidad de Cuidados Paliativos, Santa Cruz de Tenerife, Spain

Objective: To assess the characteristic of the continuous palliative sedation (PS) until death in a palliative care unit of a university hospital.

Methods: We performed a retrospective analysis of a sample of the medical charts of the patients who died in 2010. Sample was designed to provide 85% power with a type I error of 0.05 for an estimated sedation rate of 50%. 11 randomized medical charts were selected from every month. Patients and treatment characteristics were collected. Opioid doses were expressed as oral equivalent morphine. Data were described as median and percentages. Kolmogorov - Smirnov, Mann-Whitney U and Spearman correlation, Pearson χ² tests were performed for statistical analyses. SPSS 21 was used.

Results: 127 of 330 medical charts were analyzed. 79% of patients were sedated. PS was not associated with sex (p=0.2), age (72 versus 69 years;p=0.5) and cancer type (digestive 35%, lung 27%, others cancers 32%, non-cancer 6%). 71% were sedated by delirium with signs of respiratory failure; no one by pain. In 90% of the patients, sedation was started in the last 2 days before death (median 18 hours, min-max:0.5-140). The agreement of the patients or family with PS was reported in all charts. Sedated and nonsedated patients did not differ in survival: a) after admission (3 vs 3.5 days;p=0.9), b) since the diagnosis of dying was recorded on the patient charts (2 vs 1.5 days;p=0.9). Sedated and nonsedated patients did not differ in opioid doses (60 vs 40 mg/d;p=0.06). In 98% of the patients, midazolam (MDZ) (72 mg/d;min-max 30-288) was used for sedating. MDZ doses were not related with sex (p=0.7), opioid doses (rho=0.1;p=0.1), age (rho=-0.1;p=0.06), excessive alcohol consumption (p=0.9), and prior anxiolytic treatment (p=0.6). MDZ doses was related with head and neck cancer (95 vs 70 mg/d;p=0.05).

Conclusions: Palliative sedation was started in the last days of the life to relieve delirium and dyspnoea suffering. Survival was not affected.

Abstract number: P197
Abstract type: Poster

Do Hospital Palliative Care Support Teams Really Have the Necessary Means for their Ambitions?

Results from a Nationwide Survey in France

Morin L., Aubry R., Nectoux M.
French National Observatory on End of Life Care, Paris, France

Aims: Hospital palliative care support teams have been widely developed in France since the late 90s, in order to facilitate access to advice and support for non-specialist professionals. But the recent policy incentives to broaden their clinical activity and to spread the palliative care approach in long-term care facilities and in nursing homes contribute to raise a concern: do hospital palliative care support teams really have the means to face this challenge?

Methods: This survey was conducted between July and October 2012 amongst all hospital palliative care support teams in France. Questionnaire was sent electronically, and included 380 items related to the organization, the composition, the clinical activities and the teaching and research activities of the team. Quality-check was performed to ensure the reliability of the data.

Results: Response rate was 84% (297 of 353). While only 19% of the teams created before 1999 count less than 1 physician (FTE), this is the case of 48% of the teams created between 2006 and 2012. However, each team provides advices and support for 361 patients per year on average, most of the time in hospital wards (93%): this clinical activity is mainly focused on oncology, internal medicine, gastroenterology and pulmonology units, whereas intensive care, geriatric and long-term care units are rarely visited. Furthermore, despite the recent development of "partnership conventions" with nursing homes and other residential facilities, elderly residents still represent less than 5% of the clinical activity. In addition, if 88% of the teams provide training for non-specialist professionals within their hospital, only 46% of them give training in nursing homes.

Conclusion: The recent development of Palliative Care in France has led to the creation of smaller Palliative Care Support Teams, which clinical activity is mostly dedicated to acute inpatient units, whereas the need for palliative care mentoring in residential facilities is rising.

Abstract number: P198
Abstract type: Poster

MASCC Palliative Care Leadership Survey: Palliative Care Program Structure

Davis M.1, Strasser F.2, Cherny N.3

1The Harry R. Horvitz Center for Palliative Medicine, Department of Solid Tumor Oncology, Taussig Cancer Center, Cleveland Clinic, Cleveland, OH, United States, 2Kantonsspital, St Gallen, Switzerland, 3Shaare Zedek Medical Center, Jerusalem, Israel

Background: Palliative care (PC) program structure is diverse and evolving. This MASCC survey queried palliative care leaders internationally regarding program structure, service research and education.

Methods: A survey adapted from Hui et al was used. Palliative care leaders were contacted through MASCC, ESMO and EAPC to complete this survey on the MASCC website.

Results: 62 program leaders completed the survey. Overwhelmingly, most services included outpatient clinics (82%) inpatient consultation services (80%) and dedicated inpatient palliative beds (62%) Most programs were small, with 2 physician FTEs. Leaders were commonly from Med Oncol, Int.Med, Anesthesics and family medicine. All services incorporated inpatient and outpatient nursing services. Paramedical staffing was less consistent: dieticians 66%, pharmacist 46%, psychologists 88%, social workers 84%. 75% of services indicated that most referrals were > 4 weeks before death, 25% reported referrals less than a month prior to death. Symptoms were by far the most common reason for referral to inpatient PC, other reasons included terminal care, psychosocial issues and respite. Average LOS 10 days and mortality 40%. Half of programs had weekly grand rounds; half required rotations for medical oncology-hematology fellows.

Discussion: Most PC programs incorporate inpatient consultation services, outpatient clinic services and inpatient acute palliative care beds. A substantial minority do not have dedicated acute palliative inpatient services. Staffing levels are often low with small and constricted teams carrying very large clinical loads. Protected time for research and teaching is limited.

Conclusion: Defining characteristics and scope of services anticipated from a palliative care service is still developing. Program development is hampered by inadequate allocation of resources to effectively staff interdisciplinary academic and clinical services.

Abstract number: P199
Abstract type: Poster

Non-pharmacological Interventions to Decrease Anxiety in Advanced Cancer Patients: A Systematic Review

Zweers D.1, de Graaf E.2, Teunissen S.3

1University Medical Center Utrecht, Medical Oncology, Utrecht, Netherlands, 2Academic Hospice Demeter, De Bilt, Netherlands

The aim was to make an inventory of non-pharmacological interventions and their effectiveness to provide evidence based knowledge to manage anxiety in advanced cancer patients. Randomized controlled trials found in Pubmed, Embase, Cinahl, PsychINFO were included. Outcomes of interest were i) anxiety: described as a symptom due to progressive illness and/or side effects of treatment and ii) Quality of Life (QoL)/Quality of Dying (QoD) with a focus on physical, psychological, social and spiritual
aspects. Two authors independently assessed potentially relevant studies. Methodological quality were analyzed by using the risk of bias tool consisting of:

1) random sequence generation,
2) allocation concealment,
3) blinding of participants and personnel,
4) blinding of outcome assessment,
5) incomplete outcome data,
6) selective reporting,
7) sampling and
8) other bias.

The heterogeneity of the studies makes it inappropriate to pool the results together. So this review presents a descriptive synthesis of the most common interventions.

Three categories of interventions were found: 1) telemonitoring and education, 2) psychotherapeutic and 3) complementary care interventions. Only 4 of the 16 included studies showed significant improvement in the experienced anxiety within group differences. Probably a loss of power causes these findings. We cautiously conclude that integrated treatments are more effective than single interventions. The intervention(s) should be based on patient’s needs and the underlying cause(s) of anxiety, give patients the opportunity to tell their story, evaluate and monitor anxiety at scheduled times, effective in a short time period, based on physical, psychological, social and existential aspects and accessible in an easy way.

Future research is needed to understand why some of the interventions are effective. Quality of life remains the ultimate goal of palliative care whereby management of anxiety is still a major challenge.

Abstract number: P200
Abstract type: Poster

Palliative Care Needs in Terms of Signs, Symptoms and Health Related Quality of Life (HRQoL) among Patients with Advanced Chronic Heart Failure

Årestedt K.1, Strömberg A.1, Jaarsma T.2, Öhlén J.3, Henriksson A.1

1Linköping University, Department of Medical and Health Sciences, Linköping, Sweden, 2Department of Social and Welfare Studies, Linköping University, Linköping, Sweden, 3Palliative Research Centre, Ersta Sköndal University Collage and Ersta Hospital, Stockholm, Sweden

Purpose: Despite that chronic heart failure is associated with a poor prognosis, only few patients receive palliative care. Among patients with advanced stages of heart failure, previous studies have mainly focused on solitary specific signs or symptoms and few have described the patients' situation from a more comprehensive perspective. The aim was therefore to undertake a comprehensive description of potential palliative care needs in terms of signs, symptoms and health related quality of life (HRQoL) among patients with advanced chronic heart failure.

Methods: The study included 72 patients with advanced chronic heart failure (NYHA III and IV), taken from a larger multi-centre study. The study variables included demographic data, medical and nutritional status, sleeping disordered breathing, physical activity, self-perceived symptoms and HRQoL, and cognitive function.

Results: A large number of the patients scored appetite levels at increased risk for weight loss (53%), scored mild or worse depressive symptoms (47%), was short of breath in rest (43%), and had moderate or worse pain (82%). Mobility problems were common (72%) as well as problems conducting usual activities (33%). Problems with low physical activity according to average number of steps (2691±2022) and METs (1.0±0.2), insomnia (64%), daytime sleepiness (44%) and sleep disorders breathing (AHI ≥ 15, 56%) were common. The mean BMI was high (30.2±5.7) and 18% had albumin levels ≤ 35 (mean 38.8±3.7). Impaired cognitive functioning was also common (MMSE ≤ 27, 54%). HRQoL was in general low, but with a great individual variance (EQ-index 0.65±0.22; EQ-VAS 50.8±17.6).

Conclusion: Despite that none of the participants received palliative care, this comprehensive description shows that these patients with heart failure have complex health care needs. Therefore, health professional should focus on palliative care needs earlier in the disease trajectory.

Abstract number: P201
Abstract type: Poster

Palliative Care and Pre Hospital Emergency Services: A Marriage of Convenience to Drive Innovation at the End of Life

Garcia-Baquero Merino M.T.1, Quiros Navas E.2, Fernández Gómez M.C.2, Molina Cara C.2, Azuara Rodriguez L.2, Monleón Just M.2

1Coordinación Regional de Cuidados Paliativos, Consejeria de Sanidad, Comunidad de Madrid, Madrid, Spain, 2PAL24, Coordinación Regional de Cuidados Paliativos, Consejeria de Sanidad, Comunidad de Madrid, Madrid, Spain

Background: Continuity of care in End of Life is a clinical concern and a priority for policy makers. Aim. This initiative provides round the clock specialist palliative care for a 6.3m population by interconnecting and coordinating creatively PC teams, pre-hospital emergency professionals and providers 24 hours a day.

Methods: Retrospective analysis of number of patients, caregivers, primary, secondary care and pre-hospital
emergency professionals, that contacted platform; reason for calling, range of responses and resulting outcome for first two years. The service combines PC expertise with the technological and logistic infrastructure provided by regional Emergency Services (SUMMA112). It supports and advises patients, caregivers and professionals from all levels of care, in particular pre-hospital emergency services with whom they can do home visits.

Results: This Emergency Palliative Care Support Team has 41000 contacts, relating to 13503 patients, dealt with 63.6% of which came during normal working hours- 70.6% initiated by carers, 3.7% by Emergency professionals. 71% of the patients were over 65 with 83% of the total included in the regional Palliative Care Program. Most frequent aetiology: oncological (91%); pain (11.7%) being the most common symptom 54.8% of calls were resolved by specialist advice without resource or patient mobilization. Visits to emergency department have dropped by 67%.

Conclusion: Our platform shows:

(1) how combining PC expertise, modern IT, with up to date medical records, underpinned by existing (emergency) services with advanced infrastructures, offers round the clock continuity of care for those at EoL.
(2) Avoids unnecessary transfers to A&E departments.
(3) Makes all Palliative Care resources available 24 hours a day.
(4) Most issues prompting calls are resolved with minimum patients distress.
(5) The platform is recognised as the best supportive and training unit for pre hospital emergency professionals.

Abstract number: P202
Abstract type: Poster
Burden of Nursing Staff Caring for Nursing Home Residents with Dementia at the End of Life

Albers G.1, Vander Stichele R.2, Van den Block L.1, On behalf of EURO IMPACT

1Vrije Universiteit Brussel, End-of-life Care Research Group, Ghent University & Vrije Universiteit Brussel, Department of Family Medicine, Brussel, Belgium,
2Heymans Institute of Pharmacology, Ghent University, Ghent, Belgium

Background: With the growing number of people with dementia dying in nursing homes, nursing staff in nursing homes have an important role in providing care for people with dementia at the end of life.

Aim: To investigate how often nursing staff perceive caring for nursing home residents with dementia at the end of life as an emotional and/or physical burden, and to identify associated factors.

Methods: A postmortem study conducted in 2010 in Flanders, Belgium. Nursing homes were selected through random cluster sampling. All residents who died with dementia within a 3-month period were reported. For each case a structured questionnaire was completed by the nurse most involved. Nursing staff were asked to indicate how they perceived the burden of caregiving for this resident on a 10-point scale.

Results: We identified 198 deceased residents in 69 nursing homes (58% response rate). In respectively 37% and 32% of the cases nursing staff perceived high emotional and physical burden. Pearson correlation coefficient between emotional and physical burden was 0.5 indicating a moderate correlation. When the resident was competent for decision-making during the last week of life and when the nurse spoke with relatives about wishes for medical end-of-life treatments, nursing staff more often reported emotional burden. Physical burden was more frequently perceived when the resident had decubitus or pneumonia.

Conclusion: A considerable number of nursing staff experience high emotional and/or high physical burden when caring for people dying with dementia in nursing homes. While physical burden of nursing staff seems to be related to a poorer clinical status of the residents, emotional burden was more related to more and closer contact with resident/relative and being involved in the process of care and decision-making in the last phase of life. Our findings highlight the importance of supporting nursing home staff in providing compassionate end-of-life care for people with dementia.

Abstract number: P203
Abstract type: Poster
Promoting a Better Understanding of Dying at Home in England: A Narrative Analysis from the ‘Unpacking the Home’ Study

Payne S.A.1, Soroka J.T.2, Firn J.3, Gale B.1, Turner M.1, Thomas C.1

1Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 2Mayo Clinic Health System Hospice, Mankato, MN, United States, 3University of Michigan, Palliative Care Program, Ann Arbor, MI, United States

Background: In the UK, there is a key policy directive to increase the proportion of people dying at home. Family carers are crucial to enable patients to remain at home but there is evidence that they find the role demanding and receive inadequate support. Little is known about how carers make sense of their experiences of caring and how it impacts on their understanding of ‘home’.
**Aim:** To examine accounts of bereaved family carers describing how the home is transformed in the process of providing end of life care, and the ways in which these changes impact on them.

**Methods:** In-depth audio-recorded interviews elicited accounts of end of life care at home in two diverse regions of England: the South West and the North West. Transcripts were coded using a narrative analysis framework to identify narrative threads.

**Results:** 30 family carers who delivered care to a patient dying from cancer or other non-malignant condition who spent ≥2 weeks at home (median 10.5 months, range 2 weeks-11 years) were recruited (54% response rate). The majority were female spouses (n=23) and 37% were aged ≥80 years (median 73.5 years, range 44-88 years.). Carers were pleased that the death occurred in the home although witnessing and supporting this was a demanding experience, especially if dying was prolonged. They found that both practical and emotional support were essential to a dignified and acceptable death, but often preferred to delay input from professionals until absolutely necessary. They reported a lack of information about the scope of services, and how to co-ordinate them. Carers felt their home space disrupted, but most continued to live there after the death.

**Conclusion:** Retrospective narratives revealed that caring for dying patients at home was a positive experience for all the family carers despite challenges, interruptions to the feel of the home and suffering caused by witnessing distressing symptoms of dying.

**Funded by:** Marie Curie Cancer Care

**Abstract number:** P204

**Abstract type:** Poster

**Factors Associated with Feelings of Reward during Ongoing Palliative Family Caregiving**

****Årestedt K.**1,2, Carlander I.**2, Henriksson A.**2

1Linköping University, Department of Medical and Health Sciences, Linköping, Sweden, 2Palliative Research Centre, Ersta Sköndal University Collage and Ersta Hospital, Stockholm, Sweden

**Objectives:** Of the few studies that have paid attention to feelings of reward in palliative family caregiving, most are retrospective and examine the experiences of bereaved family caregivers. Although feeling rewarded has been described as an influence that may facilitate the way family caregivers handle the caregiving situation, no study has sought to identify factors associated with feelings of reward while providing ongoing family palliative care. The aim of this study, therefore, was to identify influential factors in feelings of reward in family palliative caregivers.

**Methods:** The study had a correlational cross-sectional design. Family caregivers (n = 125) of patients receiving specialized palliative care were consecutively recruited from four settings. These caregivers answered a questionnaire including the Rewards of Caregiving Scale (RCS). The questionnaire also included questions about demographic background and scales to measure preparedness for caregiving, feelings of hope, perceived health, and symptoms of anxiety and depression. Correlation and regression analyses were conducted to identify factors associated with rewards.

**Results:** The results showed that more prepared caregivers with higher levels of hope felt more rewarded, while caregivers with higher levels of anxiety and those in a spousal relationship to the patient felt less rewarded by caregiving.

**Significance of results:** It seems reasonable that feeling rewarded can significant to the overall experience of providing ongoing palliative care. The situation of family caregivers has been shown to be multifaceted and complex, and co-varying factors such as preparedness, anxiety, hope, and being in a spousal relationship with the patient influence the experience.

**Funded by:** Marie Curie Cancer Care

**Abstract number:** P205

**Abstract type:** Poster

**Use of Drugs at the End of Life in a Palliative Care Unit: Influence of Information Level and Emotional Dimension**

Rodriguez Valcarce A.A., Exposito Blanco A.A., Gonzalez Billalabeitia M.M.

Hospital Santa Clotilde, Palliative Care, Santander, Spain

**Objective:** Influence of emotional situation and level of information in the use of drugs at the end of life during 2012.

**Material and method:** Descriptive and Retrospective Study in all inpatients discharged in Palliative Care Unit from the 1st January to 31st of December 2012. Systematic Review of all clinical reports getting social, demographic, clinic, emotional patterns, and Knowledge of disease on admission.

**Results:** 157 inpatients: 137 (87.26%) oncologic disease and 20 (12.74%) other conditions. Mean of stay 33.67 +/- 38.69 days: rank 0-208, median 19. Mean age: 71.53 +/- 12.18 years: rank 29-95. 83 males (52.87%). 13 (8.28%) returned home; 4 (2.55%) were referred to Acute Unit; 6 (3.82%) were discharged to a Nursing Home and 134 (85.35%) died: 92 (69.41%) clinical evolution, 14 (10.45%) acute complication, and 27 (20.15%) palliative sedation.

87 (55.41%) Knew diagnosis and 25 (15.92%) Knew prognosis. 115 (73.25%) used opioid drugs, 88 (56.77%) non-steroidal anti-inflammatory drugs, 92 (58.97 %) benzodiazepines, 66 (42.31%) corticosteroids, 35 (22.44%) neuroleptics, 16 (10.26%) anticonvulsants, 15 (9.62%)
antidepressants on admission. Mean of drugs 5.60 +/- 2.41: rank 2-15. 31 (19.75%) inpatients suffered anxiety on admission. During stay 87 (55.41%) received psychological support: 42 (48.27%) had emotional distress on admission. Impatients suffered anxiety used more drugs (p 0.01). The patients who Knew their diagnosis did not use more drugs, but Knowledge of prognois increased the use (p 0.0591). We did not find statistically significant differences in dosage of opioid among inpatients with anxiety or not. We did not find differences in number of drugs used in relationship with emotional distress.

Conclusions: Not influence in the use of drugs in patients who Know their diagnosis, but the Knowledge of prognois increased the used of drugs in palliative care. The anxiety symptom is in relation with a more used of drugs but emotional distress is not.

Abstract number: P206
Abstract type: Poster
Plasmatic Level of Interleukines, Pain and Opioid Doses in Advanced Cancer Patients
Castillo M.R.1, Benitez-Rosario M.A.1, Abreu-González P.2, Feria M.3
1Hospital Universitario Nuestra Señora de Candelaria, Unidad de Cuidados Paliativos, Santa Cruz de Tenerife, Spain, 2Universidad de la Laguna, Departamento de Fisiología, Santa Cruz de Tenerife, Spain, 3Universidad de la Laguna, Departamento de Farmacología, Santa Cruz de Tenerife, Spain

Objective: We assessed if pain and opioid doses were related with interleukins plasmatic levels (IL) in terminal cancer patients.

Methods: In this prospective cohort study we included cancer patients attended by our palliative care service and they were followed until death. Informed written consent for the study was gained from every patient. Plasmatic IL were determined in the first evaluation of the patient. For the analysis, patients were categorized in 2 groups according to the presence of any type of pain in the illness course. Opioid doses were recorded as equivalent morphine doses (EMD) at the moment of death. SPSS 21 was used to perform Kolmogorov - Smirnov, Mann-Whitney U, Spearman correlation tests and logistic regression, stepwise forward, as statistical analyses.

Results: 248 patients (63 % male, 37% female) were included in the study. The median survival was 43 days (range 4-280). Mean of age, without difference between sexes (p=0.2), was 69 years (range 17-104). 63% of the patients experienced cancer pain, 65% males versus (vs) 35% females (p=0.4). Levels of IL (pg/ml) were not statistically different between patients with / without pain: IL1b (7.1 vs 3.8; p=0.5); IL2 (44.5 vs 38;3;p=0.4); IL6 (12.0 vs 15.5; p=0.1); IL10 (25.9 vs 27.1;p=0.6). Median of EMD was 60 mg/d (range 10-900), it was related with age (rho = -0.3;p=0.000), but not with the sex (p=0.3). IL were not related with EMD in cancer pain patients: IL1b (rho=0.03;p=0.6), IL2 (rho=0.1;p=0.9), IL6 (rho=-0.1;p=0.07), IL10 (rho=0.1;p=0.2); but IL2 (pg/ml) (33 vs 42;p=0.02) and IL6 (pg/ml) (11 vs 15;p=0.01) were associated with EMD≥ 3th quartile (180 mg/d). On logistic regression analysis only age (B= -0.03; p=0.003) and IL2 (B= -0.008; p= 0.005) were inversely associated with EMD≥3th quartile.

Conclusions: Plasmatic levels of IL were not related with pain. Opioid requirements ≥180 mg/d were inversely related with IL2 in advanced cancer patients with pain.

Abstract number: P207
Abstract type: Poster
Parenteral Nutrition Survey - Do we Prescribe According to Guidelines?
Simanek R.1, Nestor K.2, Bozzetti F.3, Chasen M.4, Fearon K.5, Jatoi A.6, Lundström S.7, Muscaritoli M.8, Orrevall Y.9, Watzke H.10, Strasser F.2
1Hietzing Hospital, 5th Medical Dept. with Oncology, Vienna, Austria, 2Kanton Hospital St. Gallen, Department of Internal Medicine and Palliative Care Center, St. Gallen, Switzerland, 3University of Milan, Faculty of Medicine, Milan, Italy, 4University of Ottawa, Division of Palliative Care, Ottawa, ON, Canada, 5University of Edinburgh, Department of Clinical Surgery, Edinburgh, United Kingdom, 6Mayo Clinic, Department of Medicine, Rochester, MN, United States, 7Stockholms Sjukhem Foundation, Department of Palliative Medicine, Stockholm, Sweden, 8Sapienza University of Rome, Department of Clinical Medicine, Rome, Italy, 9Karolinska Institute, Department of Clinical Science, Intervention and Technology, Stockholm, Sweden, 10Medical University of Vienna, Department of Internal Medicine I, Vienna, Austria

Aims: Indications for parenteral nutrition (PN) in patients with incurable cancer and malignant bowel obstruction remain controversial. We aim to investigate indications of PN by survey selected experts on the basis of their experience.

Methods: Internet-based survey investigating decisions on PN in patients with malignant bowel obstruction based on two case-vignettes. We analysed the participants’ answers regarding indications of PN and compared them to current guidelines (ESPEN, ASPEN) and the cancer cachexia classification.

Results: Eighty-one participants completed the survey. Forty-eight of them (59.3%) recommend PN in case of malignant obstruction routinely, 72.7% in cases where secondary causes of decreased nutritional intake exist.
Reversibility / improvement of oral intake does not influence the decision on starting PN for 26.6%, 31.6% would wait with PN if oral intake was expected to increase to 60% of normal within the next weeks, 69.6% if reversibility was expected in < 2 weeks. There was no consistent opinion on the impact of the patient’s desire for PN. PN is recommended in patients with a Karnofsky-index > 50 by 88.6%, 34.1% recommend PN in patients with progressive disease and new planned anti-cancer treatment. 43 participants (53.8%) recommended PN in precachexia and cachexia, only 13.8% recommend PN in refractory cachexia, another 13.8% made no recommendation. The guidelines recommend PN in intestinal failure and if inadequate food intake is anticipated for more than 10 days. PN should be offered as requested by the patient but not routinely as adjunct to anti-cancer treatment, an acceptable performance status is assumed. According to the cachexia classification there is no evidence for benefits of PN in refractory cachexia.

**Conclusion:** Most of the participants recommend PN according to guidelines and the cachexia classification. A large heterogeneity of views and understanding of cachexia affects prescribing modalities of experienced clinicians.

**Abstract number:** P208
**Abstract type:** Poster

**Palliative Sedation for Terminal Patients: Family Concerns and Levels of Grief**

*Lin C.-C.*
Taipei Medical University, Taipei, Taiwan, Republic of China

**Aims:** To determine the family concerns and levels of grief in palliative sedation.

**Methods:** The survey of the families of cancer patients who received palliative sedation at ICU in one of the medical center in Taipei. The questionnaire survey assessed 406 death patients in the ICU and 62 bereaved families participated.

**Results:** There were 31 participants whose families used palliative sedation therapy; the other 31 participants’ families in the ICU did not use palliative sedation therapy. According to the result, the terminal patients whether used palliative sedation therapy or not, the levels of their families’ grief did not show significant influence. Only when the palliative sedation therapy was given continuously, we could find the longer the therapy was applied, the lower the level of the bereaved families’ grief would achieve. In Taiwan, 44.8% of patients in the ICU used palliative sedation therapy. The average duration of using palliative sedation therapy until to death was 11.43 days. Most of these patients continually and routinely used palliative sedation therapy. It was similar with other foreign research. However, this study found that families of these terminal patients still had some concerns about using palliative sedation therapy.

**Conclusions:** It expects that knowing this result can help health professionals to understand the feelings of families of terminal patients in the ICU and to communicate with these families timely and early. It will allow patients and their families to have more time to consider the situations and to communicate each other, in order to help patients in the ICU care process to achieve optimal symptom control and high-quality care.

**Abstract number:** P209
**Abstract type:** Poster

**Identifying and Changing Attitudes toward Palliative Care in Ireland: An Exploratory Study**

*McLoughlin K.E.*, *McGilloway S.*

1The Irish Hospice Foundation, HFH, Dublin, Ireland, 2NUI Maynooth, Psychology, Maynooth, Ireland

Research suggests that palliative care is poorly understood and often associated with imminent death. This, in turn, can negatively impact upon the transition to palliative care services.

The aims of this three phase, multi-method study were to:

1. examine and compare the attitudes of health professionals toward palliative care;
2. examine and compare the attitudes and personal constructs of patients and carers; and
3. to examine potential educational strategies to change attitudes.

Phase One used a postal survey (HPAQ) to assess health professionals’ attitudes toward, and understanding of, palliative care (182/700) and one-to-one interviews (n=5). Attitudes toward palliative care, measured by the HPAQ, were explained by a number of key factors including:

1. knowledge of SPC services;
2. relationships; and
3. personal reflection on mortality.

Thematic analysis of interview data further developed this factorial model.

Phase Two utilised one-to-one semi-structured interviews (n=30) and quantitative measures (n=75) to identify and compare attitudes toward, and experiences of, palliative care amongst patients receiving palliative care services (n=15), people living with cancer (n=25) and their carers (n=35). Repertory grids (n=12) were used for further exploration.

Thematic analysis revealed four key themes and associated subthemes, describing patients’ and carers’ attitudes toward palliative care.
The findings were used to inform the development of two health professional and patient interventions for Phase Three that aimed to:

1. provide information about palliative care services;
2. utilise the patient ‘voice’ and story;
3. focus on the health promoting benefits of palliative care; and
4. demystify hospice, palliative care and the dying process.

The study adds to the small pool of evidence and the use of the repertory grid technique, in particular, offers an interesting psychological tool for investigating palliative care research and practice.

Abstract number: P210
Abstract type: Poster

Fears Related to Death and Dying: A Representative National Survey in the Czech Republic

Závadová I.
Mobil Hospice Cesta Domů, Prague, Czech Republic

Aim: The aim of this survey was to investigate fears related to death and dying in the Czech Republic (CZ).

Study population: A representative sample of Czech population (N=1147) older than 15 years of age. The sample was weighted for age, gender, education and geographical region to achieve the representativeness for the whole population in the CZ.

Methods: This study was a part of a large survey conducted by hospice Cesta Domu and marketing agency STEM/MARK in August 2013, focused on public opinion on death and dying in CZ. Respondents in age of 15-59 years were interviewed using the Computer Assisted Web Interviewing method and older respondents using the Computer Assisted Personnel Interviewing. The question was “What do you fear most about dying?” with multiple response options. Descriptive statistics and chi-square test were used to assess the associations between responses and various demographic variables.

Results: The fears indicated by respondents were loss of dignity (47%), pain (41%), separation from family and friends (28%), loneliness (21%), psychological deprivation (15%), and afterlife (13%). 6% of respondents indicated that they do not fear anything related to death and dying (males more than female, p<.05) and 10% of respondents did not know (respondents in age of 60 years and older more often than younger respondents, p<.05). Respondents with experience of having somebody close dying in an institution were more likely to indicate fear of psychological deprivation than respondents who did not have this experience (p<.05).

Conclusion: These results highlight the importance of palliative care that is focused on patients’ quality of life, preservation of patients’ dignity, pain control, and role of family, which were indicated as the most significant fears related to dying. Promotion of palliative care is essential to ensure that public and health care professionals understand the role of palliative care.

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Abstract number: P211
Abstract type: Poster

The Influence of an Mobile Geriatric Consultant Service in a Long Term Care Institution on Advanced Care Planning

Pilgram E.H.1,2, Reicher M.1, Roller R.E.1, Schippinger W.1,2
1Geriatric Hospital Graz, Internal Medicine, Graz, Austria,
2Geriatric Hospital Albert Schweitzer, Graz, Austria,
3Medical University of Graz, Department of Geriatrics, Graz, Austria

Introduction: There is lack of international research on advanced care planning in nursing homes. It was the aim of this survey to evaluate advanced care options in nursing homes and to look at the influence of an mobile geriatric consultant service (GECO) at documented DNR-(do not resuscitate) orders in one urban nursing home.

The increasing number of older - disabled people necessitates development within long term care settings. Despite the challenging medical situation of these people, support is limited to primary care physicians. As a consequence many of the nursing home residents are admitted to emergency departments in the last hours of their life. This causes a detrimental burden affecting the patients’ somatic, psychological and spiritual status and of their relatives too.

Methods: A cross country survey was performed from February 2013 - August 2013. To assess the documented prevalence of DNR - orders a structured questionnaire was developed and distributed to a total of 200 nursing homes in the region of Styria/Austria and also to the nursing home, which is supported by GECO since 2011.

Results: The survey response rate was 44 % (88 nursing homes), representing 5255 residents (3811 ♀ / 1339 ♂).

An explicit DNR-order by a medical doctor is found only in 209 (3,98%) of all residents.

In the GECO-nursing home (97 residents; 79♀ /18♂) there are 38 (39,2%) DNR orders documented.

Conclusion: Our results prove that end of life orders are not regularly present in patient documentation - even though the topic of end-of-life decisions is essential in everyday nursing home discourse. And our survey shows that a mobile medical geriatric consultant service can ensure best supportive care for older people in long term insitutions by supporting nurses and family doctors.
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Abstract number: P212
Abstract type: Poster

Care of the Dying Cancer Patient - Recommendations of the National Palliative Care Guideline in Germany

Doll A.1, Simon S.1, Geffe V.1, Pralong A.1, Bausewein C.2, Voltz R.1, Ostagthe C.1, on behalf of the German Guideline Group Palliative Care (funded by the German Guideline Program Oncology)

1University of Cologne, Department of Palliative Medicine, Köln, Germany, 2Klinikum der Universität München Campus Großhadern, Klinik und Poliklinik für Palliativmedizin, München, Germany,

Background: To improve the quality of end of life and palliative care in cancer patients the German Association of Palliative Care initiated the development of an evidence based guideline for palliative care. One of the 7 priorities is “Care for the Dying Cancer Patient”.

Methods: In an initial consensus process of multiprofessional and interdisciplinary experts, key questions were determined. A systematic literature search on the key questions was conducted. Based on the existing evidence and clinical experience recommendations were developed. In an online Delphi consensus process, all recommendations were reviewed and adapted until an agreement rate of at least 75% was reached. This guideline will be finalized in a national consensus conference in November 2013.

Results: The following issues were regarded essential by the experts: diagnosing dying, basic attitudes, symptom management for delirium, death rattle, xerostomia, anxiety and agitation, pharmacological and non-pharmacological interventions, management of artificial nutrition and hydration, bereavement and team care, legal aspects and decision making. Overall 45 recommendations were developed (6 are evidence and 39 consensus based).

Conclusion: The existing evidence for the care of the dying is still low. However, through a broad multiprofessional expert consensus this first national guideline will have the potential to improve the quality of care of dying cancer patients in Germany. Further research on implementation is planned.

Abstract number: P214
Abstract type: Poster

Dyspnea, Relative Youth and Small Daily Dosages of Opioids Are Predictors of Increased Opioid Dosage in the Last 7 Days of Terminal Cancer Patients’ Lives

Miura T.1, Matsumoto Y.1, Motonaga S.2, Abe K.3, Kinoshita H.3

1National Cancer Center Hospital East, Department of Palliative Medicine, Kashiwa, Japan, 2National Cancer Center Hospital East, Department of Pharmacy, Kashiwa, Japan, 3Shimane University Hospital, Palliative Care Center, Izumo, Japan

Background: Most cancer patients have anxiety about suffering in their end-of-life stage. This anxiety can be
ameliorated by providing accurate information about expected escalation of opioid dosage as symptoms worsen. The objective of this study was to identify predictors of increased opioid dosage in the last 7 days of terminal cancer patients lives.

**Methods:** We retrospectively reviewed charts of patients who had died in our palliative care unit. We excluded patients who had died within 6 days of admission, had taken no opioids in the last 7 days, or were receiving continuous midazolam for status epilepticus. We assigned the remaining patients to increased group or decreased groups according to changes in oral morphine equivalent (OME) dosage in their last 7 days and analyzed relevant data to identify predictors of increased OME dosage in the last 7 days.

**Results:** We analyzed data of 158 patients (female: 43.7 %, median age: 64 years). The median OME dosages on days 7 and 1 before death were 50 mg (range 0-1520) and 60.8 mg (range 3-1784), respectively. Step-wise logistic regression analysis showed that independent predictors of increased OME dosage included dyspnea (OR 11.5; 95% CI, 4.98-28.83; P < 0.001), age < 65 years (OR 2.3; 95% CI, 1.04-5.26; P = 0.04) and OME dosage < 50 mg on day 7 before death (OR 3.7; 95% CI, 1.68-8.89; P < 0.01). The median OME dosages on day 7 and day 1 before death were 48 mg (range 0-1520) and 75 mg (range 3-1784) in those with dyspnea, 50 mg (range 0-1160) and 56.5 mg (0-820) in those with other reasons.

**Conclusions:** Dyspnea, relative youth and OME dosage < 50mg on day 7 before death are predictive of increased OME dosage in the last 7 days. This study was limited by its retrospective. However, our findings will help oncologists to more accurately inform patients about expected opioid requirements and thus relieve their distress about suffering in their last few days.

**Abstract number:** P215
**Abstract type:** Poster

**Palliative, Non-surgical Treatment of Malignant Bowel Obstruction (MBO) in Patients with Advanced Gynecological or Gastrointestinal Cancer: A PICO Question-based Critical Review of the Literature**

Heegaard H.B.1, Glud E.2

1Sankt Lukas Hospice, Hellerup, Denmark, 2Hillerød Hospital, Gyn, Hillerød, Denmark

**Background:** Malignant bowel obstruction (MBO) is a common complication of advanced cancer. Due to variability in criteria for and definition of MBO, the best management of these patients is controversial, and mainly based on expert opinions and non-systematic reviews.

**Aim:** For the first time, the “PICO” framework is used to systematically evaluate pharmacological treatment of inoperable MBO patients, with the purpose of making evidence-based clinical decisions. Four specific clinical research questions were formulated. The questions were defined in relation to treatment routines of MBO, considering the most common drugs used to treat MBO, as well as representing different mechanisms of action.

**Methods:** PubMed and Cochrane databases were searched for English and Danish literature published after 2000, using predefined search terms. The search yielded a reproducitive dataset of 579 studies. Data extraction tables were used to collect data from the studies included in the PICO questions, and to assess the risk of bias.

**Main results:** Plain radiography or single contrast study can be used in the decision making process in palliative cancer patients with clinical symptoms of MBO. Computed Tomography might provide further information over and above plain and contrast radiographies (Evidence level 5). Metoclopramide can be first choice drug in attempting to resolve a functional or partial MBO (Evidence Level 4). Dexamethasone or methylprednisolone can be used to resolve symptoms of inoperable patients with clinical symptoms of MBO (Evidence Level 1). Octreotide is compared to Hyoscinbutylbromide, the most effective anti-secretive and antinematic drug in inoperable patients with clinical symptoms of MBO. Octreotide can be considered as the first-choice anti-secretive drug in MBO (Evidence Level 1).

**Conclusion:** This review illustrates that more studies are needed, on the treatment of inoperable patients with clinical symptoms of MBO, to establish evidence-based guidelines.

**Abstract number:** P216
**Abstract type:** Poster

**The Use of Bioelectrical Impedance Analysis to Evaluate Hydration in Patients with Advanced Cancer**

Nyosu A.C.1, Mayland C.R.2, Varro A.3, Ellershaw J.E.1

1Marie Curie Palliative Care Institute Liverpool (MCPCIL), University of Liverpool, Dept of Molecular & Clinical Cancer Medicine, Liverpool, United Kingdom, 2Institute of Translational Medicine, University of Liverpool, Liverpool, United Kingdom

**Background:** Bioelectrical impedance analysis (BIA) is an accurate validated method of assessing body composition; however, its clinical use in the assessment of fluid states in advanced cancer is uncertain.

**Aims:** This study aims to measure hydration in advanced cancer patients using BIA, in order to determine the relationship between symptoms, biochemistry, and performance status.

**Methods:** A cross-sectional prospective analysis of advanced cancer patients within a specialist palliative care unit in Liverpool, UK.
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BIA measurements: Resistance (R - Ohm), Reactance, (Xc - Ohm), total body water (TBW - through proxy measurement using height/resistance [Ht²/R]), Phase angle (PA) and BIA vector analysis (BIVA) were used to compare for differences in hydration based on WHO performance status (0= asymptomatic, 4=bedbound), symptoms, physical examination and biochemistry.

Results: From a possible 118 patients, 90 (76.3%) provided consent. Ht²/R was lower in patients with a WHO performance status of 4 compared to those with a performance status < 4 (mean 43.0 [SD 9.0] vs. 53.6 [SD 15.9], p=0.001), and greater in those with clinically detectable oedema (mean 60.37 [SD 19.2] vs. 47.8 [11.8], p=0.004). Ht²/R correlated negatively with thirst [r = -0.29, p=0.006], dry mouth [r = -0.336, p=0.001], nausea [r = -0.226, p=0.032], unpleasant taste [r = -0.282, p=0.007], fatigue [r = -0.315, p=0.002], BIVA showed significant difference in hydration between groups classified by the presence or absence of oedema (p=0.0036), and dry mouth (p=0.01). There was no significant relationship between hydration (Ht²/R and BIVA) vs. biochemical tests or between symptoms vs. biochemistry or performance status.

Conclusion: In advanced cancer, hydration status (as measured by Ht²/R and BIVA) relates to clinically measureable signs and symptoms. Further work is needed to determine whether BIA can be used to guide the management of fluid states in advanced cancer.

Abstract number: P217
Abstract type: Poster

What is the Most Appropriate Time Frame for Assessing Symptoms? A Validation Study of the Edmonton Symptom Assessment System-Revised (ESAS-R) in Advanced Cancer Patients

Nekolaichuk C.1, Watanabe S.1,2, Mawani A.2
1University of Alberta, Oncology, Edmonton, AB, Canada, 2Cross Cancer Institute, Edmonton, AB, Canada

Aim: The Edmonton Symptom Assessment System (ESAS) is a widely used symptom assessment tool developed for advanced cancer patients. In response to recent concerns regarding the ESAS, a revised version, the ESAS-r, was developed. The ESAS-r offers distinct advantages over the ESAS, by revising problematic items, while still retaining core elements of the ESAS, including assessing symptoms “now.” Validity evidence is needed to determine an appropriate time frame for assessing symptoms and to compare the tool with similar measures.

Purpose: The overall aim of this study was to gather validity evidence by assessing differences in ESAS-r responses between “now” and “24 hour” assessments, as well as comparing the ESAS-r with a quality of life measure, with symptoms rated “over the past 7 days.”

Methods: 32 cognitively intact advanced cancer patients receiving palliative care services in a tertiary cancer facility completed two versions of the ESAS-r: Form A (rating symptoms “now”) and Form B (rating symptoms “during the last 24 hours”), as well as the EORTC QLQ-C15-PAL, a quality of life measure designed for palliative care. Correlations were calculated using Spearman’s rho (r).

Results: Most patients were women (56%), married (72%) and outpatients (75%); average age = 61 (SD 9). Forms A and B were moderately to highly correlated for total symptom distress scores (SDS) (r = .90) and individual items, ranging from .70 (drowsiness) to .87 (depression). Total SDS for Forms A and B were moderately correlated with the total score for the QLQ-C15-PAL (r = .67 and .65, respectively).

Conclusions: Using a time frame of “now” versus “during the last 24 hours” did not substantially influence patients’ responses in this predominant outpatient population. The moderately high correlations between the QLQ-C15-PAL and Forms A and B suggest that the ESAS-r is effective for assessing quality of life. Further validity evidence using larger non-metastatic and non-cancer samples is warranted.

Abstract number: P218
Abstract type: Poster

Family Management Style Framework and its Use with Families who Have a Child Undergoing Palliative Care at Home

Bousso R.S., Santos M.R., Mendes-Castillo A.M.C., Misko M.D., Rossato L.M.
University of São Paulo, São Paulo, Brazil

Background: Palliative care settings in many countries acknowledge families as their prime focus of care, but in Brazil, to date, researchers have devoted scant attention to that practice setting. In this study, we aimed to explore how families define and manage their life when they have a child or adolescent undergoing palliative home care.

Methods: Data included individual semistructured interviews with 14 family members of 11 different families. Interviews were transcribed and the coding procedure featured qualitative content analysis methods. The deductive coding was based on the major components of the Family Management Style Framework (FMSF) and the eight dimensions comprising these components.

Results: The analysis provides insight into families’ daily practices and problems inherent in managing their everyday lives that are encountered when they have a child in palliative care. The study supported the usefulness of the FMSF for specifying unique areas of family strength and difficulty in the management of a child in palliative care at home. Recurring themes covering social, emotional, and physical aspects in the family interviews suggest useful
issues to consider in the development of a palliative care program and point to the importance of addressing family grief as part of pediatric palliative care at home.

**Discussion:** Palliative care claims a holistic and family centered view, and, the literature argues, we can extend and intensify our quality of care by challenging assumptions based on our own culture. Many professionals, including those in Brazil, continue to look more at the purely medical/biological situation and find it difficult to assess family relationships and intervene in them if necessary. To advance in the training of health professionals for work in family care in palliative care situations, we must adjust or approximate the family assessment tools to the Brazilian reality of the health care professionals involved.

**Abstract number:** P219
**Abstract type:** Poster

**Family Caregivers’ Perceptions of Depression in Patients with Advanced Cancer: A Qualitative Study**

Rhondali W.1,2, Chirac A.1, Laurent A.1, Terra J.-L.3, Filbet M.1

1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3Centre Hospitalier du Vinatier, Bron, France

**Background:** Depression is a serious issue in cancer patients, resulting in impaired quality of life and probably shorter survival. However, many cancer patients with depression are not treated because of the difficulties in identifying depression in this population. Our study aimed to examine caregivers’ perceptions of depression among advanced cancer patients.

**Methods:** This qualitative study used semi-structured interviews, and we analyzed data using grounded theory and qualitative methods. We recruited caregivers from our Palliative Care Unit (PCU) in an Academic Medical Center.

**Results:** We interviewed 15 caregivers. Cancer patients’ caregivers had a good theoretical knowledge of depression but also acknowledged that in the context of cancer and because of their relationship with the patient, identification of depressive symptoms could be challenging. They considered themselves as partners in the patient’s care with a supportive role. However, by assuming the role of partner in patient care, caregivers exposed themselves to emotional difficulties and an increased need for support and information.

**Conclusions:** Our results suggest a significant impact of depression in advanced cancer caregivers and it is therefore crucial that health care professionals develop education programs targeting cancer patients’ families as well as specific interventions to minimize the impact of the burden of patient care on caregivers.

**Abstract number:** P220
**Abstract type:** Poster

**Bereavement Support in Palliative Care in Portugal**

Frade P.1, Tavares F.2, Coelho A.2, Delalibera M.1, Correia A.3, Presa J.1, Barbosa A.1, Matos A.2

1NAEIL/Centro Bioética Faculdade Medicina, Universidade de Lisboa, Lisboa, Portugal, 2Centro Hospitalar Lisboa Norte, EPE - Hospital de Santa Maria, Lisboa, Portugal, 3Faculdade de Psicologia da Universidade de Lisboa, Lisboa, Portugal

**Objective:** The aim of the study is to identify the existing human and technical resources providing bereavement support in palliative care units in Portugal.

**Method:** Nationwide, 49 palliative care teams were contacted by telephone, or via e-mail, between July and August 2012.

**Results:** Concerning the support given to bereaved families, only 8% of the teams reported not providing this service. The assistance to these families is provided mostly by psychologists, although nurses and social workers also offer this support. Most of the teams pay individual and family support and two teams also use group intervention methodology. The referral protocol for bereavement care covers several procedures: sending a letter of condolence (38.8%), telephone contact (59.2%), spontaneous demand (42.9%) and referral by health professionals (38.8%). Most palliative care teams assess the risk factors for grief complications with informal interviews. The evaluation of grief complications is also informal with the exception of five teams that use the Prolonged Grief Disorder Instrument (PG-13). Most professionals providing support have palliative care training or a basic education on grief and only 5 psychologists are currently undertaking specialized training on grief intervention. Only 48.8% of the teams have any kind of support for the health care professionals, which mostly consist of meetings to share and express feelings. More than half of the teams showed need and interest in a more structured support directed to the professional’s grief.

**Conclusions:** Palliative care services in Portugal include bereavement support to families and professionals. However, the intervention protocol is mostly informal and there is a lack of assessment tools and specialized training on grief. This study contributes to the recognition of the existing resources and needs, from which could derive guidelines for the development of a more stringent procedure in grief assessment and intervention.

**Abstract number:** P221
**Abstract type:** Poster

**Developments in Spiritual Care Education in German Speaking Countries**
This study examines spiritual care (SC) trainings provided to healthcare professionals in Germany, Austria and Switzerland and reveals the extent of available trainings, defines the target group(s) and teaching goals, additionally providing a list of delivered competences, applied teaching and performance assessment methods.

In 2013, an online survey was conducted among the members of the International Society for Health and Spiritual Care. The survey contained 10 questions and an open field for best practice advice. SPSS21 was used for statistical data analysis and the MAXQDA2007 for thematic content analysis.

33 educators from Germany, Austria and Switzerland participated in the survey. The main providers of SC trainings are hospitals (36%, n=18), 57% (n=17) of SC trainings are part of palliative care education. 43% (n=13) of SC education is primarily bound to Christian tradition. 36% (n=11) of provided trainings have no direct association with any religious conviction. 64% (n=19) of respondents admitted that they do not use any specific definition for SC. 22% (n=14) of available SC education leads to some academic degree. 30% (n=19) of trainings bring on some new qualifications. The content analysis revealed that spiritual trainings for medical students, physicians in paediatrics, and chaplains take place only in the context of palliative care education. Courses provided for multidisciplinary team may be part of palliative care training.

The study demonstrates that SC is often approached as an integral part of palliative care, (medical) ethics, grief management, interaction training, psychological and religious counselling or cultural safety. Educators point out the importance of competency based SC education, practical training and maintaining the link between SC education and clinical practice.

Abstract number: P222
Abstract type: Poster

Hospitalizations of Cancer Patients in the Last Month of Life in Four European Countries: Do Duration and Frequency Reflect the Quality of Care?

De Roo M.L.1, Frick E.2, Roser T.3

1Ludwig Maximilians Universität, University Hospital, Campus Grosshadern, Palliative Care, München, Germany, 2Ludwig Maximilians Universität, University Hospital, Campus Grosshadern, München, Germany, 3University of Münster, Practical Theology, Münster, Germany

Background: Although most patients prefer to be cared for at home at the end of life, cancer patients are frequently admitted to the hospital in the last month of life. High rates of hospitalizations may be a marker of low quality of palliative care.

Objective: To describe the scores of the previously developed quality indicators ‘the percentage of time spent in the hospital’ and ‘the proportion with more than one hospitalization in the last 30 days of life’ in four European countries; and to determine the care characteristics associated with these quality indicator scores.

Methods: A dynamic retrospective cohort study was conducted, based on registrations from representative GP networks regarding home-dwelling cancer patients who died non-suddenly in Belgium (n=500), the Netherlands (n=310), Italy (n=764) and Spain (n=224). The relationship between the quality indicators and care characteristics was assessed using logistic regression models.

Results: ‘The percentage of time spent in the hospital’ ranged between 14.1% in the Netherlands and 24.6% in Belgium. ‘The proportion with more than one hospitalization in the last 30 days of life’ ranged between 0.6% in the Netherlands and 5.4% in Belgium. When the GP had provided palliative care this was associated with less time spent in the hospital in all four countries. When cure was still an important care goal in the last month, more time was spent in the hospital in Belgium and the Netherlands.

Conclusion: These two quality indicators concerning hospitalizations are able to reveal differences between the four countries, providing interesting insights in the palliative care delivered. In countries where GPs have an important role in palliative care provision (e.g. in the Netherlands), quality indicator scores are better: hospitalizations are shorter and rehospitalizations are less frequent.
**Dying in Cancer Centers: Do the Circumstances Allow for a Dignified Death?**

**Jors K., Adami S., Xander C., Meffert C., Becker G.**

University Clinic Freiburg, Clinic for Palliative Medicine, Freiburg, Germany

**Aim:** Prior research has shown that hospitals are often ill-prepared to provide care for the dying. The purpose of this study was to assess whether the circumstances for dying on cancer center wards allow for a dignified death.

**Methods:** In this cross-sectional study, we surveyed physicians and nursing staff in 15 hospitals belonging to 10 cancer centers in Baden-Württemberg, Germany. A revised questionnaire from a previous study was used, addressing the following topics regarding end-of-life care: structural conditions (i.e., rooms, staff), education/training, working environment, family/caregivers, medical treatment, communication with patients, and dignified death. The Mann-Whitney U test was used to test for significant differences between groups.

**Results:** A total of 1131 surveys (response rate=50%) were returned. Half of the participants indicated that they rarely have enough time to care for dying patients, and 55% found the rooms available for dying patients inadequate. Responses of palliative care staff differed significantly from other wards (p< .001), with palliative care staff being more satisfied with the overall conditions. Only 18% of respondents felt that they had been well-prepared to care for the dying. Generally, physicians assessed the circumstances more positively than nurses, especially regarding communication with patients and use of life-prolonging measures. Overall, 56% of respondents believed that patients could die with dignity on their ward.

**Conclusions:** Although a majority of participants felt that a dignified death is possible on their ward, relevant shortcomings were also reported. We recommend that cancer centers invest more in staffing, adequate rooms for patients, and dignified death. The Mann-Whitney U test was used to test for significant differences between groups.

**Funding:** Clinic for Palliative Medicine, University Clinic Freiburg

**Background:** Little is known about acknowledgment of the diagnosis and prognosis among Southern Spanish terminally ill patients, particularly among non-cancer patients (NCP).

**Objectives:** To determine the percentages of patients with acknowledgment of their disease, and comparing both between cancer (CP) and NCP.

**Methods:** Cross-sectional study. Patients were recruited from those attended by a palliative care support team in a Southern Spain university hospital from January 2011 to March 2012. Analysed variables were age, gender, knowing the diagnosis, knowing the prognosis, specialty submitting the patient to the PCST, main diagnoses, carer and his/her profile, complexity degree, number of visits/patient, Barthel index, Karnofsky index, days of follow-up during the stay and if received potent opioids. Univariate and multivariate logistic regression analyses.

**Results:** 569 patients were included for analysis. A 49.9% of patients did not know their diagnosis or prognosis (NotKnow). This percentage was divergent among physicians (from 15.1% to 85.6%; P=.000) and the age of the patients (>85/≤ 85 years, 15.2/30.4%; P=.000). Also differed depending upon the submitting specialty (from Internal Medicine office 60% to Radiotherapy 0%; P=.013) and mainly if they had cancer or not (CP/NCP 40.3/70.9%; P=.000), so different analyses for CP and NCP were performed.

The variables independently associated to NotKnow were, among NCP: number of visits by physician (>7/< = 7, aOR = .196, P=.002), time of follow-up (aOR 3.75; P=.011) and higher complexity (aOR 2.345; P=.042). Among CP those were: number of visits (aOR.301; P=.000), age older than 80 years (aOR = 1.971; P=.006) and if the carer was the partner (aOR=.576, P=.001).

**Conclusions:** Older disabled chronically ill NCP and older CP having a carer different from the wife/husband would be less acknowledged of their diseases and prognosis. Also, several factors may have an influence on acknowledgement.

**Abstract number:** P225

**Abstract type:** Poster

**General Practitioners’ Experiences with Patients who Hasten Death by Voluntary Refusal of Food and Fluid**

**Bolt E.E.1,2, van der Heide A.3, Onwuteaka-Philipsen B.D.1,2**

1VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, 2VU University Medical Center, Center of Expertise in Palliative Care, Amsterdam, Netherlands, 3Erasmus MC,
University Medical Center Rotterdam, Department of Public Health, Rotterdam, Netherlands

Background: In the Netherlands, 0.4% of deaths follow upon voluntary refusal of food and fluid (VRFF). Half of general practitioners (GPs) consider VRFF as a possible alternative to euthanasia in some cases. According to Dutch professional standards, a competent patient who decides to deliberately hasten death by VRFF should receive guidance and supportive care by their physician. However, little is known about this practice.

Aims: Our aim is to describe how often Dutch GPs are confronted with VRFF, to describe motives and characteristics of people who hasten death by VRFF and the role GPs play in the care for these people.

Methods: Survey of a random national sample of 1100 GPs (response 72%). Of these, 500 received questions about the last patient in their care who hastened death by VRFF (response 65%).

Results: Of all GPs 45% ever cared for a patient who hastened death by VRFF, and 101 respondents described a patient. Most patients were 80 years or older (80%), suffered from physical illnesses (80%) and were dependent on others for everyday care (78%). Reasons for VRFF were related both to physical suffering and existential suffering. Patients had previously requested for euthanasia in 17% of cases. GPs were informed in advance in 49% of cases, 69% was involved in the preparation or in care during VRFF. Median time until death was 7 days (range 1-14 days). The GPs stated that in 81% of cases it went according to the patient’s wishes, although 38% of patients suffered from burdensome symptoms in the last three days of life.

Conclusions: It is not unlikely for GPs to be confronted with patients who choose to hasten death by VRFF, in which case GPs can play a role in supportive care.

Abstract number: P226
Abstract type: Poster

The Cost of Providing Care to Cancer Patients at the End of Life in England and Wales

Round J.A.1, Jones L.2, Morris S.2

1University College London, UCL Clinical Trials Unit, London, United Kingdom, 2University College London, London, United Kingdom

Background: Providing care at the end of life for those who die from cancer represents a significant cost to society. In the UK in 2009 £4.4 billion was spent on providing health care for cancer patients. In this study we use multiple data sources to estimate the total cost to society of providing care for the most commonly occurring cancers: lung, breast, colorectal and prostate.

Methods: We define end of life in cancer as that period during which treatment is no longer primarily curative in intent and the person is likely to die as a result of their illness. For these analyses end of life is considered to begin at progression to Stage IV disease. We estimate costs from a societal perspective. We include the costs of healthcare, social care, charitably- provided care and informal caregiving. Estimates of resource use and costs are drawn from publicly available datasets and the literature. Monte Carlo simulation methods are used to estimate an expected mean cost of care and interquartile range (IQR). The first disease considered was lung cancer, the leading cause of cancer related death in England and Wales, accounting for 30,148 deaths in 2011. Median survival with Stage IV lung cancer is 203 days. Analysis of data using similar methods for breast, colorectal and prostate cancers is on-going.

Results: The mean cost of providing care to a typical lung cancer patient at the end of life is estimated as £30,953 (IQR £22,862 - £37,311, median £29,357). The cost of providing care to all patients who die of lung cancer in a given year is estimated at £908 million. Health care accounts for 42% of costs and social care 45%. Informal carers (12%) and charities (1%) account for the remaining costs.

Conclusions: The cost of providing care to cancer patients at the end of life is substantial. The majority of the cost is borne by society in the form of statutory health and social care services. A smaller, though important, proportion of the costs is borne by informal carers.

Abstract number: P227
Abstract type: Poster

Impact of a Home Palliative Care Team (HPCT) on Place of Death, Chemotherapy, Hospital Use and Costs for Terminal Cancer Patients in a Portuguese Metropolitan Area: A Retrospective Cohort Study

Aguilar H.1,2, Rocha M.C.3, Fonseca B.3, Frías E.3, Rodrigues E.3, Pereira M.3, Higginson I.J.1, Gomes B.3

1King’s College London, Cicely Saunders Institute, Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2S. João Family Health Unit, São João da Madeira, Portugal, 3Palliative Care Team of Unidade Local de Saúde de Matosinhos, Matosinhos, Portugal

Background: There is evidence that home palliative care teams (HPCTs) increase the odds of home death and reduce symptom burden but most studies are from the US and UK, and findings are inconsistent on resource use and costs.

Research aims: To determine the effect of a HPCT in a Portuguese metropolitan area on place of death (primary outcome), chemotherapy sessions, hospital use and associated costs in the 90 days prior to death.
Methods: Retrospective cohort study of a population-based sample of adult residents in Matosinhos (Portugal) who died from cancer in 2011, identified via death certificates and HPCT records, matched by primary tumor. Data were collected from death certificates, 3 local health institutions and HPCT records. Hospital use was attached to costs.

Results: From 322 cancer deaths, 236 were included (118 intervention group, 118 control group). HPCT use was associated with home death (56.8% vs. 20.3%, p<.001) and was the most important factor associated with home death (adjusted OR: 7.5 [95% CI: 3.8-14.7]). Multivariate linear regression models showed that for individually matched time periods (median last 37 days to death), the rate of days with chemotherapy sessions was 66.1% lower in the HPCT group (0.22% vs. 0.65%, p=0.02) while the rate of days with emergency department visits were no different (2.0 vs. 2.3%, p=0.14). Hospitalisation periods were 29.4% shorter (95% CI: 1.7-57.0, p=0.03) and associated with a mean cost saving of 3484.1 € (95% CI: 500.5-6467.6, p=0.02) per patient for the 90 days prior to death.

Conclusions: The results show the potential for PHCTs to enable terminal cancer patients to die at home (aligning with international evidence), but also to decrease hospitalisations and aggressive therapies and, at the same time, save hospital costs. While other costs and clinical outcomes were unmeasured and prospective evidence is still needed, the results support continuing investment in PHCTs.

Funding: Calouste Gulbenkian Foundation

Abstract number: P228
Abstract type: Poster

The Role of Relationship Equilibrium in Palliative Care: A Quantitative Questionnaire Study with Patients and their Partners

Jansky M.1, Eggebrecht D.2, Stahl J.3, Friedemann N.1, Kröner-Herwig B.3

1University Medical Center Göttingen, Palliative Medicine, Göttingen, Germany, 2Red Cross Hospital, Kassel, Germany, 3University of Göttingen, Psychology, Göttingen, Germany

Introduction: Balance of investment and benefit in a relationship is at stake when one partner suffers from an advanced illness. Especially the patient’s feeling of not investing enough (UI) and partner’s feeling of being disadvantaged could be harmful. This might be connected to self-perceived burden (SPB), an important stressor for patients in palliative care (PC).

Aim: The study analyzed whether SPB influences the strength of correlation between balance in a relationship and well-being of patients. Also, physical functioning (PF) may moderate this relationship and reduce UI’s influence because the need for help might be more evident for patients with reduced physical functioning.

Method: Outcome variables (depression, anxiety, self-efficacy (SE), life satisfaction (LS), tranquility, positive mood), balance of relationship, PF and SPB were assessed using reliable scales in 39 cancer patients (15 male, 24 female; mean age 58.6) and their partners at PC units. Correlations were analyzed using Spearman’s rho; SPB was used as a moderator variable in multiple regression.

Results: Patient’s UI was positively correlated with anxiety (rₓ= .38) and depression (rₓ=.41) and negatively correlated with tranquility (rₓ=-.33), LS (rₓ=-.40) and SE (rₓ=-.36). SPB did not correlate significantly with the outcome variables. Neither SPB nor PF had a moderating effect on the correlation between underinvestment and the outcome variables.

Conclusion: It is important for patients in palliative care to be able to invest in their relationship. Being physically impaired does not help patients to accept their underinvestment, maybe because they can’t expect to restore balance in their partnership in a long-term perspective. Contrary to previous findings, participants did not suffer more when assuming to be a burden for their partner.

Abstract number: P229
Abstract type: Poster

Using the ‘Patient Dignity Question’ as a Person-centred Intervention for Patients with Palliative Care Needs in an Acute Hospital setting

Johnston B.M.1, Gaffney M.2,3, Buchanan D.3

1University of Nottingham, Sue Ryder Care Centre Research Group, Nottingham, United Kingdom, 2University of Dundee, School of Nursing and Midwifery, Dundee, United Kingdom, 3NHS Tayside, Palliative Care, Dundee, United Kingdom

Background: The aim of palliative care is to improve the quality of life of patients who are living with a progressive, life threatening illness. In order to achieve this, the patient needs to be cared for as a person. However, current research indicates that this is not always achieved in the acute hospital setting.

Aim: This feasibility study set out to determine the practicabilities and effectiveness of using the ‘Patient Dignity Question’, (Chochinov 2010) an intervention derived from extensive, empirical research on dignity near the end of life, in order to enhance person-centred care.

Methods: A mixed methods feasibility study using both patient reported outcomes measures (person centred climate questionnaire PCCQ; Patient Dignity Questionnaire (developed by Chochinov et al), and semi-structured interviews was adopted underpinned by pragmatic theory.
The study was conducted in a large teaching hospital with a purposive sample of nine patients and five healthcare professionals.

**Results:** The results of indicate that is feasible to carry out this type of study for people with palliative needs in the acute care setting. Adopting a mixed methods approach was effective in answering the research questions and meeting the study aims. The primary outcome measure was effective in determining the person-centred nature of the hospital climate. However, it was unable to determine if the ‘Patient Dignity Question’ had a direct influence on this.

**Conclusion:** Study participants were willing and happy to take part in this study despite their illness and environment. Participants found the ‘Patient Dignity Question’ and summary both useful and practical. They described it as an intervention that can help to improve the care patients receive and help them feel valued as an individual. A funded study with 30 patient, 30 family members and 30 health professionals is now being undertaken with a before and after trial design.

**Abstract number:** P230  
**Abstract type:** Poster  
**Family Communication and Knowledge about Disease at the End of Life. Influence in Emotional Dimensions**  
Hospital Santa Clotilde, Palliative Care, Santander, Spain

**Objective:** To Know the influence of family communication in the level of information in advanced inpatients. Assessment of impact degree of Knowledge about diagnosis and prognosis in emotional dimensions in a Palliative Care Unit during 2012.

**Material and method:** Descriptive and Retrospective Study in all inpatients discharged in a Palliative Care Unit from the 1st January to 31st of December of 2012. Systematic Review of all clinical reports getting social, demographic, clinic, emotional patterns using likert scales from 0-10, and Knowledge of disease on admission.

**Results:** 157 inpatients during 2012: 137 (87.26%) had oncologic disease and 20 (12.74%) other conditions. Mean of stay 33.67 +/- 38.69 days: rank 0-208, median 19. Mean age: 71.53 +/- 12.18 years (rank 29-95). 74 were females (47.14%), 13 (8.28%) returned home; 4 (2.55%) were referred to Acute Unit; 6 (3.82%) were discharged to a Residential (RH) or a Nursing Home (NH) and 134 (85.35%) died. 87 (55.41%) Knew diagnosis and 25 (15.92%) Knew their prognosis. 31 (19.75%) inpatients suffered anxiety like main symptom on admission. During stay 87 (55.41%) received psychological support: 42 (48.27%) had emotional distress on admission.

Affective status: mean 5.45 +/-2.05; emotional distress: mean 4.64+/-3.11 and anxiety: mean 5.14+/-2.92 on admission. The patients who Knew their diagnosis scored more in anxiety (p 0.0064). There were not difference in affective status nor emotional distress. We did not find statistically significant differences in emotional distress in relation with prognosis knowledge. The patients with more family communication knew better their diagnosis (p 0.0022) and prognosis (p 0.0282).

**Conclusions:** The better communication in the family allow advanced patients have more knowledge about their disease. The main emotional response in front of diagnosis is anxiety.

**Abstract number:** P231  
**Abstract type:** Poster  
**Coordinating Care for Those Living Advanced Progressive Illness: A Longitudinal Qualitative Study with Patients and Unpaid Caregivers**

Davieson B.A.1, Harding R.3, Shipman C.4, Mason B.2, Epiphaniou E.4, Higginson I.J.1, Ellis-Smith C.1, Henson L.1, Munday D.1, Nanton V.3, Dale J.1, Boyd K.2, Worth A.2, Barclay S.4, Donaldson A.2, Murray S.2

1King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2University of Edinburgh, Edinburgh, United Kingdom, 3Warwick University, Warwick, United Kingdom, 4University of Cambridge, Cambridge, United Kingdom

**Aims:** To develop a coordination model for patients and their unpaid caregivers living with advanced progressive illness, to understand their perspective regarding coordination, and to help researchers move from the abstract to the concrete when it comes to measuring coordination.

**Design:** A prospective longitudinal, multi-perspective qualitative study involving serial in-depth interviews analysed through open-axial coding to construct categories and meta-synthesis to produce one coherent model across cases.

**Participants:** Fifty-six purposively sampled patients and 27 case-linked unpaid caregivers from contrasting primary, secondary and tertiary settings within Britain.

**Results:** Coordination is a deliberate cross-cutting action involving high-quality, caring and well-informed staff, patients and caregivers who work together in partnership and with others across health and social care settings. For coordination to occur it must be adequately resourced with efficient systems and services that communicate. Good outcomes rely on coordination, which is facilitated through flexible and patient/family-centered care, characterized by accurate and timely information communicated in a way that considers patients’ and caregivers’ needs, preferences,
circumstances and abilities. Patients and caregivers identified five types of factors that influence the coordination of their care.

Conclusions: Our model addresses the paucity of empirically derived coordination models in healthcare. It shows that coordination is a shared complex intervention that comprises an essential mix of relational, structural and information components. It is one of the first to examine patients’ and caregivers’ views about coordination. The model’s conceptual fidelity helps address the over-reliance on process and satisfaction measures as proxies for coordination. New considerations regarding research, fiscal incentives and measurement are prompted by this research.

Abstract number: P232
Abstract type: Poster

Using the LEAP Evaluation Model to Develop the Changing Minds Programme (Promoting Excellence in EOLC for People with Dementia) in Ireland

1The Irish Hospice Foundation, HFH, Dublin, Ireland, 2The Irish Hospice Foundation, Dublin, Ireland

Background: In March 2013, the Irish Hospice Foundation commenced a new initiative entitled Changing Minds that aims to enable more older people, particularly those with dementia, to live and to die with dignity at home (as most would prefer) or in residential care settings. The initiative comprises of six key projects that were scoped and agreed through utilisation of the LEAP Evaluation Framework (Scottish Government, 1999), designed to support a partnership approach to achieving change and improvement in the quality of community life.

Aim: The aim of this paper is to examine how the LEAP model was utilised to scope and plan the development of this important programme of work that in turn aims to promote excellence in end of life care for people with dementia.

Design and methods: A series of planning workshops were held with key stakeholders to apply the 5 principles and 7 questions of the LEAP Framework to the ideas generated regarding the development of the initiative. Through this process, a series of project logic models were generated that were utilised to inform the evaluation of the initiative as a whole. Qualitative feedback was obtained to determine how useful the process was considered to by those who engaged.

Results: The application of the LEAP Framework was considered useful and acceptable as a methodology to enable a complex multi-project initiative to be developed through to start-up phase. Based on exploration of the LEAP questions and principles, complex logic models emerged for each individual project and the initiative as a whole. These informed the evaluation indicators and questions. This preliminary planning was considered by staff as a vital step to ensure that the Changing Minds programme is robustly evaluated.

Conclusion: The LEAP Framework is a useful tool to engage stakeholders in the planning of complex programmes of development in palliative and end of life care.

Abstract number: P233
Abstract type: Poster

Comparison of Revised Edmonton Classification System for Cancer Pain (ECS-CP) Features across Diverse Settings

Fainsinger R., Tekolaichuk C., Fainsinger L., Muller V., Amigo P., Brisebois A., Burton MacLeod S., Gilbert R., Tarumi Y., Thai V., Wolch G.
1University of Alberta, Division of Palliative Care Medicine, Edmonton, AB, Canada, 2University of Alberta, Edmonton, AB, Canada, 3Palliative Institute, Covenant Health, Edmonton, AB, Canada

Aims: The primary objective of this pilot study was to assess feasibility and predictive validity of the ECS-CP in a sample of palliative care patients, using modified definitions and a personalized pain goal (PPG). We hypothesized that frequencies of pain classification features would vary across sites and location of care, with the palliative care unit (PCU) having more complex pain features than other acute settings.

Methods: 300 advanced cancer patients are being recruited from 3 palliative care sites - a PCU and 2 hospital consult services. A palliative care specialist completed the ECS-CP. Additional information included patient demographics; patient-generated symptom assessments; opioid and adjuvant analgesics; other pain control methods and a PPG. Data were directly entered in an electronic data form and analyzed using SPSS-19.

Results: Interim analysis was performed on 150 patients: mean age 68. 82% (n=123) had a pain syndrome. ECS-CP features for all sites: Nociceptive pain (61%), Neuropathic pain (16%), Incident pain (27%), Psychological distress (17%), Addictive behavior (9%), Cognition normal (66%).The PCU had a higher percentage of patients (33%) with severe pain (pain intensity 7-10) on initial assessment. Data analysis demonstrated significant differences in ECS-CP features between the PCU and other sites on neuropathic and incident pain.

Conclusion: Patients admitted to the PCU had more complex pain syndromes and higher pain intensity ratings. The next stage in validation of the ECS-CP: increase the sample size, expand to international sites, analyze the relationship between the complexity of pain and the
Abstract number: P234
Abstract type: Poster

High Doses of Hydromorphone and Oxycodone/Naloxone in Patients with Cancer Pain
Mencucci A., Maurizi P.
S. Donato Hospital in Arezzo, Arezzo, Italy

Introduction: Strong opioids are considered the drugs of first choice for treatment of moderate to severe pain. The new recommendations suggest oral use of morphine, oxycodone and hydromorphone as drugs of first choice. The opioids are effective, but burdened by side effects, especially gastrointestinal, autonomic, neurological.

Aim: To evaluate the response to treatment with high doses of opioid in terms of analgesic efficacy and incidence of side effects in a population of patients with oncological and uncontrolled pain.

Method: In the observational study which lasted 7 months, 29 patients, 18 males and 11 females, were enrolled with chronic cancer pain of moderate to severe intensity. 18 patients were treated with hydromorphone and 11 with oxycodone/naloxone. The observation period was completed without interruption or suspension. We monitored pain intensity through the Numeric Rating Scale (NRS), and opioid side effects most commonly associated.

Result: The 29 patients had from moderate to severe pain (NRS average 7.55), life perspective over 3 months, mean age 65.08%. There was a pain reduction of 47.94% with hydromorphone (NRS from 7.3 to 3.8) and of 53.84% with oxycodone/naloxone (NRS from 7.8 to 3.6) with a decrease in the average NRS from 7.55 to 3.7 (pain reduction of 50.99%). The mean dose of hydromorphone used was 177mg/day, with a maximum dose of 364mg/day. The average dose of oxycodone/naloxone used was 202mg/day of oxycodone and 101mg/day of naloxone, with a maximum dose of 240mg/120mg/day. The only side effect noted was a moderate constipation by hydromorphone, poorly correlated with opioid dose, and mild constipation by oxycodone/naloxone, likely correlated to therapeutic dose.

Conclusion: The study suggests that both hydromorphone that oxycodone/naloxone at high doses are able to produce a significant analgesic efficacy with a reduced incidence of constipation than as treated with laxatives.

Abstract number: P235
Abstract type: Poster

Changing to Alternative Opioid in Greece Cancer Patients
Symeonidi M.1, Tsilika E.1, Parpa E.1, Panagiotou I.2, Mystakidou K.1
1Pain Relief and Palliative Care Unit, School of Medicine, University of Athens, Radiology, Athens, Greece, 2Pain Relief and Palliative Care Unit, School of Medicine, University of Athens, Athens, Greece

Aim: This study was developed to investigate the effects of intolerance of transdermal delivery therapeutic system (TTS) of fentanyl in the sense of inadequate pain relief and/or appearance of adverse events. Also, to recognize possible factors responsible for this insufficiency and the need of switching to alternative opioid oral morphine.

Methods: 289 cancer patients suffering from chronic pain were included in the study, recruited in a palliative care unit with patients coming from all over Greece including urban, suburban and rural areas. All patients received TTS fentanyl in the beginning. 86 patients needed to change their opioid medication so as to obtain the desirable analgesia and/or avoid adverse events. To investigate the ineffectiveness of fentanyl we studied its relation with patients’ history, demographic and disease related characteristics and the scores from Eastern Cooperative Oncology Group performance status scale, Mini Mental State Examination questionnaire, M.D.Anderson Symptom Inventory and Greek Brief Pain Inventory.

Results: The most common side effects among the switchers were nausea and vomiting, sleepiness and respiratory depression. Univariate analysis indicated small but notable statistical significance between the need of switching and performance status and body mass index. Higher statistical significance indicated with age (p=0.041), higher impact and severity of symptoms in patient’s life (p<0.0005), cognitive impairment for any reason (p=0.008) and recent chemotherapy (p=0.025). After multiple logistic regression analysis younger age, obesity, recent chemotherapy, higher impact of symptom severity in daily life and low cognitive function confirmed as the strongest predictive factors.

Conclusion: Changing to alternative opioid seems necessary in many patients. 5 factors finally proved to play an important role. This knowledge may be helpful to improve person-center care in patients with cancer suffering from chronic pain.
Abstract number: P236
Abstract type: Poster

Does Hope Correlate with Symptom Burden

Davis M.P.1, Gross J.2, Platt A.2, Lagman R.2, Parala A.2
1The Harry R. Horvitz Center for Palliative Medicine, Department of Solid Tumor Oncology, Taussig Cancer Center, Cleveland Clinic, Cleveland, OH, United States, 2Cleveland Clinic, Cleveland, OH, United States

Introduction: The Herth Hope Index (HHI) is a validated and reliable tool that measures hope and emotional well being. Hope may diminish with increased symptom burden. Comparing the HHI with Edmonton Symptom Assessment Scale (ESAS) provides a means of comparison between symptom burden and hope. We assessed hope and its relationship to symptom burden in an inpatient palliative medicine unit.

Methods: Eligible patients verbally consented, participated in the study. Patients completed or were assisted in completing the HHI and ESAS. Correlation between the HHI and symptom burden will be estimated using a 95% confidence interval once the study is completed. A correlation of >0.20 or < -0.20 would be considered clinically relevant. 193 patients will be needed to have 80% power at a 5% significance level based on pilot data.

Results: From the pilot data of 25 patients, there appeared to be no correlation between hope and symptom burden. At present 92 of 193 total patients have been enrolled. Mean ESAS score is 35 / 90, mean Herth score is 35 / 48. The mean ESAS NRS scores for pain is 4 / 10, nausea 2 /10, and tiredness 5 /10.

Discussion: Comparison between symptom burden and hope is relevant to patient care. Symptom management is appropriate if high correlation is found and symptom management plus healing / spiritual services if no or low correlation is found. Timing of the questionnaire may be important bias and concern. Patients with high symptom burden may have reduced hope but unwilling to complete the questionnaire; when symptoms are alleviated, HHI scores may improve. A floor effect bias may occur.

Conclusion: This ongoing study has potential to influence patient care and service delivery in an inpatient palliative medicine units. This study is expected to be completed by October of 2013.

Abstract number: P237
Abstract type: Poster

Methodological, Ethical and Governance Issues for Patient and Public Involvement in a European Health Technology Assessment of Palliative Care

Breteron L.1, Goyder E.1, Ingleton C.2, Gardiner C.3, Chilcott J.1, van der Wilt G.J.4, Oortwijn W.J.3, Mozygemma K.6, Lysdahl K.B.7, Sacchini D.8, Leppert W.9
1University of Sheffield, ScHARR, Sheffield, United Kingdom, 2University of Sheffield, School of Nursing and Midwifery, Sheffield, United Kingdom, 3University of Auckland, School of Nursing, Auckland, New Zealand, 4Radboud University Medical Centre, Department of Primary and Community Care, Nijmegen, Netherlands, 5ECORYS Nederland B.V., Health Unit, Rotterdam, Netherlands, 6University of Bremen, Department of Health Services Research, Bremen, Germany, 7University of Oslo, Institute for Health and Society, Oslo, Norway, 8Università Cattolica del Sacro Cuore, Institute of Bioethics, Rome, Italy, 9Poznan University of Medical Sciences, Department of Palliative Medicine, Poznan, Poland

Background: Patient and Public Involvement (PPI) to ensure that research findings are useful to the end users (patients, families, carers, staff and service commissioners) is widely advocated and well developed in some areas including palliative care. However PPI is underdeveloped in Health Technology Assessment (HTA). Better understanding of methodological issues relating to PPI in HTA for complex interventions such as palliative care is needed.

Aims: To identify methodological ethical and governance issues for PPI in HTA using palliative care in Europe as a case study.

Methods: Co-ordinators in six countries (England, Germany, Italy, Netherlands, Norway and Poland) engaged PPI using locally appropriate methods. ‘Patient and Public’ includes patients, carers and family. Three countries used a qualitative research approach and conducted 21 individual, face-face interviews which were analysed thematically. Three countries engaged stakeholders as ‘research partners’. An adapted version of the EUnetHTA core model guided 30 face-face discussions. Thematic analysis and conceptual mapping were used to identify key issues.

Results: Challenges for PPI included sensitively identifying credible, legitimate participants and clarifying the aims for PPI involvement. Uncertainty over what constitutes appropriate methods for engaging PPI representatives as research partners; ethical requirements and what constitutes ‘advice’ and ‘data’ and training when using patients as research partners were identified as specific issues.

Discussion: Tailoring methods to the local context by recognising philosophical differences relating to how PPI is best implemented and cultural sensitivities to palliative care enhances successful PPI engagement. However this limits comparability of findings. Ethical guidance needs developing for when patients contribute as research partners.

Conclusion: PPI methods must be further developed in a culturally sensitive way, especially in palliative care.
Abstract number: P238
Abstract type: Poster

Characteristics of Family Conferences in a Private Palliative Care Unit

Aparicio M., Guedes A., Marques L., Abril R.
Hospital da Luz, Lisbon, Portugal

Introduction: Palliative care (PC) aims to support the families and meet their needs (1). To achieve this goal we use the Family Conference (FC), defined as a structured intervention (2). In literature, there are referred situations, methodologies and the structure to follow (2,3,4). We know little scientific evidence about the FC evaluation, but it is consensual its use for the patients and families care planning (7,8).

Based on the literature (2,3,4,5) reviewed and experience, we made a recording instrument, available in the information system.

Objectives: To characterize the CF registered in a PC Unit, trough the analysis of the FC registers during 9 months.

Methodology: Retrospective and descriptive quantitative study, with the analysis of FC done with Microsoft Excel.

Results: In this period, there were 452 FC. 58.4% were scheduled. 47.6% lasted 30-60’. 42% took place in patient rooms and 34% in appropriate living rooms. 53.9% were performed by physicians, 27.2% by nurses and 17% by more than 1 professional. 30.7% were conducted with sons/daughters and 19.7% with spouse. On the rest there was more than one relative. In 43% the patient was present. Identified as the main reasons to perform FC: 63% treatment plan discussion, 42% benefits clarification and 39.2% worsening of the clinical situation or symptoms. As the main related topics: 82.3% care or symptom goals clarification, 74.1% assess information about the diagnosis and 75.2% expectations about illness, treatment and outcomes. In 67% of cases the relatives expressed feelings: sadness, anger and gratitude.

Discussion and conclusion: It’s referred as good clinical practice the evaluation thereof. We objectified how FC are done and how they reinforce the positive aspects and introduce the necessary changes. The identification of the main reasons allow better planning for interventions. A uniformed registration allows comparing data, measuring interventions and clarifying health gains for families in PC.

Abstract number: P239
Abstract type: Poster

Undergraduate Interprofessional Education in Palliative Care: Is it Worth the Effort?

Sweeney C.1,2, McAuliffe A.3, O’Neill S.M.4, Murphy M.1,2, O’Brien T.1,2, O’Flynn S.1

1University College Cork, School of Medicine, Cork, Ireland, 2St Patrick’s University Hospital/Marymount University Hospice, Cork, Ireland, 3University College Cork, School of Nursing, Cork, Ireland, 4University College Cork, Cork, Ireland

Aim: To examine the educational impact of an optional Interprofessional Education (IPE) module in palliative care for undergraduate medical and nursing students.

Methods: Mixed methods were used. The 40 enrolled students completed validated educational assessment tools pre and post module:

1. Self Efficacy in Palliative Care (SEPC)
2. Thanatophobia Scale (TS)
3. Readiness for Interprofessional Learning Scale (RIPLS)

Pre and post scores were analysed using Paired Student’s t-tests.

Qualitative information was obtained from a student feedback questionnaire that was completed by students at the penultimate session. The questionnaire asked students to identify what was well understood and what remained unclear or confusing. Responses were thematically analysed.

Results: Pre and post SEPC, TS and RIPLS were completed by 32 students. The results of analysis of SEPC (3 components - communication, patient management and teamwork) and TS are summarised in Table 1:

<table>
<thead>
<tr>
<th></th>
<th>Mean (pre)</th>
<th>SD (pre)</th>
<th>Mean (post)</th>
<th>SD (post)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>32.47</td>
<td>16.61</td>
<td>58.75</td>
<td>19.98</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Patient management</td>
<td>46.15</td>
<td>20.77</td>
<td>60.99</td>
<td>15.14</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Team work</td>
<td>52.59</td>
<td>16.34</td>
<td>67.50</td>
<td>15.06</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Thanatophobia Scale</td>
<td>3.08</td>
<td>1.07</td>
<td>2.30</td>
<td>1.00</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Pre and post RIPLS scores were high and no significant differences were found.

Analysis of qualitative data revealed increased understanding of:

- Patient and family issues including the concept of Total Pain
- Interdisciplinary teamwork
- Value of interprofessional education
Conclusions: The module demonstrated educational benefits in terms of both understanding of key aspects of palliative care and interdisciplinary teamwork. The IPE aspect of the module provided added value as evidenced by qualitative analysis.

Abstract number: P240
Abstract type: Poster

Using Realistic Evaluation to Identify Influences Affecting the Successful Implementation and Sustainability of the Liverpool Care Pathway for the Dying Patient

McConnell T., O’Halloran P., Porter S., Donnelly M.
Queen’s University Belfast, School of Nursing and Midwifery, Belfast, United Kingdom

Background: End-of-life care has become a clinical priority, and thus creative approaches to evaluating how to successfully implement end-of-life care pathways are required to enable generalist staff to improve care for patients and their families. However, in light of a recent independent review of the Liverpool Care Pathway (LCP), research identifying areas of weakness that compromise successful implementation and sustainability in practice is timely.

Aims: To determine the processes and underlying influences that facilitated or hindered appropriate implementation of the LCP.

Method: The study was an organisational case study using realistic evaluation designed to identify, test and refine programme theories of what will facilitate success. Semi-structured interviews were used to illuminate the differing viewpoints of key stakeholders involved in the implementation of the LCP in one health and social care trust in Northern Ireland. Results from the National Care of the Dying Audit Hospitals pertaining to the Liverpool Care Pathway (LCP) were reviewed. A critical incident approach was used to identify “关键时刻” moments that facilitated or hindered appropriate implementation of the LCP.

Results: Key weaknesses identified were a lack of support at organisational level for ongoing end-of-life care education and training incorporating use of the LCP for generalist staff, regular feedback to staff on LCP use and relative experiences, along with how to effectively communicate the aims of the LCP to patients and their relatives. Power dynamics among the multidisciplinary team also appeared to hinder effective decision making around use of the LCP.

Conclusion: Whilst the overall consensus was that the LCP was a good idea, in practice there were many underlying social, organisational and individual influences that hindered successful implementation and sustainability. This research provides transferable lessons for the future implementation of end-of-life care pathways.

Abstract number: P241
Abstract type: Poster

Getting the Right Things for the Right People ... by Using the Right Concepts

Garcia-Baquero Merino M.T., Martinez Cruz M.B., Pinedo F., de Luis V.
1Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 2Subdirección General de Servicios de Sistemas de Información, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 3Fundacion Instituto San Jose, Madrid, Spain

Background: More people need to access Specialist Palliative Care (SPC) to have their complex needs addressed. Patients and generalists feel apprehension at this point and fear their implications. SPC access is multifactorial: Getting it right improves patient timely care and resource use.

Aim: Our Regional Palliative Care Electronic Register (MRPCR) provides those with PC needs means to have their clinical information available only once their PC status is recognized. Knowing when to include patients in the Register is key: it depends on well established trigger points and patients acceptance. Access to MRPCR is granted by International Primary Care Classification (CIAP) and International Pathologies Classification (CIE), codes to identify PC patients. CIAP episode to identify the beginning of the PC process, in the context of advanced illness and poor prognosis, was “A99”: “Terminal Illness”. In 2012, we got CIAP Technical Unit to approve A99.01 to identify “Patient with (Identified) Palliative Care Needs”.

Results: Increase in referrals to the MRPCRRegister was impressive, the number of patient referrals to the Palliative Care Register went from of a peak of 2000 new referrals/month to 5300 new referrals/month within 6 months, for a 6.5 population.

Discussion: Once” terminal” disappeared from the referral protocol, a significant surge of referrals is maintained in time. Professionals feel uncomfortable pronouncing someone as close to death, whereas the feel more at ease calling for palliation for them. It is important to remove obstacles as once registered, patients are more likely to die in their chosen place by a significant 14%.

Conclusion: Access to PC services need patients consent. It is more acceptable to let go of treatments given with curative intent when understood it doesn’t mean being abandoned or the end being in sight. The A99.01 code will soon be applied in all Spanish Regional Autonomous Communities.


Abstract number: P242
Abstract type: Poster

Palliative Care Specialists and General Practitioners Sharing Care for Palliative Patients Living at Home: A Longitudinal, Qualitative Multiple Case Study about Digital Bedside Consultations

van Gurp J.L.P.1, van Selm M.2, van Leeuwen E.1, Vissers K.2, Hasselaar J.4

1Radboud University Medical Center, Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands, 2University of Amsterdam, Amsterdam School of Communication Research, Amsterdam, Netherlands, 3Radboud University Nijmegen Medical Centre (RUNMC), Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands

Research aim: To understand and describe how a tele-consultation (TC) technology/service and healthcare providers together can create innovative shared palliative home care.

Study population, design, and methods: An embedded multiple-case study in palliative home care settings in the service area of RadboudUMC (Netherlands). During the courses of 18 terminal care trajectories, the experiences with TC of home-based palliative patients (18), informal carers (15), specialist palliative care team members (SPCT; 12), and general practitioners (GP; 18) were recorded in serial interviews (56) and ethnographic conversations (40). In addition, consecutive observations (129) of actual TC delivery were conducted.

Method of analysis, results and interpretation: Analysis in line with a grounded theory approach resulted in three theoretical categories:

(a) TC contributed to sharing care as it enabled information-rich, interprofessional dialogues based on a patient’s actual situation. Although improving immediacy, accuracy, reciprocity, and harmony, TC, still required a code of conduct, a better fit in professionals’ daily work, and extended technical possibilities.

(b) Caring together through TC revealed co-caregivers’ working methods and practical contexts. Combined with a professional open attitude, TC resulted in increased mutual professional trust.

(c) A transfer of professional values through TC caused ambivalence among GPs as some refused hospital initiatives in palliative home care whereas others admitted that complex home cases required SPCT involvement. Unclear distribution of responsibilities, especially in case of immediate actions, often hampered cooperation through TC.

We conclude that static shared care concepts no longer suffice and propose a more dynamic model (including TC) in which information and responsibility more naturally fluctuate between professionals in transmural palliative care, to rethink and redesign palliative home care in a digital age.

Abstract number: P243
Abstract type: Poster

Experiences of Paramedics in Managing Patients with Advanced Chronic Obstructive Pulmonary Disease (COPD) and Advanced Cancer

Munday D., Clerici J., Karasouli E., Bailey C., Cole R., Hewison A., Lovick R., Griffiths F.

1University of Warwick, Warwick Medical School, Coventry, United Kingdom, 2University of Birmingham, School of Health and Population Studies, Birmingham, United Kingdom, 3West Midlands Ambulance Service, Dudley, United Kingdom

Aims: Patients with advanced disease are often admitted to emergency departments (ED) by ambulance. Few studies have explored the experience of paramedics in managing such patients and whether they report alternatives to transporting patients to ED after emergency calls. A year after mandatory online end of life care training in one UK ambulance service, we interviewed paramedics with the aim of understanding their experience of managing patients with advanced cancer and COPD. This was part of a wider study of emergency admission. Patient experiences are presented elsewhere.

Method: Qualitative semi-structured telephone interviews. Verbatim transcripts were analyzed thematically. 8 paramedics participated.

Results: All had experience of emergency calls to patients with COPD and cancer. They reported: calls to patients with advanced COPD were common but less so for those with cancer; all had decided not to transport patients to ED basing their decision on the patient’s condition and assessment of their best interest. They made arrangements for community professionals to provide ongoing care for patients remaining at home; occasionally direct hospice admission was possible. The challenges they faced included: lack of information concerning the patient, difficulty in accessing community professionals out of hours and fear that deterioration in the patient’s condition if left at home could lead to disciplinary action. Making alternative arrangements was more time-consuming than admitting patients to ED. Some reported that their practice had changed following the online training. Some thought that less experienced paramedics would be more likely to default to transporting all patients to ED.

Conclusion: Paramedics report managing patients with advanced COPD and cancer to be challenging. However
they are able to make decisions not to transport to ED having after undertaking training and receiving support from community professionals.

**Funding:** Macmillan Cancer Support

**Abstract number:** P244

**Abstract type:** Poster

**Needs and Expectations at the End of Life in Palliative Care Patients in Catalonia, Spain**

Font T.1, Cunill M.2, Ivanova I.3, Royo J.4

1Corporació de Salut del Maresme i la Selva, PADES, Calella, Spain, 2Universidad de Girona (UdG), Girona, Spain, 3University of California, Psychiatry and Psychology, San Diego, CA, United States, 4Fundació Hospital Sant Jaume i Santa Magdalena, EAPS Maresme, VIDDA, Research and Studies in End of Life, Mataro, Spain

**Background:** Care needs of palliative patients may change as they approach death. Attending to the biomedical, psychosocial and spiritual needs of each patient is an important challenge for the health-care system to offer quality and humane attention for a dignified death.

**Aims:** To identify the needs of terminally ill patients in the early stages of palliative care and their expectations for the last days of their lives. To compare care needs in early versus last stages of palliative care.

**Methods:** Qualitative study using in-depth interviews with 10 terminally ill patients (cancer and severe chronic diseases) from a palliative home care program and a palliative care unit. Interviews were audiotaped and transcribed verbatim. The data were analysed using latent content analysis and constant comparison techniques. Three independent researchers coded the data and discussed the outcome to develop conceptually meaningful categories of main themes.

**Results:** Needs at early stages: 39 categories were identified, composing 10 main themes: symptom management, support and non-abandonment, care tenor, maintaining privacy and intimacy, daily life functioning, preserving the sense of self and wholeness, not feeling a burden, hopefulness, resolution, and spirituality. Expectations for the last days: 20 categories were identified, composing 8 themes: symptom management, support and non-abandonment, care tenor, preserving the sense of self and wholeness, time, respect of previous decisions, and spirituality. There were differences between early and last stages in symptom management (being/not mentally aware), support & non abandonment (by their loved ones), hopefulness (maintaining/not) and time (not prolonging the dying process).

**Conclusion:** Better understanding of how patients’ needs may change as death approaches may enable clinicians to better appreciate the experiences of their palliative patients and identify ways to improve the quality of care at the end of life.

**Abstract number:** P245

**Abstract type:** Poster

**Hospital Deaths and Emergency Admission of Nursing Homes’ Residents at the End of Life: Results from a Retrospective Cross-sectional Study in France**

Morin L., Rotelli-Bihet L., DéHPAD Study Group

French National Observatory on End of Life Care, Paris, France

**Aims:** We lack large-scale, reliable data to describe and assess the place of death of nursing homes’ residents. Using the results of a French nationwide study, this presentation aims to highlight the factors influencing hospital deaths of these residents.

**Methods:** A cross-sectional, retrospective survey was conducted in all nursing homes in France. Attending physicians were asked to describe the organization of end-of-life care in their facility and to report the place of death of all residents who died in 2012. Additionally, participants were asked to identify residents who had died non-suddenly amongst the five most recent death cases which occurred within the nursing home, and to collect detailed information about their last two weeks of life.

**Results:** 3705 nursing homes participated in this study (response rate: 53%), representative of all elderly care homes facilities in France. Among 70,606 reported deaths, 17,869 (25.3%) occurred in hospital. In addition, upon 15,276 residents who died non-suddenly in the facilities, 23.6% were transferred at least once into an emergency department during their last 2 weeks of life. However, these results vary considerably depending on the nursing homes’ characteristics (Table 1).

**Conclusion:** The presence of a nurse at night and the palliative care training of the attending staff have a major influence on the rate of hospital deaths and emergency admissions amongst nursing homes’ residents. The existence of regular contacts with a Palliative Care Support Team seems to have a smaller impact.

**Abstract number:** P246

**Abstract type:** Poster

**Translating an EORTC Measure of Spiritual Wellbeing (SWB) into Persian: Patient Feedback**


1Health Metric Research Center, Iranian Institute for Health Sciences Research, ACECR & Cancer Research
Aims: Responding to spiritual problems is an unmet need of patients with cancer in many countries and measures addressing spiritual well being can help address this need, by detecting patients’ concerns and problems in this area. The EORTC Quality of Life Group (QLG) is developing a cross-cultural measure of spiritual well being (SWB) for palliative care patients. Part of the validation phase of this study involved translating the measure into Persian.

Methods: The provisional 36-item measure was translated into Persian following the EORTC QLG translation guidelines, with two forward, two backward translations and reconciliation. To receive feedback, a rigorous structured interview was carried out with patients with incurable cancer referred to a major cancer hospital in Tehran, Iran.

Results: Of the 45 patients who participated in the study, 33 commented on the measure (including reflections on the measure as a whole, and whether any items were difficult or problematic). None of the patients found any items irrelevant or offensive, although 14 patients found one item (“I have felt at peace with myself”) odd.

3 patients found the phrase “life after death” in one of the items upsetting and suggested that this be changed to omit the word “death” e.g. by using the phrase “afterlife” rather than “life after death”.

Following the measure developers’ guidance on patient feedback, alternative translations were made for 2 items, seeking to keep the original sense, while making the items more acceptable for Persian respondents. The revised version was tested, and the final version is understandable and acceptable to Persian patients.

Conclusion: Using rigorous procedures has resulted in an acceptable Persian version of the measure, which can be used in future psychometric studies of spiritual wellbeing in Iran. This experience emphasizes the importance of cross cultural collaboration during measure development, not just after validation and upon final translation.
Knowledge of General Population of Attention at the End of Life

Jorge Tufet C.1, Carre Gaya G.1, Reixach Soler R.1, Espino Garcia A.1, Porta Acosta S.1, Nabal Vicuña M.1

1Hospital Universitari Arnau de Vilanova, Residente MFyC, Lleida, Spain, 2Hospital Universitari Arnau de Vilanova, Centro Atención Primaria Bordeta, Lleida, Spain, 3Hospital Universitari Arnau de Vilanova, UFISS, Lleida, Spain

Palliative care and end of life care are usually taboo for general population. Although there are no studies on the information that people have on the subject, we approach this knowledge to evaluate population. To assess the knowledge level of the general population towards the discipline of palliative care and end of life.

Descriptive study based on a self-administered questionnaire and 10 semi-structured questions. The study population are aged over 18 who voluntarily want to participate without presenting cognitive, literacy and/or language barrier. Total sample is 198 respondents, responses were recorded in a database that analyzed through objective studies establishing a typical type 1 error estimates of 0.05 and SPSS statistical package.

Most respondents are married and 24% have a college education. Words that have been linked to palliative care are hospitals, doctors, drugs, death, cancer and words with positive connotation as peace and comfort also statistically significant (p=0.001). 78.68% of the respondents answered the question of what is meant by palliative care (p=0.037), but only 26.26% were in contact with this unit. 31.37% of women have thought about getting a living will, 41.67% of men not know this document. 76.26% know who integrates palliative care team. Patients with college education are best understood definition of palliative care, its objectives and performance of the multidisciplinary team. 43.54% are convinced that if they keep a family or advanced disease and/or terminal that would treat palliative care unit.

There is no acceptable level of knowledge about palliative care units, its goals and members except in patients with college education. Most respondents are clear that would like to be treated themselves and/or their families if needed. It is not insignificant number of respondents who know the value of advance directive. Should give greater publicity to the service from all areas to encompass more population health.

Abstract number: P247
Abstract type: Poster

PALLI-study: Retrospective Study of Cases of Deceased Persons with ID


1Erasmus MC, Intellectual Disability Medicine, Rotterdam, Netherlands, 2Radboud UMC, Healthcare for People with Intellectual Disabilities, Nijmegen, Netherlands, 3Radboud UMC, Expertise Center Palliative Care, Nijmegen, Netherlands

Background: According to the definition of the WHO, early identification of physical, psychosocial and spiritual problems is an important aspect of palliative care. Professional caregivers in the care of people with intellectual disabilities (ID) experience many barriers in the identification of people suffering from these problems. Quality of palliative care is expected to benefit greatly with early identification of needs.

Purpose: The purpose of the PALLI-study is to develop an instrument that will help caregivers to identify people with ID who are in need for palliative care. In the present study we collected information on identification of palliative care needs for use in the checklist.

Study population: 90 ID physicians and general practitioners (GPs) who provided medical care to a patient with ID who did not die suddenly.

Study design: A retrospective survey.

Methods: ID physicians and GPs filled in a comprehensive retrospective questionnaire about the process of palliative care provided to a deceased patient with ID. Questions include the cause of death, signals and symptoms that led to identification of palliative care needs and the barriers and facilitators for identification.

Results and interpretation: Preliminary results show that pneumonia was the most reported immediate cause of death (37%). Factors most often cited as indicators for identification of palliative care needs were increasing fatigue (51%), somnolence (41%), weight loss (34%) and loss of appetite (34%). In 46% of the cases start of providing palliative care was discussed less than four weeks before the patient deceased. Factors associated with early identification will be presented at the conference. This retrospective survey study will generate more insight in the experiences of ID physicians and GPs with identification of palliative care needs in people with ID.

This research has received funding from The Netherlands Organisation for Health Research and Development.
Pain is a stressful event for children and adolescents and can have negative consequences even more when it is accompanied by a chronic disease with no possibility of cure. In this context, the Pediatric Palliative Care is a philosophy of care that must be instituted from the diagnosis until the illness no longer responds to curative interventions. Therefore, the focus of care is to provide the highest quality of life possible to children and adolescents and their families while minimizing suffering and pain. The principal aim of this study is knowing the experience of the child and adolescent in palliative care for the daily management of pain. We used the Theory of Cognitive Development Piaget as theoretical framework and the Oral History as the methodological one. Moreover, these frameworks allow that children and adolescents, suffering from a chronic disease that caused pain and in palliative care have a voice. School children described their pain using sensory and evaluative components. Teenagers, on the other hand, expressed their pain using all components. Of the six collaborators to this study, five are still in school and relate to peoples of the same age. All collaborators use drugs and non-pharmacological alternatives for pain relief, reporting improvement in their pain. Some collaborators need to deal with their physical appearance which is affected by the disease. Despite the difficulty of interviewing children and teenagers, we have realized that they have a lot to say and to teach us, especially with regard to how they deal with pain in their daily lives. The present work is important for health professionals to understand that, with adequate pain management, children and adolescents can live a life as normal as possible, thus reducing their suffering.

**Abstract number:** P250  
**Abstract type:** Poster  
**A Systematic Review of Palliative Care Competency Assessment Instruments Related to Education**  
**Pereira J.**1,2, Hall P.3, Bush S.H.1,2, Weaver L.4, Rice J.1,2, Grassau P.5, Allen D.5, Ummel D.7, Ufholz L.-A.8, Tsang T.9, Zinkie S.3

1Bruyère Continuing Care, Division of Palliative Medicine, Ottawa, ON, Canada, 2University of Ottawa, Division of Palliative Medicine, Ottawa, ON, Canada, 3University of Ottawa, Faculty of Medicine, Ottawa, ON, anada, 4Bruyère Continuing Care, Department of Palliative Care, Ottawa, ON, Canada, 5Bruyère Research Institute, Ottawa, ON, Canada, 6McGill University, 7Division of Palliative Medicine, Montréal, QC, Canada, 8Université de Montréal, Clinical and Health Psychology, Montréal, QC, Canada, 9University of Ottawa, Library, Ottawa, ON, Canada

**Background:** The evaluation of competencies requires evaluation processes and assessment instruments that are robust and appropriate. Although a number of instruments have been reported, there are few recommendations regarding the selection of tools and there is no central repository of these. The goal of this study is to conduct an extensive systematic literature (formal and grey) review, make recommendations and create an on-line repository of the instruments with their description and reported psychometric properties.

**Methods:** A systematic review of the literature (formal and grey) from 1991-2011 was conducted by an interprofessional team using a Knowledge-to-Action Cycle approach. Three databases, the internet and references of publications were searched.

**Results:** 2555 articles were initially identified. Of these, 620 were included in the data extraction phase. A further 125 were found through searching the references. Instruments can be classified according to four domains:

- **a)** knowledge;
- **b)** attitudes;
- **c)** self perceived competencies/comfort;
- **d)** behaviour/psychomotor skills.

Analysis of the final data is in progress and the final results will be reported. Preliminary findings reveal:

- **a)** general lack of reporting on validity (including reliability) properties;
- **b)** use in learner populations for which the tool not specifically developed for;
- **c)** outdated items in several tools;
- **d)** poor item construction; and
- **e)** an overly narrow interpretation of the concept of validity (eg Messick’s framework).

There are, however, several robust tools that the study identified and will recommend.

**Conclusion:** There are a number of instruments available for use. However, proper selection requires knowledge about the instruments’ respective properties, strengths and limitations. A web based repository of instruments is being developed. Palliative Care educators should be attentive to best practices with regards to instrument development and use and validity constructs.

**Abstract number:** P251  
**Abstract type:** Poster  
**Complex Decision Making before Emergency Admission by Patients with Advanced Chronic**
Obstructive Pulmonary Disease (COPD) and Lung Cancer: A qualitative Critical Incident Study

Munday D.1, Karasouli E.1, Bailey C.2, Hewison A.2, Lovick R.1, Griffiths F.1

1University of Warwick, Warwick Medical School, Coventry, United Kingdom, 2University of Birmingham, School of Health and Population Studies, Birmingham, United Kingdom

Aim: Emergency admissions of patients with advanced cancer and other chronic illnesses continue to increase in the UK, leading to quality of care and public health challenges. Patients with lung cancer and COPD are amongst the commonest groups admitted. Whilst numbers and frequency of emergency admission have been investigated, few studies report patient experience. As part of a wider study we aimed to explore patient and carer decision-making processes in the time leading up to emergency admission.

Population and sample: 24 patients with metastatic lung cancer and 15 with advanced COPD admitted as emergencies to 3 UK hospitals and 20 of their carers.

Design: Qualitative critical incident study.

Method: Semi-structured interviews with participants were undertaken as soon as possible after emergency admission, transcribed verbatim and analyzed thematically.

Results and interpretation: Breathlessness was the commonest reason for admission in both groups. Pain was also common in the lung cancer group. Fewer patients were admitted suddenly after a collapse or by their GP for investigation of medical problems, sometimes unrelated to their condition. Most were admitted after worsening symptoms over hours or days.

We constructed a descriptive model after analysis, with 3 overlapping stages identified in the period before admission: self-management, negotiated decision making and ‘letting go.’ These were dynamic, characterized by a rapidly changing clinical condition, uncertainty and anxiety; this we termed ‘unstable complexity.’ Patients considered their options drawing on experience and advice either currently or previously received. Patients reluctantly accepted admission, but with a sense of relief if self-management was unsuccessful.

Conclusion: Patients use logical and complex decision making before emergency admission. Clinicians and policy makers need to understand this process in order to design and offer effective services.

Funder: Macmillan Cancer Support

How Do Nurses Working in Specialist Palliative Care Assess and Manage Breakthrough Pain? - A Questionnaire Based Multicentre Study


1Priscilla Bacon Centre for Specialist Palliative Care Services, Norwich, United Kingdom, 2Martlets Hospice, Hove, United Kingdom, 3North Hampshire Hospice, Hove, United Kingdom, 4West Suffolk Hospital, Bury St Edmunds, United Kingdom, 5Workplace Palliative Care, University of Plymouth, Plymouth, United Kingdom, 6Academic Medical Centre, Amsterdam, Netherlands

Background: Many children treated in the Emma Children’s Hospital AMC suffer from life limiting/threatening diseases (LLD/LTD). To improve palliative care a pediatric palliative care team (Emma Home Team, EHT) was initiated. It provides Advanced Care Case Management (ACCM) and transfers secondary/tertiary expertise to the primary care situation. We aimed to provide a clear report on how much time is spent on which type of case-management and how this affects hospital admissions.

Methods: Between June 1st 2012 and April 1st 2013 we reported the amount of days patients were supported by the EHT and the actual time spent on case management, until death or end of the pilot-phase. Reasons for hospital visits and admissions were analyzed. Results were compared between oncologic versus non-oncologic patients.

Results: Forty-three patients were included; 22 oncologic, 21 non-oncologic. The median duration of case management by the EHT was 50(1-267) days in oncologic versus 79.5(5-211) days in non-oncologic patients. The median time spent on case-management was 21.8 hours(1.8-81.6) in the oncologic vs 13.8(0.5-50.7) in the non-oncologic group. The number of admissions in the oncologic group was 25; 44% for anticancer therapy, compared to 33 admissions; 36% for infectious diseases in the non-oncologic group.

Conclusion: During the past nine months we observed that oncologic patients are supported by the EHT for a shorter period of time but more intensively than non-oncologic patients. This difference underlines that oncologic patients experience a more progressive palliative phase when compared to the chronic palliative phase of non-oncologic patients. Anticancer therapy comprised the majority of admissions in the oncological group versus infectious in the non-oncological group. One of the future challenges of the EHT will be to prevent or shorten hospitalizations by improving mandatory expertized case-management in the primary care setting.
Background: Breakthrough cancer pain (BTcP) is a common problem associated with significant morbidity that has recently gained prominence as a result of the development of specific pharmacological interventions for its management. A task group of the Science Committee of the Association for Palliative Medicine of Great Britain and Ireland published guidelines around the management of BTcP in 2009. Many of their recommendations rely on nurses undertaking comprehensive pain assessments, yet to date there has been little research looking at this area of practice. This study, utilising mixed methodology, has been undertaken in two stages - this abstract reports findings from Stage Two.

Aims: To gain a better understanding of how nurses working in specialist palliative care assess and manage BTcP; consider any barriers limiting its effective management and to identify specific training needs.

Design: Anonymous postal questionnaires (designed based on themes identified within interviews undertaken during Stage One of the research) were sent to all nurses working at ten specialist palliative care services in England. Scenarios were used to compare use of terminology and BTcP management.

Results and interpretation: 104 questionnaires were returned. Respondents were experienced nurses mainly working within inpatient settings. Results suggest the use of terminology in the field of BTcP remains variable. However, this did not appear to have a negative impact on patient management which was broadly in line with published consensus recommendations. 82% of nurses wanted more training on the assessment of BTcP. Other issues highlighted were; importance of teaching patients how to use analgesia to manage BTcP, patients’ wishes to avoid sedation as an analgesic side effect and patients feeling overwhelmed if they are given too much choice of rescue medication.

Funding: Unrestricted educational grant from Cephalon UK Limited.

Abstract number: P254
Abstract type: Poster

A Retrospective Review of Alfentanil Use for Pain in the Palliative Care Setting

Gough N.1, Macdermott C.2, Boswell T.2, Wighton E.2, Khan S.3, Ross J.2, Branford R.2

1Royal Marsden and Royal Brompton Palliative Care Service, Palliative Care, London, United Kingdom, 2Royal Marsden and Royal Brompton Palliative Care Service, London, United Kingdom, 3Guy’s and St Thomas’ NHS Foundation Trust, London, United Kingdom

Background: Alfentanil is a synthetic opioid used within palliative care (PC) as an alternative to conventional opioids e.g. morphine in cancer pain. Indications include (i) renal impairment as its metabolites are inactive and (ii) ‘switching/rotating’ from conventional opioids to reduce side effects/improve analgesia. In the UK, alfentanil is used infrequently necessitating specialist PC guidance to reduce the potential for drug error.

Aims and methods: To review alfentanil use in the PC setting against standards accepted from hospital guidelines. Case notes from patients started on subcutaneous alfentanil between October 2011-12 were reviewed.

Results: 59 patients commenced regular alfentanil via syringe pump (SP) in 12 months: case notes were accessible for 40.

Alfentanil was started after PC team consultation in 39/40 cases: starting indication was documented in 85%.

Starting Indication:

(i) Renal impairment in 24/40 (60%) where initial median creatinine was 188mmol/L [range 118-552]
(ii) Opioid ‘switch/rotation’ in 16/40 (40%) documented as conventional opioid intolerance (9/40), inadequate analgesia (5/40), or ‘convenience rotation’ off patient controlled analgesia (2/40).

Alfentanil was converted from another strong opioid in 80%: the conversion calculation was documented in 16%. It was prescribed as required (PRN) in 25% of cases at a dose 1/10 of background. However PRN doses < 1mg were inconsistently prescribed as milligrams or micrograms.

Outcomes: 55% (22/40) died in hospital on an alfentanil SP, 10% (4/40) were discharged on an alfentanil SP and 35% (14/40) were converted to an alternative opioid before discharge. Median duration of Alfentanil SP before death, discharge or conversion to alternative opioid: 4 days (range 1-15).

Conclusion: Trust guidance is largely adhered to but alfentanil conversion calculations are poorly documented increasing potential for errors.

PRN doses < 1mg need prescribing as micrograms to avoid confusion and improve safety.

Abstract number: P255
Abstract type: Poster

The Breathlessness Support Service: Fulfilling the Ideal of Good Care in the Community for Patients with Advanced Disease
Aim: To explore the experiences of the care that patients received from the Breathlessness Support Service (BSS), a specialist interdisciplinary intervention for patients in the community suffering from breathlessness.

Methods: Qualitative study of face-to-face cross-sectional interviews. The interviews are part of a phase III evaluation with a randomized controlled fast-track trial (RCT), following the MRC Framework for Complex Interventions. A subsample of patients was invited to take part in semi-structured, in-depth interviews, which were transcribed verbatim and imported into NVivo. The interviews were analysed through constant comparison and frequency counts were applied to detect patterns.

Results: A total of 20 interviews were conducted with 10 patients suffering from COPD, 6 from interstitial lung disease (ILD) and 4 from cancer. The patients gained access to care attuned to their needs through the assessments made by the service’s specialist team. The perception of usefulness of the aids and techniques offered varied. The range of interventions enhanced proficiency in self-management. They valued the caring approach of the BSS most, consisting of the recognition of the symptom, the professional competence and concern, and the open, continuing approach of the service in a respectful environment.

Conclusion: Patients praised the BSS as it had helped them to manage daily breathlessness while recognizing its persistent, chronic and progressive nature. They attributed its value to the caring approach of the service consisting of the respectful, unjudgmental, holistic treatment, which enhanced their dignity.

Research questions: Exposure to death in Palliative Care Units (PCU) is a major source of stress for professionals. Such a chronic stress can cause burnout. Attachment style and coping style should be of interest to understand this phenomenon. The attachment reflects child behavior seeking closeness of the specific figure to which he is attached in case of distress or alarm. Experiences with attachment figures during childhood determine trends in terms of adult’s attachment. Attachment system is activated in case of stressful situation and it is involved in emotion regulation. Coping refers to cognitive and behavioral strategies to manage situations taxing or exceeding usual resources. We focus on possible correlations between attachment styles and burnout or coping styles.

Methods: This quantitative cross-sectional study used three questionnaires (Adult Attachment Questionnaire, Maslach Burnout Inventory and Ways of Coping). They were administered to 23 healthcare professionals in two PCU. SPSS v.18 software was used for statistical analysis of correlations.

Results: In terms of trends we find a confirmation of our assumptions about the relationship between attachment styles and burnout. One result is statistically significant (p < 0.05): a negative correlation between avoidant attachment style and personal fulfillment (one of the three dimensions of burnout). The small sample size limits the statistical power. However, our results show that attachment is a promising attempt to better understand the burnout of health care professionals working in PCU.

Conclusion: This research should result in a multicenter study to provide a larger sample. A comparative study between USP caregivers and other specialties would allow investigating whether caregivers working in USP develop specific strategies to better manage daily confrontation with death and to develop a lower burnout.

Abstract number: P256
Abstract type: Poster

Burnout, Coping Styles and Attachment Styles: Which Correlations among Health Care Professionals Working in Palliative Care Units?

Lacaze M.1, Montel S.2, Casenaz V.1, Devalois B.1
1Service de Médecine Palliative, CH René Dubos, Pontoise, France, 2Université Paris 8 (EA 2027), Laboratoire de Psychopathologie et de Neuropsychologie, Paris, France

Research questions: Exposure to death in Palliative Care Units (PCU) is a major source of stress for professionals. Such a chronic stress can cause burnout. Attachment style and coping style should be of interest to understand this phenomenon. The attachment reflects child behavior seeking closeness of the specific figure to which he is attached in case of distress or alarm. Experiences with attachment figures during childhood determine trends in terms of adult’s attachment. Attachment system is activated in case of stressful situation and it is involved in emotion regulation. Coping refers to cognitive and behavioral strategies to manage situations taxing or exceeding usual resources. We focus on possible correlations between attachment styles and burnout or coping styles.

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Conclusion: This research should result in a multicenter study to provide a larger sample. A comparative study between USP caregivers and other specialties would allow investigating whether caregivers working in USP develop specific strategies to better manage daily confrontation with death and to develop a lower burnout.

Abstract number: P257
Abstract type: Poster

Do we Need Questioners for Emotional Assessment?

Nabal M.1, Abella F.2, Nadal L.3, Martinez M.3, Sarret C.2
1Hospital Universitario Arnau de Vilanova, Palliative Care Supportive Team, Lleida, Spain, 2Hospital Santa Maria GSS, Mental Health, Lleida, Spain, 3Hospital Santa Maria GSS, Unidad Socio Sanitaria, Lleida, Spain

Background: The questionnaire for the detection of emotional distress (DME) is a tool developed and validated in Spain with a sensitivity between 75 - 90.9 %, and a specificity between 72.7% - 78.8% with a cut-off of ≥ 9.

Aim: To analyze whether the implementation of the DME questionnaire is better than the clinical interview in a Palliative Care Unit (PCU).
Methods: Prospective comparative study.
Population: Older than 18, advanced disease receiving palliative care as inpatient, acceptance of psychological interview. Exclusion criteria: Performance status ≤30 (KPS scale), Pain or Dyspnea more than 5/10, Cognitive impairment (Pfeiffer>2), Psychological assessment rejection. Control group (CG): patients treated in the palliative care unit before DME was validated. Emotional assessment was conducted by appraisal interviews Experimental group (EG): patients treated after DME validation using the DME added to the normal emotional assessment.

Variables: Age, Gender, Diagnosis, Time since diagnosis, Psychopathological background, Level of information, Pain, Spiritual resources, Conspiracy of Silence, Place of discharge and DME score.

Statistics: Descriptive analysis with frequencies and central tendency measures. Comparative analysis by t Student and Chi square test (α of 5%, a level 95 % and p < 0.05). SPSS (v.17).

Results: 35 patientes were included for both groups. Overall, 58.6% were men with no significant differences between groups (p = 0.72). Mean age in the CG was 68.4 ± 12.59 and 69.8 ± 15.13 in the EG (p = 0.67). Range 27-94. Cancer was the diagnosis in 91.4%. There were not significant differences regarding diagnosis and the presence of psychopathological antecedents. The presence of emotional distress was significant different, in CG it was detected in 51.4 % and 77.1 % in the EG (p=0.0025).

Conclusion: The DME is a useful tool to improve awareness about emotional distress in palliative care settings.

Abstract number: P258
Abstract type: Poster

Role of Edmonton Symptom Assessment System (ESAS) in Symptoms Recognition

Mehle M.G., Zavratnik B., Ebert Moltara M.

Oncology Institute of Ljubljana, Department of Acute Palliative Care, Ljubljana, Slovenia

Introduction: One of the key elements of palliative care is symptoms assessment and their management. Symptoms are often overlooked. Use of a tool such as the Edmonton Symptom Assessment System (ESAS) can improve recognition, assessment and subsequently management of symptoms.

Aim: To indentify role of ESAS in symptoms registration.

Method: In retrospective analysis we have compared prevalence of symptoms documented in patient medical records of Department of oncology (DO) - no ESAS and Department of acute palliative care (DAPC) - using ESAS. We have selected a group of patients with an advanced cancer who were admitted to the DAPC from any DO. In medical documentation we looked for any symptoms documented at DO and DAPC when admitted. We have accounted only symptoms graded ≥4 in ESAS.

Results: 94 patients were included (50% male, 50% female). The average age was 67 years (range 40 - 89). The most common cancer was colorectal 22%, breast 16%, lung 10% and prostate 10%. The most common metastatic localizations were bones 36%, lung 33%, liver 29% and retroperitoneal nodes 16%. Prevalence of pain recorded was in DO 49% and in DAPC 56%, shortness of breath 18% vs. 22%, constipation 20% vs. 36%, fatigue 40% vs. 80%, lack of appetite 27% vs. 64%. Symptoms which seem to be mostly overlooked were anxiety (4% vs. 36%), depression (2% vs. 20%), drowsiness (2% vs. 32%) and sleeplessness (0% vs. 27%).

Conclusion: Our analysis has confirmed that recognition of symptoms can be improved when using ESAS. Symptoms which are not acute and severe tend to be overlooked. Tool such as ESAS should be implemented in the everyday oncological practice of any medical setting that deal with patients with advanced cancer.

Abstract number: P259
Abstract type: Poster

Getting the Right Things for the Right People ...by Using the Right Vocabulary

Garcia-Baquero Merino M.T., Martinez Cruz M.B., Pinedo F., Ruiz López D.

1Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 2Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 3Subdirección General de Servicios de Sistemas de Información, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain

Background: More people need to access Specialist Palliative Care (SPC) to have their complex needs addressed. Patients and generalists feel apprehension at this point and fear their implications. SPC access is multifactorial: Getting it right improves patient timely care and resource use.

Aim: Our Regional Palliative Care Electronic Register (MRPCR) provides those with PC needs means to have their clinical information available only once their PC status is recognized. Knowing when to include patients in the Register is key: it depends on well established trigger points and patients acceptance. Access to MRPCR is granted by International Primary Care Classification (CIAP) and International Pathologies Classification (CIE), codes to identify PC patients. CIAP episode to identify the beginning of the PC process, in the context of advanced illness and poor prognosis, was “A99”: “Terminal Illness”. In 2012, we got CIAP Technical Unit to approve A99.01 to identify “Patient with (Identified) Palliative Care Needs”.

Abstract number: P259
Abstract type: Poster
Results: Increase in referrals to the MRPCRegister was impressive, the number of patient referrals to the Palliative Care Register went from of a peak of 2000 new referrals/month to 5300 new referrals/month within 6 months, for a 6.5 population.

Discussion: Once “terminal” disappeared from the referral protocol, significant surge of referrals is maintained in time. Professionals feel uncomfortable pronouncing someone as close to death, whereas the feel more at ease calling for palliation for them. It is important to remove obstacles as once registered, patients are more likely to die in their chosen place by a significant 14%.

Conclusion: Access to PC services need patients consent. It is more acceptable to let go of curative intent treatments when understood it doesn’t mean abandonment or the end being in sight. The A99.01 code will soon be applied in all Spanish Regional Autonomous Communities. A simple action improves understanding and educates large populations.

Abstract number: P260
Abstract type: Poster

Palliative Care Education in High School. A Pilot Study
Carrasco J.M.1, Ochoa B.2, Urdiroz J.3, Teixeira I.1, Centeno C.1
1University of Navarra, Institute for Culture and Society, Pamplona, Spain, 2University of Navarra, Pamplona, Spain, 3University Clinic of Navarra, Pamplona, Spain

Background: It is known that when medicine or nursing students come in to contact with palliative care (PC) they change their attitude facing terminal patients and end of life care.
Aim: To assess the changes in the adolescents attitude facing terminal patients or end of life care after an intervention showing the basic principles of PC.
Method: Pilot study. An intervention in a high school with 61 sixteen years old adolescents (43 women) was carried out: a video with pieces from commercial films was projected (20 minutes) following a debate with PC professionals (40 minutes). Before and after the intervention adolescents were invited to respond a questionnaire related to three cases:

1) grandfather hospitalization due to a health worsening,
2) imminent death of an aunt and
3) diagnosis of a brain tumour in a friend. In a 0-10 scale they graded their fear for the situation, if they would visit the ill person and if they would like to be alone with them.

Means differences pre-post intervention were assessed using Wilcoxon Signed Rank Test.

Results: After the intervention, both the video and the debate were considered helpful by the adolescents (8.3 and 7.7 respectively). The pre-post test showed higher punctuation in all the cases, but those who graded with lower punctuation in the pre-intervention scarcely modified their attitudes. Adolescents declared to be more afraid after the intervention in the friend case (7.5 vs 8.1, p=0.002) but a better disposition to visit (8.3 vs 8.7, p=0.05). Both grand-father and aunt cases adolescent declared a greater desire to be alone with them (6.6 vs 6.8, p=0.024; 6.6 vs 7.0, 0.025; respectively).

Conclusion: Although the differences are small, data show a positive effect of the intervention. A further study with more population should be addressed to confirm the results and to determine the effect magnitude.
Funding: The ATLANTES Research Program, Institute for Culture and Society, University of Navarra, has founded this research.

Abstract number: P261
Abstract type: Poster

Receiving Bodily Care at the End of Life
Håkanson C.1,2, Öhlén J.1,3
1Ersta Sköndal University College, Palliative Research Centre, Stockholm, Sweden, 2Karolinska Institutet, Neurobiology, Care Science and Society, Dept. of Nursing, Stockholm, Sweden, 3Gothenburg University, The Sahlgrenska Academy, Institute of Health and Care Sciences, Gothenburg, Sweden

Background: In the palliative context, bodily care includes all activities aiming to reduce the burden of dying, i.e. alleviating suffering, caring for basic needs and providing comfort. Dying persons often face difficulties when the body becomes ‘unbounded’ and most private matters i.e. undressing, showering, passing urine or faeces, and body excretions from wounds, fistulas etc. are exposed. Chochinov argues that all bodies are subject to vulnerability, but the more or less conditional state of dependency in dying may add to this and thus challenge the person’s sense of agency, integrity and self-value.
Aim: To enrich the depth of the existing knowledge about meanings of receiving bodily care for the assistance with physical needs and relief from troublesome symptoms from the perspective of persons enrolled to inpatient specialist palliative care.
Methods: Nine persons (4 men and 5 women) between 57 and 76 years, with various cancer diagnoses, enrolled in one palliative care ward, participated in the study. Fieldwork was performed with an approach that comprised interviews in the form of open-minded conversations and supplementary participating observations, with the objective of following the participants during their remaining
period of life. Data analysis was performed qualitatively with an interpretative phenomenological method.

**Findings:** Four overlapping themes were revealed: maintaining and losing body capability, breaching borders of integrity, being comforted and relieved, and being left with unmet needs. The findings outline the complexity in providing bodily care in the palliative context, through the interlink of; the particularity of bodily care situations in relation to each person’s particular needs, and how these are shaped by own experiences of the body, and of health care professionals’ approaches, in ways that foster comfort or distress. The tension between reality and goals of quality in palliative care is stressed.

**Abstract number:** P262  
**Abstract type:** Poster

**Continuous Subcutaneous Infusions - Analysis of UK Practice**

Dickman A.

Marie Curie Palliative Care Institute Liverpool (MCPCIL), University of Liverpool, Cancer Research Centre, Liverpool, United Kingdom

**Background:** Continuous subcutaneous infusions (CSCI) are commonly used to maintain symptom control once the oral route is no longer available. Analysis of a local hospice database identified morphine as the most commonly prescribed opioid and midazolam as the most frequently prescribed non-opioid for administration by CSCI. In addition, 70% of the combinations identified by analysis of the database comprised 3 or more drugs. Previous national surveys do not corroborate local practice.

**Aims:** To identify national practice and compare with local practice in terms of:

1) the frequency of drugs prescribed for administration by CSCI
2) the composition of drug combinations administered by CSCI

**Methods:** UK pharmacists and pharmacy technicians were invited to complete an internet-based national survey of current practice. For each CSCI, participants recorded information about constituent drugs, doses, diluent, total volume, duration of administration and visual appearance. The data were analysed to identify the frequency drug prescribing and composition of drug combinations.

**Results:** A total of 2000 CSCIs were recorded in the national survey completed by 35 centres distributed across the UK. Midazolam was the most frequently prescribed drug, being present in 48.5% of all combinations. Morphine was the most commonly prescribed opioid, occurring in 28% of drug combinations. The majority of combinations identified by this study comprised two drugs, typically an opioid plus non-opioid.

**Discussion and conclusion:** Combinations comprising two drugs were most commonly reported by the national survey, which differs from practice that occurs in the local specialist inpatient unit. Midazolam and morphine have been shown to be the most commonly prescribed non-opioid and opioid respectively in the UK for administration by CSCI, which corroborates local practice.

**Abstract number:** P263  
**Abstract type:** Poster

**How Do Primary Care Physicians Make Decisions about End of Life Care for Older People with Non-cancer Diagnoses?**

Preston J.C.

Kings College London, London, United Kingdom

**Aims:** Palliative and end-of-life care (EoLC) needs of older adults are underrepresented in research, especially beyond a cancer context. Death from non cancer conditions is more common, compounding inequalities in EoLC planning and access to palliative care. GPs deliver both curative and generalist palliative care yet little is known about how they balance the two, towards EoL. The small number of studies on decision-making focus on managing multimorbidity or EoLC with cancer diagnoses. This study examined the decision-making of GPs in recognising and navigating the transition from curative to palliative care in older adults with multimorbidity.

**Method:** Qualitative, semi-structured interviews with GPs from 1 English county. Transcripts analysed using a grounded theory approach. Older adults were defined using pragmatic needs based, rather than chronological, criteria.

**Results:** 8 participants were recruited, 6 were female, 1 male was excluded. Experience ranged from 2 to 30 years. Three themes were identified. Recognising EoL: Occurs through patient events or patient-initiated discussions, increasing contact with professional services and physical changes. Procedural facilitators / barriers to EoLC: Barriers were GSF meeting format, time constraints and lack of reimbursement. MDT support facilitated recognition and delivery of care. Guideline-directed and patient-centred care seen as opposing activities: Alternative end points to support decision-making such as falls, EoL needs or quality-of-life are unavailable creating bias towards curative care until later stages in the absence of well demarcated commence of decline.

**Conclusions:** Reimbursements and structure favour disease-based trajectories that inhibit holistic care of older adults including recognition of EoL through subtle, indirect triggers often reliant on MDT / carers, with knock on effects for ability to advance care plan. Current GP palliative care meetings do not meet the needs of older adults.
Abstract number: P264
Abstract type: Poster

Experts’ Perspectives on Current Debates over End-of-Life Sedation: An International Qualitative Study

Papavasiliou E., Payne S., Brearley S.
Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom

Background: Much debate has been generated over end-of-life sedation with almost every aspect of the practice being questioned on conceptual, medical and ethical grounds. Research indicates that confusion and inconsistency persist leading to an increase in current debates.

Objective: To elicit the perspectives of leading international palliative care experts on current debates on end-of-life sedation.

Methods: This qualitative study enrolled 21 participants from diverse professional backgrounds who had expertise on end-of-life sedation established by significant scholarly contribution. Topic-oriented, semi-structured interviews were conducted, with topics designed to focus on current debates. Data were analysed using thematic content analysis.

Results: Certain aspects of end-of-life sedation were identified and discussed as potentially problematic:

a) continuous deep sedation as an extreme facet of end-of-life sedation,
b) psycho-existental suffering as an ambivalent indication for end-of-life sedation and

c) withdrawal or withholding of artificial nutrition and hydration as potentially life-shortening.

In such cases, concerns were reported over end-of-life sedation being a covert form of euthanasia. Intentions were used as the basis to distinguish between end-of-life acts and protective safeguards which distance sedation from euthanasia were considered.

Conclusions: This study shows that debates over end-of-life sedation seem to focus on certain aspects of the practice, particularly those with which parallels are being drawn to euthanasia. Similarly, the role of intentions associated with the practice is open to criticism and questioning. This reaffirms the existence of a grey area between sedation and euthanasia, evidenced in countries where euthanasia is legal. More clarity over the issues that generate this grey area, with their causes being uncovered and eliminated, is essential for current debates over end-of-life sedation to be brought to a close.

Abstract number: P265
Abstract type: Poster

Planning for the End of Life: The Translation of Policy in Real World Settings

Pollack K., Wilson E., Seymour J.
University of Nottingham, School of Health Sciences, Nottingham, United Kingdom

Background: Advance care planning (ACP) is promoted as a key component of ‘the good death’ enabling individuals to preserve autonomy through the exercise of choice and control about the place and circumstances of dying and death. However, little is known about the implementation of ACP in real world settings and how patients respond to the opportunity to plan their future care.

Aim: To investigate patient and carer responses to ACP in community health care settings and how closely expressed preferences influence outcomes of end of life care.

Method: Qualitative study involving longitudinal case studies triangulating patient, carer and health professional perspectives and experiences of advance care planning over six month follow up.

Results: The study findings reveal the real world difficulties that patients, carers and professionals can confront in establishing the best thing to do in challenging and difficult circumstances. Patient preferences are inclined to be uncertain, pragmatic, complex and shifting in response to unfolding uncertainty and the exigencies of contingency. Participants struggle to balance conflicting interests of obligation and imposition. The language of ‘choice’ and ‘empowerment’ has little salience for patients’ experience.

Conclusion: The study findings reveal a substantial discrepancy between the idealised and voluntaristic depiction of ACP in policy rhetoric and how this is translated on the ground. The process of discussion and anticipation which should be an important component of ACP may be of great value. However, the notion that planning may be a sufficient and effective means of controlling, and even ‘choosing’ the future and enabling ‘a good death’ is simplistic and hubristic. The language of ‘choice’ and ‘empowerment’ in relation to death and dying does not resonate with patients’ experience and risks raising expectations and false promises that elude delivery.

Abstract number: P266
Abstract type: Poster

Supportive Care in the Last Month of Life

Brinkman-Stoppelenburg A.1, Onwuteaka-Philipsen B.D.2, Van der Heide A.1
1ErasmusMC, Public Health, Rotterdam, Netherlands,
2VU University Medical Center, EMGO Institute for Health and Care Research, EMGO, Amsterdam, Netherlands

Background: In the last month of life, patients may suffer from multiple symptoms and problems. Supportive care may be needed to address these problems.
Objective: Our aim was to investigate how often palliative care consultants, pain specialists, psychological experts, and spiritual caregivers are involved in caring for patients in the last month of life and to identify determinants of their involvement.

Methods: Questionnaires were mailed to physicians attending a stratified sample of 8496 deaths that occurred in 2010 in the Netherlands. The response rate was 74% (n=6263).

Results: In 3% of all non-sudden deaths, a pain specialist had been involved in the last month of life, in 12% a palliative care team or consultant, in 6% a psychologist or psychiatrist, and 13% a spiritual caregiver. Involvement of palliative care or pain specialists was most common in patients aged 0-64 (26%) and 65-79 (19%), who were diagnosed with cancer (28%), in patients who died at home (20%), and for patients whose care was aimed at palliation (17%), for whom morphine was used in the last 24 hours before death (17%), who received continuous deep sedation (26%) or who did not forgo life prolonging treatment (17%).

Conclusion: Supportive caregivers are involved in about a quarter of all non-sudden deaths. Their involvement is related to patients’ age and diagnosis, place of death and intensity of symptom treatment.

Abstract number: P267
Abstract type: Poster

Beyond the Verbal: Photo-elicitation Interviewing about the Surroundings for End-of-Life Care

Tishelman C.1, Carlander L.2, Hajdarevic S.1, Rasmussen B.H.3, Lindqvist O.1,3

1Karolinska Institutet, LIME, Stockholm, Sweden, 2Ersta Palliative Center, Stockholm, Sweden, 3Umeå University, Department of Nursing, Umeå, Sweden

Aims: In our prior research, staff working in palliative care (PC) documented many activities they carried out in the last days and hours of a patient’s life related to “creating an aesthetic, safe and pleasing environment.” This however, says little about how patients’ perceive their surroundings at the end-of-life (EoL). The aim of this project was therefore to learn about people’s experience of their surroundings in EoL care by using photo-elicitation interviewing (PEI).

Methods: 23 people in 3 PC inpatient units in 2 Swedish cities, 1 PC home care service, and 1 residential care home participated in the study. Participants were given a digital camera and asked to take 3 pictures depicting that which was meaningful for them, positive or negative, in their surroundings. The interviewer returned the next day, to view the photographs with the participant. An open interview followed based on the questions: what is this picture of? And why did you take it? Data was analyzed by the researchers as a team, focusing on the participants’ descriptions in relation to the photographs themselves.

Results: Initial analysis indicated there could be a gap between the manifest content of the photos and the participant’s intended focus, as clarified in the interview. Despite differences in manifest content, PEI provided explicit examples of the manner in which people create meaning in relation to their past, present and future through their surroundings, in part through efforts to maintain contact with the familiar, and live on one’s own terms.

Conclusion: We found that photographs functioned in part as a trigger for discussion and as a means of generating unique in-depth interview data, but also as a form of communication in itself, relaying more than was possible in an interview alone. We will discuss limitations and also strengths of PEI in EoL settings, including offering an alternative form for communication as verbal ability decreases, and fatigue and symptom burden increases.

Abstract number: P268
Abstract type: Poster

The Provision of End of Life Care for Patients with End Stage Liver Disease in a Tertiary Liver Unit

Davis S.1, Low J.1, Vickerstaff V.1, Greenslade L.2, Hopkins K.3, Marshall A.2, Jones L.1

1UCL, Mental Health Sciences, London, United Kingdom, 2Royal Free Hampstead NHS Foundation Trust, Hepatology, London, United Kingdom, 3Royal Free Hampstead NHS Foundation Trust, Palliative Care, London, United Kingdom

Background: In the UK chronic liver disease is the 5th largest cause of death. Access to good quality end of life care (EOLC) in end stage liver disease (ESLD) is limited. People have complex needs suitable for palliative care but referrals occur late.

Aim: To explore barriers to health professionals initiating EOLC for people with ESLD.

Methods: Using Rapid Participatory Appraisal we have collated data from multiple sources. We held 3 focus groups and 4 interviews with health professionals in a tertiary liver unit. We are holding focus groups (i) with primary care professionals to understand management of ESLD in the community (ii) with patients and carers to understand their experience of primary and secondary care.

Results: The main barriers to EOLC are poor communication at all levels, and a confused patient pathway. Patients...
commonly experience frequent unplanned hospital admissions for acute exacerbations as they deteriorate and reach end of life. Treatment decisions are reactive and taken when a crisis occurs. Patient preferences for care are rarely discussed or documented. Communication with palliative care occurs late as clinicians are unsure when to refer. Repeated patient admissions indicate deterioration and could act as a trigger for clinicians to discuss and document ‘ceiling of care’ decisions, and consider with patients their place of care. Earlier palliative care referrals would address symptom burden and future choices.

**Conclusion:** Care in ESLD is complex; the illness trajectory includes episodes of exacerbation and recovery responsive to both active and palliative treatments when offered in parallel. This should not prevent clinicians from starting early discussions with people who are deteriorating. Topics might include preferences for future care, limits of treatment and referral to palliative care for management of complex needs. This approach would allow a responsive pathway for people with ESLD to address clinical and supportive needs.

**Abstract number:** P269  
**Abstract type:** Poster  
**Palliative Care Interventions in the Emergency Department (ED): Healthcare Professionals Views of Improving End of Life Care**  
*Weatherhead E., Efstathiou N., Bailey C.*  
University of Birmingham, Birmingham, United Kingdom

**Aims and objectives:** This study aims to identify and explore current interventions used in ED’s to assist and improve quality of end of life care.

**Background:** Despite the national priority to reduce emergency admissions at the end of life, people with life-limiting illnesses are increasingly accessing the ED. There has been a significant increase in cancer and non-cancer admissions in the last year of life but concerns that emergency care for patients with life-limiting illness is inadequate. Understanding staff perspectives of the barriers to quality care provision at the end of life in the emergency setting is fundamental in order to recommend improvements for service provision.

**Methods:** Focus groups were conducted with ED staff (nurse, doctors, and support workers) and palliative care nurses. Semi-structured interview questions were based on the results of the literature review in the initial phase of the project. Data was analysed thematically.

**Results:** ED staff identified barriers in the ED that hinder the provision of end of life care. They recommended interventions which they felt could improve care provision including, a patient pathway, universal documentation and improving education. Overall, participants felt the ED environment was inappropriate to provide end of life care suggesting that the primary function of the ED is not conducive to palliative care.

**Conclusion:** The ED culture does not account for end of life care which presents barriers for patients who attend for palliative emergencies. Within the UK very little attention has been paid to interventions to improve end of life care in the ED. This study highlights that interventions to improve end of life care need to consider the organisational culture that exists in the emergency setting; this is important when considering service provision and improving healthcare.

**Abstract number:** P270  
**Abstract type:** Poster  
**Anti-Co: Antithrombotic Approach in the Palliative Care Setting. A Retrospective Study**  
*Bertola A., Saber B., Valle A., Vivalda P., Veronese S.*  
Fondazione FARO Onlus, Torino, Italy

The role of antithrombotic therapy and prophylaxis (ATP) in hospice care is not clearly defined although a well-established literature on this topic for cancer patients is available.

In order to define a common strategy within a specialist palliative care team (SPCT) a research project was conducted. The aims of the study were to compare the indications, risk factors and recommendations of the existing guidelines for cancer patients with the characteristics of the patients cared for by our SPCT and to explore the attitude of care adopted by our team.

**Methods:** A retrospective study on the medical charts of a random sample of cancer patients cared for by our SPCT was conducted. Data collection was focused on clinical features, cancer and not cancer related risk factors for thromboembolic disease (DVT) and ATP prescriptions at admission, during the assistance and in the last days of life.

**Results:** 165 (15%) medical records of cancer patients (median age=73, Karnofky score ≤40 in 80%, median length of care 23 days) out of the 1108 assisted by our SPCT in 2012 were searched. 35% of the sample had non cancer (mainly cardiovascular) and 55% cancer related risk factors for DVT at admission. 36% of the patients were in ATP at the first visit. 85% of this ATP was continued during the assistance (15% ≥ 1 month and 67% ≤3 days before death) and 11% was still in act at the death.

**Conclusions:** Our evidence suggest the inapplicability of ATP guidelines for cancer patients to the palliative care population because almost the whole sample would have required ATP if they were applied. Most of the ATP were discontinued in the last days of life mainly for deterioration. All the ATP discontinued ≥ 1 month were due to diagnosis.
Decision making for ATP for far advanced patients cannot be borrowed by existing guidelines but should be tailored on specific outcomes and goals of the palliative care setting.

**Abstract number:** P271  
**Abstract type:** Poster

**Consultation for Palliative Sedation in the Netherlands: A Descriptive Study for the Years 2004 - 2011**


1Radboud University Medical Center, Nijmegen, Netherlands, 2IKNL Comprehensive Cancer Care Centre the Netherlands, Utrecht, Netherlands

**Research aims:** Several guidelines advise to consult an expert when considering palliative sedation (PS). In the Netherlands, Palliative Care Consultation Teams (PCC-Teams) are 24/7 available for expert consultation on palliative care, including PS. These teams advise formal, professional caregivers of patients. We aimed to describe the extent and features of these consultations and compare the characteristics of consultations related to PS (PS consultations) to consultations not related to PS (non-PS consultations).

**Design, method and analysis:** We performed a retrospective analysis on all consultations by PCC-Teams, requested from 2004 - 2011. Several characteristics were systematically registered in a national registration system for each consultation. To prevent duplicates, only the first consultation for every patient was included for analysis. Characteristics of PS consultations and non-PS consultations were compared by conducting uni- and multivariate regression analyses.

**Results and interpretation:** 44,443 consultations were analyzed, of which 8,038 were PS consultations. Characteristics independently associated with a higher likelihood of PS being addressed during consultation were, among others, 1) patients having a neurological disease (OR 1.79; 95% CI: 1.51 - 2.12) or COPD (OR 1.39; 95% CI: 1.15-1.69), 2) patients suffering from dyspnea (OR 1.30; 95% CI: 1.22 - 1.40), agitation/ delirium (OR 1.57; 95% CI: 1.47 - 1.68) and fatigue (OR 2.89; 95% CI: 2.61 - 3.20), and 3) consultations in which euthanasia-related issues (OR 2.65; 95% CI: 2.37 - 2.96) or existential problems (OR 1.55; 95% CI: 1.31 - 1.83) were discussed.

The number of PS consultations rose after the introduction of the Dutch guideline on PS in 2005. However, in 2010, the number of PS consultations by PCC-teams (0.8% of all deaths) was still far behind the estimated number of performed palliative sedations (12.3% of all deaths). The aforementioned advise on expert consultation for PS, stated in several guidelines, seems to be only marginally implemented.

**Abstract number:** P272  
**Abstract type:** Poster

**Prescribing Patterns in a Palliative Population - A Prospective Consecutive Casenote Review**

**Russell B.J.**, **Rowett D.**, **Currow D.**

1Centre for Palliative Care, Melbourne, Australia, 2Repatriation General Hospital, Drug and Therapeutics Information Service, Adelaide, Australia, 3Flinders University, Discipline of Palliative and Supportive Services, Adelaide, Australia, 4Cancer Institute New South Wales, Sydney, Australia

**Aim:** The aim of this study was to provide descriptive data regarding the scope and patterns of prescribing for comorbid illness in the setting of terminal illness at the time of referral to a Palliative Care service, with particular focus on lipid-lowering medications, as well as world-first data regarding *pro re nata* (PRN) prescriptions for symptom control.

**Method:** A consecutive prospective casenote review of 203 patients in regional Australia was performed, documenting the complete medication list (including indication for lipid-lowering medications) for analysis by primary diagnosis, comorbidities, performance status and phase of illness.

**Result:** The mean number (and standard deviation) of regular medications prescribed was 7.2 (3.7) with higher rates observed in those patients with a non-malignant primary diagnosis (rate ratio 1.28) or poorer performance status (rate ratio 1.37). There were lower rates for those in the terminal phase of care (rate ratio 0.48). Over one fifth of patients were prescribed one or more lipid lowering medications and two fifths of these prescriptions were for primary prevention of cardiovascular disease. Mean number of PRN medications prescribed was 3.0 (2.0) with higher rates observed among those patients in the terminal phase of care (rate ratio 1.36) and those who died within one week of admission (rate ratio 1.30).

**Conclusion:** These findings suggest that polypharmacy is the norm rather than the exception, placing this group of patients at high risk of adverse drug interactions. Prescribing may be driven by risk factors despite high number needed to treat and prolonged time until benefit. The PRN prescribing findings potentially represent the uptake of end-of-life care pathways. This unique data highlights the importance of a rational, patient-centred approach to prescribing for patients with terminal illness.
Abstract number: P273

Abstract type: Poster

Palliative Care Stepping towards Integration in Spain? An Answer from the Literature

Centeno C.1, Garralda Domeain E.1, Carrasco J.M.1, Van Beck K.2, Siouta N.2, Menten J.2, Groot M.1, Radbruch L.4, Payne S.1, Csikos A.4, Hasselar J.3

1University of Navarra, Institute for Culture and Society, Pamplona, Spain, 2KU Leuven, Leuven, Belgium, 3Radboud University Nijmegen Medical Center, Nijmegen, Netherlands, 4University Hospital Bonn, Bonn, Germany

Background: Integrated Palliative Care aims to reach continuity of care between all actors involved in the care network of patients receiving palliative care (PC).

Aim: The current study attempts to identify existing models, initiatives, guidelines and clinical pathways for integrated PC in Spain.

Method: Systematic review of the literature included in PubMed; manual review of the national Palliative Care Journal (Medicina Paliativa); grey literature search (Google and mailing organizations and experts). Between 1995-2013.

Results: After reading titles, 30 works were selected from the 587 identified in PubMed, 15 from the 15 years of Medicina Paliativa, Google search provided 40 documents and 2 more came from organizations. Considering the 87 full text, we obtained 69 valid documents about PC integration (22, 13, 32, and 2 respectively). 30 documents on health strategy were found (13 national or regional strategic plans, 9 strategic plans for specific situations, 8 others); 18 guidelines were identified (3 general guidelines about PC, and other about chronic disease as cancer, heart or pulmonary diseases); 4 were documents on pathways (Spanish version of Liverpool Care Pathway, two renal failure pathway and a PC pathway for a concrete University Hospital) and 17 analytic studies. Most of the documents identified were written in the last 7 years.

Conclusion: The review shows that Health providers and Policy makers agree on the need of PC integration. Only a few national guidelines have been distributed. There are still poor evidence about pathways and initiatives on integrative palliative care with positive result. It could point out the first steps towards PC integration in Spain.

Financial: This research is part of the Insup-C Project (7th FP): Patient centered pathways in advanced cancer and chronic disease.

Abstract number: P274

Abstract type: Poster

Prognosis Disclosure: A Survey of the Attitude of Family Physicians


1Portuguese Institute of Oncology, Palliative Care, Porto, Portugal, 2USF Famílias, Santa Maria da Feira, Portugal, 3USF Santa Clara, Póvoa de Varzim/Vila do Conde, Portugal, 4USF Santa Maria, Bragança, Portugal, 5Terras de Ferreira, Paços de Ferreira, Portugal, 6USF Lethes, Ponte de Lima, Portugal, 7USF Lagoa - Senhora da Hora, Matosinhos, Portugal, 8USF Gil Eanes, Viana do Castelo, Portugal, 9USF Ramalde, Aldoar, Porto, Portugal, 10USF Porta do Sol, Matosinhos, Portugal, 11USF Infesta, Matosinhos, Portugal, 12USF Mar, Póvoa de Varzim/Vila do Conde, Portugal, 13USF Arco do Prado, Gaia, Portugal, 14USF S. Mamede Infesta, Matosinhos, Portugal, 15USF Oceanos, Matosinhos, Portugal, 16USF S. João, Porto, Portugal, 17USF Dunas, Matosinhos, Portugal, 18USF S. Martinho, Penafiel, Portugal, 19USF Renasca, Gondomar, Portugal, 20USF Macedo de Cavaleiros, Macedo de Cavaleiros, Portugal, 21UCSP Aldoar, Porto, Portugal, 22USF Navegantes, Vila do Conde, Portugal

Aim: To study the attitudes of family physicians concerning this important aspect of care.

Methods: A questionnaire specifically developed for this survey was sent to about 10% of the family physicians in the Northern region of Portugal.

Results: The study included 159 doctors with a median age of 43 years (26 to 64) and 108 (68%) of them were females. 47 (30%) disclose the prognosis often and 54 (34%) do it sometimes. That rate of doctors who often disclose the prognosis rose to 48% when patients requested the disclosure. When disclosing the prognosis 120 (76%) doctors do not try to give a precise time to death (ex., 3 months) but they try to give an idea which would be useful but not precise. 59 (37%) disclosed the prognosis to families often and 57 (36%) do it sometimes; 23 (15%) doctors only do that with the patients’ authorization. The percentage of doctors who disclose the prognosis often increases to 70% if the patient is cognitively incompetent. For 69 (43%) the disclosure is psychologically deleterious often to always and more 72 (45%) answered sometimes. For 43 (27%) the disclosure has a detrimental effect on patients’ hope often to always; the oldest have that opinion more often than the youngers: 29 (37%) vs. 14(18%) (p=0.023).
On the other hand, 69 (43%) think that the disclosure gives patients control of the situation often to always and more 61 (38%) answered sometimes. 45 (28%) doctors answered that families ask them frequently not to disclose the prognosis to the person; the oldest gave that answer more often than the younger: 28 (35%) vs. 17 (21%). 50 (31%) take often to always into account families’ request and 85 (54%) do it sometimes.

Conclusion: Family physicians do not disclose the prognosis of a life-threatening disease often, even at patients’ request, especially the oldest ones. Most doctors take into account the families’ request not to disclose the prognosis.

Abstract number: P275
Abstract type: Poster
End-of-Life Care for Elderly Patients with Advanced Frailty: Current Practice and Challenges from the General Practitioners’ Perspective

Geiger K., Klindtworth K., Müller-Mundt G., Bleidorn J., Schneider N.
Hannover Medical School, Institute for General Practice, Palliative Care Research Group, Hannover, Germany

Aims: Community-dwelling elderly patients with advanced frailty are an increasingly important target group for general practitioners (GP). The ELFOP-Project (End of life care for frail elderly patients in family practice) aims to explore and understand these persons’ needs, appropriateness and utilization of services, from the perspective of the frail elderly themselves, their next of kin and GPs, with special attention to general palliative care needs.

Method: In 2012, we set up an ongoing qualitative longitudinal study including 31 elderly patients with advanced frailty. Recruitment took place in 14 general practices in Northern Germany. We conduct semi-structured face-to-face-interviews with the patients and their GPs 6-monthly up to 18 months. The GPs are asked about their patients’ health situation and needs as well as about their general experience concerning the care for frail elderly patients, with a focus on the patients’ last phase of life. Analyses are carried out using Grounded Theory and narrative approaches.

Results: The results of the baseline interviews with the 14 GPs will be presented. According to the GPs delivering care for elderly patients with frailty is highly time-consuming, and their needs are complex (multimorbidity, multi-medications, coordination of care). For most GPs home visits and end-of-life care are an important part of their work. Needs for improvements are seen with respect to the cooperation with other professionals e.g. community nurses, delegation of responsibilities, bureaucracy and adequate remuneration.

Conclusion: Elderly patients with advanced frailty are a major target group for generalist palliative care delivered by GPs. GPs feel responsible to deliver optimal health care but recognize severe challenges in the daily practice to appropriately meet the complex needs. Frail elderly patients should have an important role in the development of palliative care concepts.

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Abstract number: P276
Abstract type: Poster
Palliative Care in Advanced Dementia: A Qualitative Study Exploring the Views of Consultants Involved in Dementia Care

Ellis A.¹, Gough N.², Brewer K.¹
¹King’s College London, Gerontology, London, United Kingdom, ²St Christopher’s Hospice, London, United Kingdom

Background: Evidence suggests the palliative care (PC) provided to those with advanced dementia (AD) is sub-optimal with limited specialist PC access, an under-appreciated symptom burden and poor advance care planning (ACP).

Aim: To explore the views of consultants from different specialities involved in dementia care regarding the role of PC and potential areas for improvement.

Method: Thirteen semi-structured qualitative interviews were conducted with consultants from geriatrics, old age psychiatry and specialist PC. Interviews were audio-recorded, transcribed verbatim and analysed using the Framework approach.

Results: All professional groups described the value of PC in those with AD, emphasizing the importance of optimizing symptom control and reducing unnecessary admissions to hospital. Challenges with adopting a PC approach in patients with advanced dementia included prognostication and recognition of dying. This was identified as more difficult than in a cancer population. The end of life care those with dementia currently receive was felt to be sporadic and limited by poorly integrated services. Neither acute hospitals nor hospices were viewed as appropriate locations for end of life care: an environment familiar to the patient was considered preferable. Providing PC was felt to be within the remit of the generalist physician with specialist PC input for complicated cases. There is a need for a new model of generalist led ‘dementia-specific’ PC, which acknowledges the uncertainties associated with disease trajectory. Education was identified as paramount to improve services, incorporating the sharing of knowledge and skills between specialities.

Conclusions: In an ageing society it is vital that we improve palliative care for people with dementia. A multidisciplinary approach to the development of a model of...
care is important to empower the generalist physician to lead the care provision whilst ensuring easy access to support from other specialists.

**Abstract number:** P277  
**Abstract type:** Poster  
**Perceptions of Patient Centred Factors in a Palliative Care Approach in Advanced Heart Failure**  
**Gadoud A., Macleod U., Johnson M.**  
University of Hull, Hull York Medical School, Hull, United Kingdom

**Background:** Patients with advanced heart failure have significant unmet palliative care needs. Difficulty in prognostication and clinicians’ reluctance to initiate conversations about end of life care, for fear of taking away hope, mean that palliative care needs often remain unrecognised and unaddressed.

**Aim:** Patients’ and carers’ perceptions of the effects of a palliative care approach in advanced heart failure.

**Method:** As part of a larger qualitative study, patients with advanced heart failure who were receiving a palliative approach to their care participated in an in-depth semi-structured interview. If possible their family carers were interviewed with the patient or separately.

**Results:** Interviews with 19 patients were conducted (average age; 70, range 54 - 93; men = 11): nine patients and carers together, ten patients and three carers alone. Patients showed numerous coping strategies such as humour, meaningful relationships, life experiences, spiritual beliefs and stoicism. A wide variety of concerns included physical symptoms, social isolation and carer strain. Contrary to concerns expressed by clinicians, patients receiving a palliative approach to their care did not lose hope, but rather, reframed their goals, using coping mechanisms similar to those seen elsewhere to maintain hope in the face of terminal illness. A palliative care approach helped to maintain adaptive coping mechanisms such as individual worth/value and maintaining meaningful relationships by reducing carer strain and social isolation.

**Conclusions:** Patient factors should be at the centre of both recognition and delivery of palliative care in advanced heart failure. Recognition of need such as poorly controlled symptoms rather than prognosis would reduce the problems associated with difficulty in prognostication in heart failure and be more meaningful to patients.

**Abstract number:** P278  
**Abstract type:** Poster  
**An Evaluation of a United Kingdom Hospice-based Circuits Exercise Programme: Patient Uptake, Outcomes and Feedback**

**Talbot Rice H.1, Malcolm L.1, Jones A.2, Norman K.1, Lee K.1, Preston G.1, Mckenzie D.2, Maddocks M.2**  
1St Christophers Hospice, London, United Kingdom, 2Cicely Saunders Institute, King’s College London, London, United Kingdom

**Aims:** Evidence suggests that exercise may benefit patients with advanced progressive illness and some hospice day services now provide dedicated gym space. However, supporting data for such a service development are limited. Our aims were to describe patient referrals, interventions, feedback and potential impact of a 9-week, outpatient, hospice-based, circuit exercise programme.

**Methods:** All outpatients referred to physiotherapy over a 6-month period commencing March 2013 were followed prospectively. Measures of physical function (Short Physical Performance Battery (SPPB), grip strength), fatigue and psychological well-being (FACIT-F, GHQ-12) were assessed pre- and post-programme. Patient satisfaction (FACIT-PS) was assessed on programme completion.

**Results:** Of 212 referrals, 61 (29%) were considered appropriate for the circuits of whom 54 (89%) started. Patients had a range of cancer and non-cancer diagnoses and median [IQR] survival of 67 [50–137] days. There were no statistical differences between those completing 18 (33%) and not-completing with regards to age, diagnosis, social status or survival. In completers, only the sit-to-stand (STS) element of the SPPB changed statistically (mean ∆ [95% CI] gait speed 0.26 [-0.06, 0.58]m/s; SSTS -8.23 [0.65,12.13]s; grip strength 0.68 [-2.13,3.48]kg). Psychological well-being, quality of life and fatigue remained unchanged. Patients felt the physiotherapists gave clear explanations, understood their needs and would recommend the service to others.

**Conclusion:** A hospice-based programme is one means to offer exercise to a range of patients with advanced progressive illness. Despite excellent feedback, only one-third of patients completed the 9-week programme in full and evidence of benefit was limited. Future work should explore the broader benefits of participation and whether delivering programmes, or elements of them, in shorter time frames is more beneficial.
Background: Opioid Rotation (OR) is the clinical practice of substituting one strong opioid for another. The indication is to improve balance between pain relief and adverse effects. Opioid Rotation incidence is 20-44% internationally. The scientific basis for this practice is unclear.

Aims: Capture opioid prescribing patterns of Palliative Medicine Consultant Physicians (C), Physician Trainees (T) and Nurse Specialists (NS):

1. Opioid choice: 1st, 2nd, 3rd line
2. OR choice in opioid toxicity (OT): brain, kidney, liver failure
3. Indication for alfentanil
4. Conversion ratios relative to morphine: oxycodone and alfentanil


Results: National sample: C 11/35 (31%); T 13/14 (93%); NS 11/49 (22%).

Opioid Choice:
1st line morphine (C 100%; T 100%; NS 100%).
2nd line oxycodone (C 91%; T 100%; NS 100%).
3rd line hydromorphone (C 55%; T 85%; NS 64%)

Opioid Rotation Choice in Morphine Toxicity:
Brain Failure: oxycodone (C 82%; T 85%; NS 73%)
Kidney Failure: alfentanil (C 45%; T 69%; NS 36%)
Liver Failure: oxycodone (C 36%; T 38%; NS 73%); hydromorphone (C 9%; T 38%; NS 18%); fentanyl (C 36%; T 0%; NS 0%).

Oxycodone: Morphine conversion ratio:
1:1.5 (C 55%, T 54%; NS 27%)
1:2 (C 27%; T 38%; NS 64%)

Alfentanil widely prescribed: C 100%; T 77%; NS 54%.
Kidney failure major indication: C 91%; T 90%; NS 36%.
Parenteral morphine: alfentanil conversion ratio 15:1 (C 73%; T 69%; NS 36%)

Conclusions:
1. Morphine first choice in opioid naïve
2. Variations in opioid rotation practice evident
3. Toxicity: rotation practice consistent in brain and kidney but not liver failure
4. Physicians favour 1:1.5 oxycodone: morphine conversion ratio
5. Nursing experience of alfentanil limited

Abstract number: P280
Abstract type: Poster

Development of a National Guideline for Refractory Breathlessness in Cancer Patients


1University Hospital Munich, Department for Palliative Medicine, Munich, Germany, 2University Hospital of Cologne, Department of Palliative Medicine, Clinical Trials Unit (BMBF 01KN1106), and Centre for Integrated Oncology (CIO) Cologne/Bonn, Cologne, Germany, 3Hospital Grosshansdorf, Lung Clinic, Grosshansdorf, Germany, 4Hospital Havelhoehoe, Department of Palliative Medicine, Havelhoehoe, Germany, 5Kliniken Essen-Mitte, Center for Palliative Medicine, Essen, Germany, 6Marienhospital Aachen, Diagnostik- und Therapiezentrum, Aachen, Germany, 7RWTH Aachen University, Department of Palliative Medicine, Aachen, Germany, 8KU Leuven, Research Group Health Psychology, Leuven, Belgium, 9University of Mainz, Department of Dermatology, Mainz, Germany, 10HELIOS Klinikum Emil von Behring, Department of Pneumology, Heckeshorn, Germany, 11University Hospital of Würzburg, Interdisciplinary Center for Palliative Medicine, Würzburg, Germany, 12Fachkrankenhaus Coswig GmbH, Centre for Pulmonary Diseases and Thoracic Surgery, Coswig, Germany, 13University of Heidelberg, Thoraxklinik, Heidelberg, Germany, 14University of Lübeck, Department of Otorhinolaryngology, Head and Neck Surgery and Plastic Surgery, Lübeck, Germany, 15Hospital Grosshansdorf, Center for Pneumology and Thoracic Surgery, Grosshansdorf, Germany

Aim: To improve the management of refractory breathlessness in patients with advanced malignant disease, the German Association of Palliative Care initiated the development of an evidence based guideline for palliative care for cancer patients including a guideline on breathlessness.

Methods: Experts from various clinical (medical, nursing and physiotherapy) and research backgrounds developed key questions in an initial consensus process. Current evidence from existing guidelines and systematic reviews (including updates) was collected and new systematic reviews on the role of steroids and sedative drugs were conducted. Based on this evidence and clinical experience, recommendations were developed. All recommendations were reviewed and adapted in an online Delphi consensus process until agreement of at least 75% was reached. This guideline will be finalized in a national consensus conference in November 2013.

Results: 20 recommendations were developed on assessment (n=5, expert consensus), pharmacological therapy (evidence based: opioids (n=3), benzodiazepines (n=2), phenothiazines (n=1), antidepressants (n=1), steroids (n=1)), non-pharmacological measures (1 expert consensus, evidence based: hand-held fan, rollator and
Oxygen (1 each) and care in the dying phase (2 consensus based).

Conclusion: This evidence and consensus based guideline will hopefully improve the care of breathless cancer patients in Germany. An international adaptation of the guideline is planned.

Funding: This project is supported by the German Guideline Program in Oncology.

Abstract number: P281
Abstract type: Poster

A Comparative Study of Two Artificial Saliva Products for Treatment of Dry Mouth

Ibrahim E., Lawrie I.

The Pennine Acute Hospitals NHS Trust, Department of Palliative Medicine, Manchester, United Kingdom

Background: Oral health requires a normal production of saliva, and any alteration in the quality or quantity may cause oral problems. Saliva has many functions, including enhancing taste, lubricating the mouth, neutralising harmful acids and washing away food residue. Dry mouth, known as xerostomia, can have a significant impact on activities of daily living such as speaking, eating and sleeping. Patients who suffer from chronic dry mouth may be at increased risk of psychological distress and depression. Studies have suggested that topical products are beneficial in the management of dry mouth. However, few comparison trials have been carried out.

Objective: To compare patient feedback about two artificial saliva products, AS Orthana® and Biotène Oralbalance Gel®, regarding change in severity of dry mouth symptoms, ease of use and change in frequency of dry mouth symptoms.

Methods: Participants were randomised to receive one or other of the artificial saliva substitutes first for 5 days, then an overnight ‘washout’ period, followed by cross-over to the other product for a further 5 days. Feedback was made by using a visual analogue scale and the Summated Xerostomia Inventory.

Results: 30 patients were recruited to the study, and 26 completed it. AS Orthana® appeared to be more effective in improving severity of symptoms relating to speech and chewing, as well as improving ability to swallow. Biotène Oralbalance Gel® improved severity of dry mouth sensation and taste, as well as being easier to use. Overall, 13 patients preferred AS Orthana® and 12 preferred Biotène Oralbalance Gel®. One patient had no preference.

Conclusion: There appears no statistical difference between AS Orthana® and Biotène Oralbalance Gel® in management of xerostomia, and it would suggest that individual patient preference is the most important factor when choosing which artificial saliva substitute to prescribe.

Abstract number: P282
Abstract type: Poster

Patient and Public Involvement in the EURECA Study

Staniszewska S.1, Gunn K.1, Munday D.2, Lovick R.2, Karasouli E.3, Bailey C.1

1University of Warwick, RCN Research Institute, Warwick Medical School, Coventry, United Kingdom,
2University of Warwick, Warwick Medical School, Coventry, United Kingdom,
3University of Birmingham, School of Health and Population Studies, Birmingham, United Kingdom

Background: Patient and public involvement has become an important element within healthcare research. It aims to enhance the relevance, acceptability and appropriateness of research (INVOLVE 2012, Staniszewska et al 2011). The EURECA study examined emergency admission by patients with advanced Chronic Obstructive Pulmonary Disease (COPD) and Lung Cancer.

Aims: To understand the impact of the EURECA Patient Reference Group, particularly in relation to the discussion, interpretation and synthesis of study data.

Methods: In total 3 EURECA Reference Group meetings were recorded and transcribed, in addition to the final meeting. Data analysis was conducted using NVivo qualitative analysis software. Codes were identified from the data, agreed in discussion between members of the research team, and applied across transcripts. Key themes were identified and confirmed after further discussion with the Reference Group.

Results: A number of themes were identified which reflect the different ways in which the Reference Group contributed to the study, particularly to the analysis of data. These include: Responding to presentation of specific emerging findings, identifying and considering solutions, raising additional concerns, providing a different perspective and contributing to patient and public involvement.

Conclusion: Overall, the Reference Group provided reassuring confirmation and validation of the researchers’ developing understanding of the data. Discussions also allowed for a useful exploration of issues, anomalies, and potential recommendations. In addition, members of the group provided their own particular insights, based on personal experience and supported by interaction within the group.

Abstract number: P283
Abstract type: Poster

Signs of Post-traumatic Stress Disorder in Caregivers Following an Expected Death: A Qualitative Study

Lobb E.A.1,2, Sanderson C.3, Mowll J.2, Butow P.N.4, McGowan N.3, Price M.4

1,2School of Health and Population Studies, Birmingham, United Kingdom
3University of Birmingham, School of Health and Population Studies, Birmingham, United Kingdom
4Fellow in Palliative Medicine, Manchester, United Kingdom

Background: Palliative Medicine, Manchester, United Kingdom

The Pennine Acute Hospitals NHS Trust, Department of Palliative Medicine, Manchester, United Kingdom

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Background: Within the literature on palliative care, the possible occurrence of PTSD as part of the spectrum of complications of grief seems to have gone largely unrecognised. Nonetheless our clinical experience suggests that trauma symptoms and possibly PTSD may contribute significantly to bereavement morbidity in this population. This is an exploratory paper examining responses to the death of a loved one who has had cancer, with a focus on possible trauma/PTSD responses.

Methods: Consecutive care-givers participating in the Australian Ovarian Cancer Study-Quality of Life Study and who were bereaved during this study were invited to participate in a follow-up study. Approximately five months post-bereavement, caregivers were sent a letter of condolence inviting them to participate in semi structured telephone interviews. Questions were developed for the following domains: the last weeks of life, end of life care, and the death itself. Interviews were tape recorded and transcribed verbatim. Caregivers’ recollections of their end of life experiences were coded and analysed.

Results: These interview transcripts describe trauma associated with these expected deaths. Highlighting the substructural emotional tone within these interviews reveals that the expressions of distress and shock identified, even though some phrases are in common usage, are repetitively present in this setting. All interviewees used language consistent with some degree of traumatisation. There was evidence suggestive of resilience and resolution. However, a number of interviewees describe intrusive memories associated with the physical sights and sounds that they witnessed at the deathbed.

Conclusions: Our study demonstrates the phenomenon of the “shocked caregiver” with evidence suggestive of PTSD symptoms. This has implications for the provision of care. The extent of PTSD within this population needs further investigation with longitudinal studies using appropriate tools.

Abstract number: P284
Abstract type: Poster

To Care for Cancer Patient in Pain - Difficulties and Misbeliefs among Caregivers from Northwestern Bulgaria
Yordanov N.R.1, Yordanova D.2, Aleksandrova S.3

1Comprehensive Cancer Center - Vratsa, Palliative Care Department, Vratsa, Bulgaria, 2UNWE - Sofia, Sofia, Bulgaria, 3Medical University Pleven, Faculty of Public Health, Pleven, Bulgaria

Objective: To evaluate the attitude of patients’ caregivers to cancer pain, their fears and misbeliefs and how these hinder the adequate pain control.

Design: Interview of caregivers of patients treated in Comprehensive Cancer Center-Vratsa.

Setting: Ambulatory and stationary part of CCC-Vratsa.

Subjects: 121 caregivers; period March - September 2013.

Main outcome measures: Profile of caregivers and of their patients; Difficulties caregiver face caused by the pain of their patients.

Results: 121 caregivers had median age 61.2y/o. Most of them live in Northwest Bulgaria and care for patients with solid tumors (119). 96% are relatives of the patients and provide care for them for more than 6 months (87%). 76% of the caregivers do not go to work to provide care. According caregivers 97% of patients experience pain daily or at least once a week. 95% of the caregivers had difficulties while caring for patients in pain. These are mainly related with the difficult access to pain medication 78% and qualified medical care in the field of pain treatment 81%. 14% had problems with patients’ unwillingness to take opioids. 82% of the caregivers believe that opioids are very addictive, 79 % of them agree that is easier for the patient to tolerate pain instead controlling opioids side effects. 74% agree that it is possible for the oncologist to stop anticancer treatment in cases of pain. 91% agree that opioids should be used only in terminal patients and are to be taken only when needed, but not as prevention.

Conclusion: Although opioids have been proven safe and effective in the treatment of cancer pain, there are still significant obstacles among caregivers from Northwestern Bulgaria about opioids use for pain control in cancer patients. There are number of causes: objective, mainly of an economic nature, and subjective, mostly from ignorance, that prevent caregivers to care effectively for cancer patients in pain.

Abstract number: P285
Abstract type: Poster

Psychological Treatment at Complicated Grief: A Group Programme Intervention
Lacasta-Reverte M.A.1, Alonso A.2, Vilches Y.2, Diez L.2, Manrique T.2, Feliu M.2

1Hospital Universitario La Paz, Cuidados Paliativos, Madrid, Spain, 2Unidad de Cuidados Paliativos, Hospital Universitario La Paz, Madrid, Spain
Background: Bibliographical review show that psychological interventions are really effective in complicated grief and lost related disorders.

Objective: To assess a group treatment of psychological intervention in complicated grief.

Methods: Quasi-experimental design, 2 groups: experimental and control assessed with Inventory of Complicated Grief (ICG) in pre-post treatment phases and follow up at 6 and 12 months. The program intervention was based on Dual Model Process and was developed in 16 sessions. Data were analyzed by SPSS9. To assess uniformity pre-treatment in both groups, we used univariate analysis; in qualitative variables Chi squared test and Student-T test for quantitative variables. The evolution of the time between the groups was analyzed with a general linear model with repeated measures within-subjects. Chi squared test was used for qualitative measures.

Results: 187 caregivers of cancer patients derive because complicated grief, are involved in the research (19% male). The average age (SD) is 59 (15) years. 81 families belong to control group (16 male) and 106 to experimental group (19 male). No pre-treatment differences in both groups (p=0.242) in ICG, neither in derivation diagnosis (p=0.104), nor pharmacological treatment (p=1.0), nor mental health history (p=0.83), nor demographical variables (p=0.774), nor in time since relative’s dead (p=0.155). There are significant differences between the 2 groups at the measures during time pass by (p< 0.01). Patients from experimental group compared with control group show a significant decrease in ICG at post-treatment phase at 6 and 12 months. 44% of experimental group show complicated grief pre-treatment, 23% at 6 months and 14% at 12 months after treatment. 74% of control group show complicated grief after treatment, 58% at 6 months and 43% at 12 months (p< 0.01).

Conclusions: Psychological treatment is effective at complicated grief.

Abstract number: P286
Abstract type: Poster

Seeking to Establish a Linkage Between Bereavement and the “Good” or “Bad” Death: Qualitative Findings

Wilson D.M., Houttekier D.

1University of Alberta, Nursing, Edmonton, AB, Canada, 2Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium

Research aim and background: Bereavements may be heavily impacted by the survivor’s perception that a “good” or “bad” death took place. A mixed-methods research study was designed to determine if a relationship exists between good or bad deaths and bereavement intensity, and to further understanding what constitutes good and bad deaths. This is a report of the qualitative phase.

Method: This phase involves interviewing bereaved volunteers. Research ethics approval was obtained in advance. To date, 23 volunteers have responded to 6 semi-structured interview questions, with interviews 35 to 110 minutes in length. Most were women, with 5 month to 8 year bereavements. Data were coded, and grouped into categories and themes. Future interviews will validate or correct understandings.

Results: Bereavement is a highly individualized, contextualized, and multi-faceted phenomenon, but three themes emerged:

(1) the huge loss and enormous gap due to the death, and particularly when it was considered a bad death,
(2) the hard hard work of grieving, and especially so when regrets about the death and/or dying process remain, and
(3) the uncertain step laddered journey of grieving to recovery, with bad deaths making the steps larger and the possibility of stepping back more likely. Quotes from participants exemplify these themes.

Discussion and conclusions: Bereavement was negatively impacted when deaths or dying processes were not viewed as positive. Despite bereavement variances, it can be understood collectively in ways that are exemplified by the 3 themes. As such, important connections between death quality and bereavement have been made. These findings are crucially important for palliative care expansion and quality developments.

Abstract number: P287
Abstract type: Poster

The Acute Hospital Setting as a Place Death and Final Care: A Qualitative Study on Perspectives of Family Physicians, Nurses and Family Carers

Reyniers T.1, Houttekier D.1, Cohen J.1, Pasman H.R.W.2, Deliens L.1,2

1Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2EMGO Institute for Health and Care Research and Expertise Center for Palliative Care, VU Medical Center, Department of Public and Occupational Health, Amsterdam, Netherlands

Introduction: While the focus of end-of-life care research and policy has predominantly been on ‘death in a homelike environment’, little is known about perceptions of the acute hospital setting as a place of final care and death.
Method: A qualitative research design was used: five focus groups with family physicians (N=39), three with nurses from different care settings (N=23) and 17 semi-structured interviews with bereaved family carers. Transcripts were transcribed verbatim and analysis was guided by a constant comparative method.

Results: Participants generally perceived the acute hospital setting to be inadequate for terminally ill patients as it might not be properly adjusted to the needs of dying patients, too focused on curative care and life-prolongation and communication can be poor. However, participants also indicated that in some circumstances the acute hospital setting might be considered a ‘safe haven’, particularly when patients and their relatives fear death and dying, or perceive care to be better in a hospital setting. Furthermore, sometimes the acute hospital setting might have become a familiar care environment or it might be the only alternative.

Conclusions: Although the acute hospital setting was predominantly perceived to be inadequate for terminally ill patients, our results suggest that in certain situations it can be an essential end-of-life care setting. This implies that the acute hospital setting should not be excluded as a proper end-of-life care provider and at the same time alternatives to the acute hospital setting need to be developed or expanded.

Abstract number: P288
Abstract type: Poster

Palliative Care Case Management in Primary Care: A Descriptive Study about Referrals in Relation to Treatment Aims

van der Plas A.G.M.1,2, Francke A.1,2,3, Jansen W.2, Vissers K.1, Deliens L.1,2, Onwuteaka-Philipsen B.1,2

1VU Medical Center, Department of Public and Occupational Health, Amsterdam, Netherlands, 2VU Medical Center, Center of Expertise in Palliative Care, Amsterdam, Netherlands, 3Nivel Netherlands Institute for Health Services Research, Utrecht, Netherlands, 4Radboud University Nijmegen Medical Center, Department of Anaesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands, 5Ghent University and Vrije Universiteit Brussel, End-of-Life Care Research Group, Brussel, Belgium

Background: Case management may assist generalist primary care providers in delivery of palliative care. Considering the WHO definition of palliative care, case management may include: 1) patients with treatments aimed at cure and life prolongation besides palliative care 2) patients with other diagnoses than cancer 3) patients and families with medical, psychological, social and spiritual care needs. This study investigates characteristics of patients referred to case management in primary care with regard to the three points mentioned.

Method: Thirteen of the 20 existing case management initiatives in palliative care in the Netherlands participated in this study. Of 687 patients, the case managers completed a questionnaire. In addition, 448 (65%) referrers completed a questionnaire. In univariate analyses patients with a sole aim of palliative care were compared to patients with a combination of palliative and curative / life prolonging treatment aims.

Results: Most patients referred to case management have a combination of treatment aims (69%). Life expectancy and functional status of patients are lower for patients with a treatment aimed at palliation. Almost all (96%) patients referred are cancer patients. A need for psychosocial support is a frequent (66%) reason for referral, regardless of treatment aim. Monitoring of pharmacotherapy is mentioned more often for patients with combined treatment aims, while knowledge of palliative care is mentioned more often for patients where palliation is the sole treatment aim.

Conclusion: Case management in primary palliative care partly facilitates palliative care according to the WHO definition. Patients are referred to it mainly for care complementary to medical care, and patients are referred relatively early in their disease trajectory. However, mainly cancer patients are referred to case management. Thus, broadening the scope to reach other patient groups is important.
Methods: Following a systematic review of the literature on use of the LCP in hospitals prospective ethical approval was received to recruit participants. Consultants and registrars, from an acute hospital in England, were purposively selected for one-to-one in-depth interviews. The topic guide covered positive and negative experiences of the LCP, individuals’ perceptions, external influences and training. Interviews were audio-recorded and transcribed verbatim for thematic analysis.

Results: In this paper we will present our thematic findings and an interpretative analysis of lessons to be learned from the ‘LCP experience’ in hospitals. We will consider how these experiences, and external factors, influenced decision-making with respect to the LCP and end-of-life care more generally. Emerging themes include communication failings, fear of diagnosing dying and the ‘tick box’ mentality.

Conclusion: The need for high quality end-of-life care in hospitals remains, regardless of how history may judge the LCP from inception to withdrawal. Now is the time for hospitals to learn the lessons of the LCP era and to work with generalists, the public, media and policymakers to improve end-of-life care.

Abstract number: P290
Abstract type: Poster

It was Just Enough to Know Someone was there’. The Introduction of a Novel End-of-Life Volunteer Companionship Programme within the Acute Hospital Setting

Mayland C.R.1, Gent M.1, Raj J.1, Mason S.2
1Aintree University Hospital NHS Foundation Trust, Liverpool, United Kingdom, 2Marie Curie Palliative Care Institute Liverpool (MCPCIL), Liverpool, United Kingdom

Aims: To evaluate progress and benefit of a volunteer end-of-life companionship programme in supporting dying patients and families within a hospital setting.

Study population: All patients and their next-of-kin (NOK) who received support from the service to date (from May 2012 - September 2013) within an acute tertiary hospital in Northwest England.

Study design and methods: The following prospective patient data was recorded: age; gender; ward; diagnosis; date referred; number of volunteer visits received; whether care supported by the ‘Liverpool Care Pathway’ (LCP); and type of support. The NOK to patients who received support and subsequently died were sent a post-bereavement questionnaire 6 weeks following the death.

Method of statistical analysis: Descriptive statistics (number; percent; mean) were used to describe the patient population. Analysis of response rate and questionnaire responses is currently being conducted using descriptive statistics. Thematic analysis is being used to group free-text questionnaire comments.

Results and interpretation: To date, 77 patients received between 1 and 4 visits from the service (total of 117 visits, average 1.5 visits /patient). There were 32 (41.5%) male patients; mean age was 78.2 years (range 45-101), and only 23 (29.9%) had malignant disease. 55 (71.4%) patients had their care supported by the LCP. Types of support provided include: sitting with patient or family; psychological support to both patients (some of who were not imminently dying) and family members (pre- and post-bereavement); spiritual support; and mouth care.

Although the value of volunteers within hospices is well recognised, their role in hospitals is less established. This programme demonstrates a novel way of supporting dying patients and their families.

Abstract number: P291
Abstract type: Poster

The Use of Sodium Valproate in a Continuous Subcutaneous Infusion (CSCI) as an Anticonvulsant at the End of Life - A Case Series

O'Connor N., Hayden C., O'Leary N.

Our Lady’s Hospice & Care Services, Harold’s Cross, Dublin, Ireland

Introduction: The use of high dose benzodiazepines (usually midazolam) via a CSCI in patients with a history of seizures who are no longer able to take oral anticonvulsants towards the end of life is a well established practice. However the doses required in order to have an anticonvulsant effect usually results in some degree of sedation.

Methods: As an alternative to a high dose benzodiazepine, we used a CSCI of sodium valproate in 3 patients who were no longer able to take their regular oral anticonvulsants and in whom sedation was not desirable. As there is currently only anecdotal information to support its use subcutaneously, we extrapolated information from the slow intravenous infusions to guide the use of the subcutaneous administration.

Case series: Our series consists of; a 39 year old man with a glioblastoma multiforme, a 68 year old woman with metastatic non-small cell lung cancer and a 62 year old man with glioblastoma multiforme who received CSCI of sodium valproate for 4, 2 and 7 days respectively in their end of life period. Between 600-1200mg of sodium...
valproate was administered in a separate syringe driver over 24 hours. Either water for injection or 0.9% saline were used as diluents.

**Results:** There were no adverse effects or reactions noted and none of our patients experienced clinically appreciable seizures during this period.

**Conclusion:** While further clinical and pharmacological investigation is required to investigate this topic, our case series found sodium valproate to be a safe and effective alternative subcutaneous anticonvulsant in patients who are unable to take oral medications and in whom sedation is not desirable.

**Abstract number:** P292  
**Abstract type:** Poster  
**Deaths from Head and Neck Cancers, (England 2002–11) - Implications for End of Life Care Planning**  
Verne J.1, Fitzgerald D.1, Harris S.1, Pring A.1, Fleming S.1, Thomas S.2

1Public Health England, Knowledge and Intelligence South West, Bristol, United Kingdom  
2University of Bristol, Bristol, United Kingdom

**Background:** This study has looked at deaths from head and neck cancer from the perspective of planning and improving the quality of end of life care for these patients. Although many people live for many years following their diagnosis, 21% of males and 17% of females have died within 12 months of their diagnosis of a head and neck cancer. There are likely to be differences in place of death between the head and neck cancers due to differing needs for end of life care.

**Methods:** Data was extracted from mortality records for deaths registered in England 2002-11) selected with underlying cause of death (UCOD) or contributory causes of death (CCOD) including a head and neck cancer. A descriptive analysis is presented based on site of cancer, place of death, age, sex and socio-economic deprivation.

**Results:** An average of 2,400 people died with head and neck cancer as UCOD each year, increasing to 2,627 if CCOD is included. UCOD include more males (1,570 p.a.) than females (830 p.a.) Amongst females about half of deaths are aged under 75, in males 69% of deaths are aged under 75 years. Hospital is the most common place of death from head and neck cancer (43%) followed by Home (25%) and Hospice (22%). Younger people are more likely to die at Home or in a Hospice, Older people are more likely to die in a care home. There are almost double the number deaths in the most deprived than the least deprived communities, the proportion of deaths in hospital increases with increasing deprivation.

**Conclusion:** These patients face a number of specific challenges in addition to general end-of-life issues such as pain and psychological and spiritual distress; the relatively young age of some of these people means they may have family responsibilities to consider. Hospital-based palliative care teams should work with GPs, social care and external palliative care providers to ensure that patients are receiving high quality care with no inequities in access to a preferred place of death.

**Abstract number:** P293  
**Abstract type:** Poster  
**Dying in Hospital: A Study of Incidence and Factors Related to Hospital Death Using Death Certificate Data**  
Houttekier D.1, Cohen J.1, Pappersack T.2, Deliens L.1,3

1Vrije Universiteit Brussel, End-of-Life Care Research Group Vrije Universiteit Brussel & Ghent University, Brussels, Belgium,  
2Université Libre de Bruxelles, Department of Geriatrics, Erasme Hospital, Brussels, Belgium,  
3VU University Medical Center, EMGO Institute for Health and Care Research and Expertise Center for Palliative Care, Department of Public and Occupational Health, Amsterdam, Netherlands

**Background:** Most people prefer not to die in a hospital and for those with palliative care needs, doing so may result in inappropriate care and poor outcomes. We examined place of death and factors associated with hospital death in a population eligible for palliative care.

**Methods:** We used death certificate data to identify deaths from conditions eligible for palliative care and to examine place of death and demographic, socioeconomic and environmental characteristics associated with hospital death in Belgium in 2008.

**Results:** Of all people eligible for palliative care (N=44,229; ie 43.5% of all deaths) 51% died in hospital, 25% at home and 24% in long-term care settings. Of those officially living at home at the time of death, hospital death occurred in more than 60%; of those living in long-term care settings this was 16%. Nine per cent of those living at home alone at the time of death died in long-term care settings; of those living with others this was five per cent. Both in those living at home and in those living in long-term care settings, hospital death was more likely in areas with higher availability of hospital beds and less likely in areas with higher availability of skilled nursing beds in long-term care settings.

**Conclusion:** Hospital death is still common among those eligible for palliative care. The significant proportion of people living at home and dying in long-term care settings indicates the need for additional inpatient beds for terminal care in palliative care institutions.
Abstract number: P294
Abstract type: Poster

Quality of Life of Patients with Advanced Lung Cancer. A Longitudinal Study in Flanders, Belgium

Ko W.1, Pardon K.1,2, Van den Block L.1, Bernheim J.L.1, Deliens L.1,3
1Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Hasselt University, Department of Behavior, Communication and Linguistics, Diepenbeek, Belgium, 3VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands

Introduction: Advanced lung cancer is a severe disease with a median life expectancy of 1 year. However, little is known about the quality of life (QOL) - including symptomatic and functioning - of advanced lung cancer patients nor about the change of QOL over time, e.g. due to the difficulty of performing studies in a vulnerable population with limited life expectancy.

Methods: We performed a longitudinal study of a consecutive sample of newly diagnosed stage IIIb/IV non-small-cell lung cancer patients in Flanders, Belgium, between 2007 and 2011. Patients were recruited by physicians in 13 hospitals and interviewed every 2 months until the fourth and every 4 months until the sixth interview with the EORTC QLC C15-PAL and the Anamnestic Comparative Self Assessment (ACSA).

Results: Sixty-seven patients were interviewed three times. The mean score on the overall QOL-scale of the EORTC was 60, on the physical functioning scale 81 and on the emotional functioning scale 80 (scores from 0 to 100, 100 is very good). Looking at the EORTC symptom scales, the most prevalent symptoms were: fatigue, appetite loss, pain and dyspnea. The QOL score of ACSA was 45 (scores from 0 to 100: QOL relative to worst (0) and best time (100) in life). The mean scores on all scales did not significantly change over time at 2 and 4 months. There were however significant changes over time at an individual level: e.g. between baseline and 2 months, 40% to 83% of patients, depending on the scale, changed at least 11 points towards more or less quality of life.

Conclusion: Newly diagnosed advanced lung cancer patients in Flanders have a significantly diminished QOL and a high symptom burden. This indicates the need of early integration of palliative care - as an approach that addresses QOL via symptom management - in standard oncological care. Since QOL significantly changes over time, caregivers should measure it regularly and adapt their care accordingly.

Abstract number: P295
Abstract type: Poster

Patient Opinions on the Role of the Family in the Therapeutic Decision-making Process

Porta-Sales 1, Garzón-Rodríguez C.1, Julià-Torras J.2, Llorens-Torromé S.1, Riquelme-Olivares M.2, González-Barboteo J.1, Sala-Suñe S.3, Calsina-Berna A.1, Barbero-Biedma E.1, Serrano-Bermúdez G.1, López-Romboli E.1, Roy-Boixader A.1
1Institut Català d’Oncologia, IDIBELL, Palliative Care Service, L’Hospitalet de Llobregat, Spain
2Institut Català d’Oncologia, Servei de Suport Integral, Cures Pal.liatives, Badalona, Spain
3Institut Català d’Oncologia, IDIBELL, Social Work Unit, L’Hospitalet de Llobregat, Spain

Objective: To assess the opinion of cancer patients (pts) regarding the role of the family (F) in the decision-making process(DM) and to assess the DM style of pts in our region and their perception of social support.

Patients and methods: Multicentre, transversal observational opinion study with consecutive enrollment via self-administered questionnaire and the Spanish version of the Multidimensional Scale of Perceived Social Support (MSPSS) & the modified Control Preference Scale (CPSm). Inclusion criteria: pts ≥18 y-old, diagnosis of cancer, intact cognition, fluent reading & writing ability in Spanish, & signed consent form.

Results: A total of 101 pts (35% female) were enrolled. Mean age was 59. Pts were included from palliative care (34%), medical oncology (34%), or hematology (32%). Mean time from diagnosis was 41 months. Most pts (86%) lived with other family members and 21% had not completed secondary school. Mean MSPSS (range, 12-84) was 75. Fifty-percent of pts included 3rd degree family members as “close” F. For DM, 75% pts always or nearly always considered the input of family members, while 75% perceive F input to be helpful, and 80% of F do not interfere in DM. Most pts (76%) do not believe that the F hides bad news, but 54% would feel hurt if this was true. DM style was active in 19% of pts, shared in 57%, and passive in 24%. Statistical analysis indicated that neither the role of F nor CPSm were associated with age, sex, educational level, time from diagnosis, or with whom the patient lives.

Conclusions: In our sample, F—considered as an extended group beyond just spouses, children, parents, and siblings—is generally perceived as an ally in DM. Patients feel strongly supported by their F(MSPSS). DM styles are predominantly shared and passive. The data suggests that the role of the family in DM is more closely related to emotional ties than to cognitive-intellectual aspects.
Abstract number: P296
Abstract type: Poster

Conceptualizing Carer Coping at End-of-Life
Washington K.1, Rakes C.2, Otten S.3, Parker Oliver D.4
1University of Missouri, Department of Family & Community Medicine, Columbia, MO, United States,
2University of Maryland Baltimore County, Department of Education, Baltimore, MD, United States, 3University of Louisville, Kent School of Social Work, Louisville, KY, United States

Background: References to coping are nearly ubiquitous in research on family carer stress, yet challenges associated with validly and reliably measuring coping often impede the ability of researchers to produce sound results that are also relevant to hospice and palliative care services.

Research aims: This study examined the nature of coping for hospice family carers. Research questions were

1) What is the structure of coping for hospice family carers?
2) To what extent are the concepts of positive and negative coping supported by hospice family carer data?
3) Is it possible to separate problem- and emotion-focused coping processes among hospice family carers?

Study population: The sample was comprised of 229 family carers of adult patients receiving hospice services from an agency in an urban setting in the Southeastern United States.

Study design and method: Volunteer participants completed Folkman and Lazarus’ Ways of Coping Questionnaire based on their behaviors when faced with stressors related to patient symptoms.

Method of statistical analysis: Confirmatory Factor Analysis and Structural Equation Modeling techniques were used to determine the relationships among coping strategies and whether second-order factors reduced the unexplained variance in the model. A wide array of fit indices was examined to determine best fit.

Results and interpretation: The inclusion of second-order factors (including positive and negative, problem- and emotion-focused coping) significantly increased rather than decreased the unexplained variance in the model (p < .0001). These results suggest that hospice professionals should not label specific coping behaviors as positive or negative or, similarly, as emotion-focused or problem-focused. Providers should instead explore with carers how these behaviors bring about meaningful outcomes in their lives.

Extramural support: This study was supported by a grant from the John A. Hartford Foundation.
Background: Patients with hematological malignancies are less likely to receive care from specialist palliative or hospice services compared to other cancers. Numerous causes for this have been postulated, like prognostication difficulties, intensive demands for anti-infective or substitutive measures, or a lower incidence of “focal” symptoms like pain. Often, hematologists are criticized that referral to specialized palliative care institutions would occur “too late”.

Methods: We therefore used a pooled analysis (2006 - 2008) of a nationwide survey (Hospice and Palliative Care Evaluation, HOPE) in order to describe clinical and treatment related characteristics of hematological patients treated in specialized palliative care institutions, and compared them with prospectively documented characteristics of hematological patients treated in palliative intent at a university hospital hematology department without being supported by specialized palliative care services.

Results: In the HOPE registry, 220 hematological patients out of 5,487 were identified, and 50 “palliative” hematological patients were documented at the hematology department. There, less focal symptoms, a better overall health condition, less nursing problems, and more supportive measures like transfusions were observed despite a comparable spectrum of diagnoses in both groups.

Discussion: We found that “palliative” patients treated at a hematology department (w/o palliative care) showed relevant clinical and treatment related differences compared to “palliative” patients in specialized palliative care institutions, justifying diverging treatment strategies. Different clinical conditions relate to different therapy settings; therefore, even when the overall likelihood for referral to palliative care is lower for hematological patients compared to patients suffering from solid tumors, our data do not support that referral from hematology to palliative care would occur “too late”.

Abstract number: P299
Abstract type: Poster

Time for Change: Patient Empowerment in Cancer Pain Management

Ivan J.C., Vissers K.C.P., Engels Y.

Radboud University Nijmegen Medical Centre (RUNMC), Anesthesiology, Pain and Palliative Medicine, Nijmegen, Netherlands

Objective: More than 50% of patients with cancer experience pain. Patient empowerment has been highlighted as central to success in pain management. In order to implement empowerment into pain practice, a more precise definition of empowerment is required. This paper examines how empowerment or related concepts have been described in relation to pain management in patients with cancer.

Methods: Using an integrative literature review, we evaluated papers discussing empowerment or related concepts in relation to pain management in patients with cancer. We searched the databases PubMed, CINAHL and PsycINFO.

Results: From a total of 5984 papers identified, we included 32 for analysis. Twenty-two of these were studies with empirical data, three case reports, one systematic review with meta-analysis, two theoretical papers, two opinion papers, one study protocol, and finally one invited commentary. None described a generally accepted definition of empowerment. Empowerment has been described/defined with the concepts self-efficacy, active patient participation, increasing abilities, control of life and as the belief that they could do something to feel better. Tse et al described a cancer pain management model including empowerment. None described an empowerment model for cancer pain management.

Conclusions: Based on the current knowledge we propose a conceptual patient empowerment model including the following elements (1) improving confidence and abilities of patients with cancer to access resources (2) to self-manage their pain, will make them more active participants in their own pain management, (3) and improve their self-efficacy, locus of control, coping and/or mastery. Increasing patients confidence and abilities to access resources results only into empowerment when the patient makes use of these resources to self-manage their pain. This model should be tested before use in cancer pain practice.

Funding: This study was funded by KWF, Dutch Cancer Society.

Abstract number: P300
Abstract type: Poster

Comparing Palliative Care in Europe: A Typology

Ko W.

Vrije Universiteit Brussel (VUB) and Ghent University, End-of-Life Care Research Group, Brussels, Belgium

Aims: There is currently a lack of theory-based research in palliative care. In view of both differences and similarities of palliative care in Europe, this study aims at constructing a typology of palliative care with reference to existing data.

Methods: A deductive approach was adopted for this study. Firstly, a selective literature review was conducted to identify elements used in existing indicators of palliative care development. Secondly, based on prior researches by Rothgang et al (2005), Wendt et al (2009) and Böhm et al (2012) on classifying healthcare systems,
these elements were reduced to three dimensions deemed relevant to palliative care: level of resources (rich vs poor), sources of finance (public vs private) and access to palliative care services (generalist vs specialist). Then, utilising both data from the EAPC Atlas 2013 and published data, countries were positioned accordingly in one of the nine categories (i.e. rich resources x private finances x generalist access; rich resources x public finances x specialist access etc). Finally, results were reduced to a five groups typology.

**Results:** A total of 22 (Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, United Kingdom) European countries were classified into either:

a) public and high accessibility (5 countries),
b) public with conditional access (6 countries),
c) private and high accessibility (2 countries),
d) private with conditional access (5 countries) and
e) hybrid model (4 countries).

**Conclusion:** The current results are limited by the availability of information and could not avoid arbitrariness in finalising the categorisations, but this is a first attempt in generating a typology of palliative care services in Europe and these findings could serve as a basis in evaluating performances of palliative care in countries in the same category.

**Abstract number:** P301
**Abstract type:** Poster

**Overcoming Barriers to Research in Palliative Care: Results from a Consensus Exercise**

*Preston N.J.1, Dunleavy L.2, Rigby J.1, Griggs A.1, Salt S.1, Parr A.2, Payne S.J.1*

1Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 2St Catherine’s Hospice, Preston, United Kingdom, 3Trinity Hospice, Blackpool, United Kingdom

**Aim:** Recruitment of palliative care patients to research studies can be problematic. The aim was to generate recommendations about removing barriers to research in the palliative care setting.

**Methods:** Three workshops were held in the UK (77 palliative care staff and patient representatives). There were presentations about the need for palliative care research and discussion around potential barriers. Nominal groups were held to make recommendations about how to overcome barriers and suggest areas for research. Each person made recommendations which were collated on a flip chart. Recommendations were sent out in an online survey to participants who were asked to rank how much they agreed with them on a scale from 1-9 (1 strongly disagree-9 strongly agree).

Median scores and inter-quartile ranges (IQR) were calculated to assess consensus.

**Results:** The top three recommendations to improve research in hospices were (Median:IQR):

1. Hospices and palliative care units should collaborate with each other in research and share best practice (9:0.25)
2. A research culture needs developing (9:1)
3. Results from research needs to be presented to staff and patients (9:1)
4. National guidelines for research governance in hospices need developing (8.8:1)
5. A public health campaign is required to promote the need for research in palliative care (9:2.25)

The main areas recommended for research were to establish the experiences of palliative care patients of out of hours services (8.5:2.75), experience of parents caring for children (8:2), whether palliative care is cost effective (8:2.75) and what is the impact on palliative care for people with no local support (8.2:7.5).

**Conclusion:** Workshops raised awareness of the need for research in palliative care and allowed staff to generate their own solutions to overcome barriers, in particular improving recruitment. Networking was highlighted as key and is reflected in the recommendations.

**Abstract number:** P302
**Abstract type:** Poster

**The Feasibility of Using the Distress Thermometer and Problem List Screening Tool in Community Palliative Care Populations: A Pilot Study**

*Moore H.M.1,2, Sutton T.3, Robertson M.4, Morris A.1, McKinnon T.1, King B.1, Finch A.1, Chye R.1,2*

1Sacred Heart Health Service, St Vincent’s Hospital, Palliative Care, Sydney, Australia, 2St Vincent’s Clinical School, University of New South Wales, Sydney, Australia

**Introduction:** A terminal diagnosis is frequently associated with increased psychological distress. Reports indicate early identification and intervention is beneficial. The National Comprehensive Cancer Network Panel has developed the Distress Thermometer (DT) and Problem List (PL) screening tool for the identification of self-reported distress over the past 7 days.

**Aim:** Determine the feasibility of using this tool to ensure timely identification and referral of patients with self-
reported distress to relevant members of our community interdisciplinary team.

Method: A pilot prospective cross sectional questionnaire study was conducted within a specialist community palliative care (PC) service over 20 weeks. New patients whom were able to express their responses through verbal/written communication were eligible. New patients received the tool at the initial visit. Patients scoring ≥4 were invited for a review with relevant member(s) of the interdisciplinary team.

Results: Interim data analysis; 44 eligible participants. Mean age 74 years (range 29-98). 39 participants had malignant disease. 16 questionnaires returned (36%). 2 participants indicated no distress, 3 participants indicated mild distress (1-4), 5 participants indicated moderate distress (5-7), 4 participants indicated severe distress (8-10). 2 participants omitted to score the DT but answered the PL.

Conclusion: Majority of participants demonstrated moderate to severe levels of self-reported distress. This study highlights the difficulty associated with sick PC patients returning the tool. Further exploration will determine if the tool identifies early/more frequent detection of distress plus if it impacts on referral rates to other interdisciplinary team members.

Recommendations: Inclusion of an acceptability questionnaire to determine reasons for non-completion of the tool. Team members will offer assistance in completing the tool on subsequent home visits. PC clinic patients will be invited to participate.

Abstract number: P303
Abstract type: Poster

Quality End of Life Care for Dementia from a Families Perspective: A Narrative Review

Davies N., Maio L., Rait G., Iliffe S.

University College London, Research Department of Primary Care and Population Health, London, United Kingdom

As their symptoms worsen people with dementia become more dependent on others, often their family members. Without family carers the ‘formal’ support system would collapse. The important role that family carers play in the end of life care of people with dementia, means they are well placed to comment on what good quality end of life care for people with dementia should look like. This study reviewed what is known about family carers’ perspectives of quality end of life care for dementia.

A review of qualitative evidence from 1990 was conducted, systematically searching MEDLINE, CINAHL, SCIE, PSYCH INFO and EMBASE, using a range of search terms, and inclusion/exclusion criteria, together with citation tracking and reference checking. A narrative approach was adopted using thematic analysis to synthesise the results.

From an initial search yielding 456 publications, eight studies were identified with a central theme of ‘a families’ beliefs about death and their preferred choice of treatment’. The studies demonstrated beliefs which spanned a spectrum of what treatment respondents believed to be good, from invasive and aggressive therapies to more palliative approaches aimed at achieving comfort. Intersecting with this was a second spectrum of beliefs about death ranging from acceptance that their relative was dying to complete denial. Several explanations for these beliefs were found, including the importance professionals play in influencing families, the emotional and commitment pressures of caring, and the families’ ability to think about death and dying.

This review shows little attention has been paid to the views of family carers of people with dementia at the end of life. More in-depth discussions are needed with families to clarify their views of what good quality end of life care is. This is becoming increasingly important as the Liverpool Care Pathway is phased out in the UK following challenges by families, to be replaced by personalised care plans.

Abstract number: P304
Abstract type: Poster

Using High Fidelity Simulation in Nursing End of Life Care Education: Is this the Way Forward?

Reed N.1,2,3, Nelson A.4

1Marie Curie Hospice West Midlands, Solihull, United Kingdom, 2Hollier Simulation Centre, Good Hope Hospital, Birmingham, United Kingdom, 3Heart of England NHS Foundation Trust, Palliative Medicine (Community), Birmingham, United Kingdom, 4Marie Curie Palliative Care Research Centre, Wales Cancer Trials Unit, School of Medicine, Cardiff University, Cardiff, United Kingdom

Aim: To explore the impact of teaching end of life care to band 5 and 6 nurses using high fidelity simulation. This study looked at the impact on nurses’ confidence and their perception of their knowledge and skills in end of life care.

Palliative care education has become a priority. The need for good quality end of life care to be delivered to all dying patients is paramount. With over half the population dying in the acute setting, all hospital staff should be trained in providing good quality end of life care. Although medical simulation is a relatively new teaching modality it does enable experiential learning.

Method: A mixed method approach was used for this study. There were a total of seven participants from two separate cohorts. All participants were asked to complete
Aim:

The study demonstrated that there was a significant impact on confidence, knowledge and skills for participants of this end of life course. The participants gained confidence and knowledge in a number of aspects of end of life care and described learning new skills surrounding communication. High fidelity simulation allowed participants to reflect on their own practice and to trial new approaches in a safe but realistic environment. The facilitated debrief sessions encouraged self-reflection, constructive feedback and the opportunity to reflect on their peers clinical practice.

Conclusion:

Although the significant participant benefits of using high fidelity simulation to teach end of life care have been shown; there are other teaching modalities available. Future research should include comparative studies looking at the impact of using high fidelity simulation compared with other teaching modalities in end of life care education.

Abstract number: P305
Abstract type: Poster

Will you Help Me? Navigating the Role of “Care” in End of Life Research

Candrian C.

University of Colorado Denver, Internal Medicine, Aurora, CO, United States

Background: Care is one of the most deeply shared feelings on earth. Well care for individuals, especially ageing and dying individuals, is fundamental to creating a developed, ethical and engaged society. In this case study, I turn to my experiences as a qualitative researcher to consider the methodological tensions and challenges involved when conducting fieldwork at hospice where the bodies of participants regularly experience injury, illness, and pain.

Aims:

- Understand the methodological challenges involved when conducting fieldwork with participants who regularly experience injury, illness, and pain;
- Understand the role of care and care-work in fieldwork; and in particular the relationship between researcher and participants;
- Examine the role of care in your own research sites and methodological practices;
- Advocate for interactions and spaces where researchers share a deep commitment to caring for the other.

Discussion: I will share two narrative accounts from fieldwork at hospice when conducting studies that include elderly participants and participants with disabilities. The stories demonstrate the “chaotic and messy” nature of human experience in research. Rather than trying to “clean up the mess,” disorder allows a more textured feeling of ageing and dying in these organizational settings. Who does the researcher become when confronted with a request for assistance or an appeal for help? What type of ethical training do researchers require to be prepared to safely and ethically perform these field roles? How can researchers come to better “know the body” as a site of understanding about the research topic and the participants themselves? What might these researcher-participant encounters in the field teach us about the value of care as a methodological tool? As the instrument of qualitative research, end of life researchers are confronted with the need to embody and perform care in the field. How do we respond?

Abstract number: P306
Abstract type: Poster

Impact of Palliative Care Nurse Champions on Nursing Care at the End of Life in the Hospital

Withamp E.1, van der Heide A.2, van der Rijt C.C.D.3, van Zuylen L.3

1Erasmus University Medical Center, Public Health and Medical Oncology, Rotterdam, Netherlands,
2Erasmus MC University Medical Center, Public Health, Rotterdam, Netherlands,
3Erasmus MC Cancer Institute, Medical Oncology, Rotterdam, Netherlands

Background: To improve the quality of palliative and terminal care, hospitals increasingly appoint palliative care nurse champions. We investigated their impact on nursing care at the end of life (EOL).

Methods: Between June 2009 and July 2012, we performed a controlled before and after study on all 18 non-intensive care wards of a university hospital. Sixteen months after the start, 2 nurse champions were appointed in 7 wards. They received education on palliative care (PC) and collaborated in a nurse network on PC. Before and after this intervention, nurses completed questionnaires on EOL care for all patients who passed away. We compared EOL care pre and post-intervention. Results were compared to EOL care in 11 control wards. Data were analyzed with t-tests, Chi2, ANOVA and Kruskal-Wallis.

Results: Of 14 nurse champions, five prematurely left the network and were replaced. In the intervention wards, nurses filled in questionnaires about 81 and 93 patients, respectively, pre and post-intervention. In the control wards, questionnaires were filled in about 114 and 121 patients, respectively. No impact was found on nurses’ awareness of patients’ imminent death. Post-intervention, nurses
discussed imminent death more often with the patient (50% post vs 35% pre-intervention, p=0.05), were more often aware of psychological symptoms, e.g. anxiety (p=0.04), and applied less nursing interventions, such as bandaging during the final hours (p=0.00). They rated the quality of dying of their patients lower post-intervention (7.3 vs 6.6; p=0.03). No difference in any of these aspects of care was found in control wards.

**Conclusion:** Nurse champions had a positive impact on the quality of care for dying patients. Findings indicate increased communication about the end of life, and more awareness of palliative care needs and shortcomings in EOL care. These results are promising, when taking into account the short-term assessment of the effects of the intervention.

**Abstract number:** P307  
**Abstract type:** Poster  
**Predictors of the Intentions to Ask A Physician for a Natural Death and for Euthanasia among the General Population, Belgium, 2008**

Roelands M., Deliens L., Van den Block L., Cohen J.  
Vrije Universiteit Brussel (VUB) & Ghent University, End-of-Life Care Research Group, Brussels, Belgium

**Background:** Due to the epidemiological transition and improvement of medical technology, difficult medical end-of-life decisions (ELD) become increasingly prevalent. Knowledge of general population’s preferences supports the discussion on an appropriate policy towards ELD. The study aimed to investigate the intentions to ask a physician for a natural death and for euthanasia, if being terminal ill, and related predictors.

**Methods:** National health survey in a representative sample of persons ≥15 y in Belgium, 2008 (N = 9,651). Outcome measures were: in a scenario of being terminal ill, ones intentions to ask a physician for a) a natural death without artificial interventions, and b) to terminate life with medication (euthanasia). Data were analysed with logistic regression for complex samples. Reported odds ratios are significant.

**Results:** In a scenario of becoming terminal ill, 56% of the population had the intention to ask for a natural death and 38% for euthanasia. In multivariable analyses age predicted both intentions; educational level predicted only the intention to ask for euthanasia. No differences were found regarding sex and income. Both intentions tended to have a U-shaped relationship with perceived emotional support. Being in bad subjective health (odds ratio, OR: 1.31) and having had a depression in the previous year (OR: 1.59) were significant predictors of the intention to ask for euthanasia. No measure of current health status predicted the intention to ask for a natural death.

**Conclusions:** A considerable proportion of the general population in Belgium has intentions to request a physician for a natural death and for euthanasia when becoming terminal ill. The evidence for depression and bad subjective health as predictors facilitates physicians’ understanding of the factors involved in the decision process that leads to a euthanasia request.

**Abstract number:** P308  
**Abstract type:** Poster  
**Patients’ Perceptions of Reasons Why they Have Been Affected by Cancer: Spiritual Concepts and Challenges**

Omidvari S.  
Health Metric Research Center, Iranian Institute for Health Sciences Research, ACECR, Mental Health Research Group, Tehran, Iran, Islamic Republic of

**Aims:** Patients’ perceptions of reasons why they have been afflicted with disease (including cancer) might make some psychological and spiritual problems for them. This study examines patients’ perceptions of what have caused them to get cancer.

**Methods:** A qualitative study using semi structured in-depth individual interview and purposive sampling was carried out in a major hospital in Tehran, Iran. The interviews were continued until data saturation. All the interviews were recorded. Then, the data were analyzed using thematic variable-oriented method.

**Results:** In all, 20 patients with cancer were interviewed. The study findings indicated 9 themes including “having anxiety and concerns”, “manipulating a lesion and converting it to cancer”, “genetic background”, “chemical substances existing in the environment”, “severe fear”, “chemical bombardment”, “the interpretation that diseases exist and human beings are afflicted with them”, “being cursed by others, and “God and spiritual/religious issues”. The latter included 10 categories including “being sinner (patient/ his close relatives) and getting cancer as a punishment from God”, “having cancer as a means to reduce the burden of sins and to achieve peace in afterworld”, “being tested by God”, “being affected by cancer as a fate that God has accounted appropriate”, “being afflicted with cancer by God in order that He wants to boast His presence and His power to human beings, as humans are His puppet dolls, and so on.

Attributing cancer to “God’ will” sometimes caused destruction of one’s relationship with God for short or long term because they did not believe that they were sinner, hence the belief that “God is unjust”. Furthermore, what was so important to some patients was being accused by others of being sinner that was sometimes so annoying like a “stigma”.

**Poster**

**Authors:** N. K. Luchterman, D. E. Starks

**Title:** The Role of Family 

**Abstract number:** P309  
**Abstract type:** Poster  
**In-patient Family Care: Family perspectives on their role in nurses’ decisions to withhold or withdraw life sustaining treatment**

Luchterman N.K., Starks D.E.  
University of Scranton, Scranton, PA, USA

**Background:** In the course of end of life care, families are expected to assume an active role in nurses’ decision-making. This study investigated family views on their role in nurses’ decisions to withhold or withdraw life-sustaining therapy.

**Methods:** An in-depth, individual interview was conducted with 15 family members whose loved one was admitted to a terminal care unit at a northeastern USA hospital. Participants were asked about their experience of the decision to withhold or withdraw treatment, and their role in the decision-making process.

**Results:** Family members described a complex and emotional process of decision-making. They reported feeling overwhelmed and uncertain, and relied on nurses for guidance. While many families felt that they played an active role in the decision-making process, they also acknowledged the limitations of their knowledge and experience. Families reported feeling that nurses provided them with information and support, but also that they often felt left out of the decision-making process.

**Conclusions:** This study highlights the importance of family involvement in end of life care decisions. Family members may feel unprepared and unsure, and rely on nurses for guidance. Further research is needed to better understand the role of family members in end of life care decision-making and to identify strategies to support families in this process.
Conclusion: Patients’ perceptions of the reasons why they have gotten cancer, is one of important issues that may damage their spiritual health.

Abstract number: P309
Abstract type: Poster

Art Therapy Intervention in a Palliative Care Unit of a Tertiary Hospital: Evaluation of Symptoms and Help Perception in Patients and Families

Collette N., Güell E., Prada M.L., Rufino M., Ramos A., Fariñas O., Magalhães R., Altuna E., Ramírez C., Pascual A.

Hospital de la Santa Creu i Sant Pau, Palliative Care Unit, Barcelona, Spain

Aims: To evaluate quantitatively the effect of art therapy intervention in adult cancer inpatients of a tertiary hospital Palliative Care Unit, as well as in their primary caregiver.

Research design: Pre-post study.

Methods: The intervention was based on the phenomenological model, performed by a certified art therapist. Immediately before and after the first, third (3rd) and fifth (5th) sessions, a member of the research team assessed pain, depression, anxiety and malaise through a visual numeric scale (VNS, Edmonton). After the 3rd and 5th sessions, the patient was asked if the intervention helped him (yes/no) and how. The primary caregiver was also asked if the intervention had helped the patient and himself. Statistical analysis was performed using SPSS 19.

Preliminary results: We included 39 patients until now, 19 women (62.4 ±12 years old) and 20 males (63 ± 14.9 years old); 38 were analyzed. The primary tumor sites were lung (25.6%), colon (17.9%) and pancreas (10.3%). Mean scores before the 84 assessments were: pain 2.8, depression 3.1, anxiety 2.9 and malaise 4.0. After art therapy session there was a statistically significant reduction in the severity of the symptoms: pain 2.2, depression 2.5, anxiety 2.1 and malaise 2.9 (p < 0.007, Wilcoxon signed-ranks test). The proportion of uncontrolled symptoms (VNS > 3) was reduced after art therapy session: pain from 32 to 25% (p = 0.238), depression 46 to 33% (p = 0.052), anxiety 40 to 25% (p = 0.004) and malaise 69 to 45% (p = 0.000) (McNemar test). After 3 sessions, 97% of the patients (30/31) and 100% of the caregivers (29/29) felt that the intervention helped them. Also, 90% of the caregivers (26/29) perceived it helpful for themselves. The most verbalized benefits were emotional issues, wellbeing and new attitudes.

Conclusions: Our art therapy intervention reduces the severity of the analyzed symptoms and it is helpful for most patients and caregivers.

Funding: This research is funded by Grupo Mémora.

Abstract number: P310
Abstract type: Poster

A Systematic Literature Review Evaluating the Effects of Opioids on Anti-tumour Immune Potential in Patients with Cancer

Boland J.W.1, McWilliams K.2, Ahmedzai S.H.3, Pockley A.G.4

1Hull York Medical School, Hull, United Kingdom, 2Beaton Oncology Centre, Palliative Medicine Research Department, Glasgow, United Kingdom, 3University of Sheffield, Department of Oncology, Sheffield, United Kingdom, 4John van Geest Cancer Research Centre, Nottingham, United Kingdom

Background: Opioids are central to the management of pain in patients with cancer. Many studies, using a range of methodologies, have shown that opioids interact with the innate and adaptive immune systems. These effects have the potential to positively or negatively impact immune surveillance against tumours and thereby the clinical course of patients with cancer. Most studies investigating these opioid mediated effects are pre-clinical.

Aim: The aim of this systematic literature review was to identify and critique all relevant clinical studies which evaluated the effects of opioids on the immune system in patients with cancer.

Methods: Two authors independently undertook electronic literature searches of Ovid MEDLINE, Embase, Cochrane database and Web of Knowledge, as well as hand-searching. They reviewed all titles and abstracts and assessed the full text of all potentially relevant studies. Surgical studies, healthy volunteer studies and animal studies were excluded as their immune and clinical status differs from the target group being evaluated.

Results: From the 487 records identified, five studies were eligible. These were all prospective observational studies, used morphine and assessed immunological endpoints. None included clinical endpoints. Morphine reduced natural killer (NK) cell activity in 2 studies, but not in another. Apart from one study which reported decreased immunoglobulin levels and lymphocyte proliferation in patients commencing opioids, no other studies have reported effects of opioids on the number, composition, and proliferation of peripheral blood mononuclear cell populations.

Conclusion: This systematic review reveals the paucity of clinical data relating to the potential influence of opioid use on protective anti-cancer immunity. Further studies that are focussed on better informing the rational use of opioids for optimising pain control in patients with cancer, without negatively impacting protective immune surveillance are required.
Background: The Latin American Association for Palliative Care (ALCP) recently developed a set of 10 indicators to monitor the development of palliative care (PC). The indicators are based on the WHO Public Health Model (number of indicators in each category): Policy (1); Education (3); Service Provision (3); and Opioids (3).

Aim: To evaluate the usefulness of the ALCP indicators as a monitoring tool of palliative care development.

Method: Cross-sectional study using comparative quantitative analysis based on the information collected in the ALCP Atlas of PC in LA and applying it to the indicators. Countries were ranked from highest to lowest in each indicator. For comparative purposes, the highest score in each category was classified as 100%. Countries that ranked below the 25th percentile were given a +1 (High), countries that ranked below the 25th percentile were given a -1 (Low) and countries in between a 0 (Moderate). Total scores were added for each country.

Results: Costa Rica registered the highest score (3), followed by Argentina and Chile (1). The 3 ranked High in the level of development. All others ranked as Low and none as Moderate. Three countries had a score of 0 (Brazil, Cuba, Mexico) while 13 had negative scores (range -1 to -7) (Uruguay, Panama, Venezuela, Colombia, Peru, Ecuador, El Salvador, Bolivia, Dominican Republic, Guatemala, Honduras, Nicaragua and Paraguay). Analysis for 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 development of PC and may be applicable in all regions of the world. Additional studies are needed to evaluate the specificity of each indicator.

Abstract number: P311
Abstract type: Poster

How Can we Monitor Palliative Care? An Analysis Using a Set of Indicators Developed by the ALCP

Pastrana T.¹, De Lima L.²

¹University Hospital RWTH Aachen, Department of Palliative Medicine, Aachen, Germany, ²International Association for Hospice and Palliative Care (IAHPC), Houston, TX, United States

Background and aim: People in the last year of life receive support to live with their illness from a range of health and care professionals. Research has highlighted the role that professionals undertake with these populations and the challenges of collaborative working between the various professionals, but less is known about the patient and carer experience. The broad aim of this study was to explore the lived experience of patients and their carers who receive care from a range of organisations. In this paper, we report on one key finding from the larger dataset in relation to how patients and carers undertake self and dyadic (both the patient and carer) managing of their situation.

Design and methods: An interpretive phenomenological methodology was used. People with a diagnosis of advanced disease and an anticipated prognosis of less than twelve months (N=12), and their spousal carers (N=8) were included. Patients and carers participated in research interviews in their own homes. Data were analysed using phenomenological methods, supported by Template Analysis to facilitate transparency in the analytic process.

Findings and interpretation: Patient and carer experiences are interconnected as they attempt to manage their lives to achieve a sense of balance between a continually changing embodied experience and the desire to maintain normality. Previous roles and relationships are negotiated in light of the multi-faceted losses that characterise advanced disease. Health and care professionals are involved in varying degrees with supporting people to maintain this balance. Patients and carers utilise a variety of strategies that help them to manage their contacts with these professionals. They make choices about when, how and who to utilise for their self-assessed needs. Where self/dyadic managing fails and the sense of balance is not achieved, there can be a breakdown in people’s sense of safety and confidence living in the home environment.
Background: Anticipatory drugs in patients’ home are recommended for terminally ill patients in the community to enable healthcare professionals to manage distressing symptoms at the end of life. Aim: To undertake an evaluation of the awareness of network guidelines along with the prescribing and usage ratios with outcomes for patients issued with JIC medication.

Method: GPs and community teams provided data relating to drugs prescribed and administered over a two month period.

Outcomes: 86% of GP’s indicated awareness of the guidelines. 90% indicated that they had prescribed JIC medication for their patients. 69% of GPs prescribing was influenced based on access to JIC information with 75% stating that levels of confidence impacted on decision making. 57% of GPs noted that confidence was a factor which influenced them when administering drugs. 55% of GP respondents indicated that prescribing was influenced by concerns about misuse of drugs. 41% of GPs indicated that cost was factor. The recommended network guidelines for 2/3 day supply of JIC costs £30.26 per patient. 2,120 ampoules were prescribed with 166 ampoules known to have been administered during the evaluation period. £2,700 - approximate cost of all the drugs prescribed for the two month period. £260 - actual cost of JIC drugs used during the evaluation period.

A significant saving in comparison to the average in-patient bed costs; based on Marie Curie estimates of £425.00 per night. The cost of prescribed drugs was £2,700 equating to 6.35 bed nights.

Conclusions: To consider a review of the number of ampoules prescribed - reducing by one half could save £15,000 per annum without detrimental impact to patient care. Evaluate the implication of health care professionals - other than GPs - having urgent access to JIC medication for patients experiencing a sudden unexpected deterioration.

Abstract number: P315
Abstract type: Poster

Overcoming Disparities in Access to Quality Basic Palliative Care in the Community

Mosoiu D.1,2, Muntean A.1, Predoiu O.1, Magayakalbermatten N.1, Dunitrescu M.1, Behnke N.1, Strasser F.2
1 Hospice Casa Sperantei, Brasov, Romania, 2 Transylvania University, Medical Faculty, Brasov, Romania

Development of palliative care (PC) in Romania was done inconsistently, based on limited financial and specialized human resources available. 2012 coverage was 5.74%, with highly uneven spread over the country (17/41 counties had no PC). Disparities encompass four dimensions: clinical patient care, general practitioners (GPs) education, legal and policies aspects in providing PC and financial barriers.
Aim: To design a new model of care for reducing gaps in access to community PC for cancer patients, based on Swiss-Romanian cooperation and expertise exchange.

Methods: First phase (18 months), a disparity and needs reality frame in providing care for patients diagnosed with cancer will be made in 4 pilot counties (Brasov, Bucharest, Cluj, Iasi) using

a) local multi-professional groups providing case stories (minimum 50 cases) illustrating disparities,
b) ten focus groups involving stakeholders (different groups icancer patients and their families, GPs, oncologists, nurses, social workers, health authorities, patients’ associations) utilizing cases for the interview guideline, and
c) a national survey quantifying identified disparities.

This systematic data collection will be discussed on a consultation day with representatives of the Swiss organisations for the four dimensions in Switzerland in summer 2014. Then a stakeholder meeting in Romania will further analyse the findings and finalize a consensus document on the situation of community PC in Romania. This reality consensus paper will be used in the second phase of the project (18 months) for the design of education programs and tailored PC clinical interventions in the community. This will be tested in 4 pilot counties for 100 patients and evaluated. The results will be disseminated and will empower authorities to produce policy and financial adjustments.

Conclusion: This approach targeting disparities may contribute to develop further community PC. This project is supported by Swiss-Romanian Cooperation Programme.

Abstract number: P316
Abstract type: Poster

Measuring Satisfaction with Supporting and Palliative Care of Cancer Patients According to their Attachment Styles

Galanopoulou A.1, Tsilika E.2, Parpa E.2, Panagiotou I.2, Mystakidou K.3

1General Hospital, Nikaia, Pireus, General Practitioner, Athens, Greece, 2Pain Relief and Palliative Care Unit, University of Athens, Radiology, Athens, Greece, 3University of Athens, School of Medicine, Areteion Hospital, Pain Relief and Palliative Care Unit, Radiology, Athens, Greece

Objective: To assess cancer patient’s satisfaction with palliative care treatment based on their attachment styles.

Materials and methods: 90 cancer patients attending a Palliative Care Unit completed a 13-item measure of patient satisfaction (FAMCARE P-13) and the Experiences in Close Relationships scale (ECR-M36), a 16-item version of ECR.

Results: Univariate analysis between demographic and clinical characteristics of patients with FAMCARE P-13 revealed that there were statistically significant differences with metastasis (p=0.095), chemotherapy (p=0.001), hormonotherapy (p=0.001) and significant correlation with years from cancer diagnosis (p=0.001). Multiple linear regression showed that only chemotherapy (p=0.023) and years from cancer diagnosis (p=0.002) were statistically significant predicting factors of patients satisfaction. Univariate analysis between demographic and clinical characteristics of patients with ECR attachment anxiety style, revealed a statistically significant correlation with age (p=0.034) and a statistically significant difference with cardiovascular disease (p=0.018). Moreover, there were statistically significant difference with chemotherapy (p=0.006), radiotherapy (p=0.077), hormonotherapy (p=0.0005) and cancer location (p=0.077) with ECR avoidant attachment style and significant correlation with years from cancer diagnosis (p=0.045). Multiple linear regression showed that cardiovascular disease was a statistically significant predicting factor of ECR anxiety attachment style, while location of cancer (p=0.081) and satisfaction (p=0.056) were statistically significant predicting factors of ECR avoidant attachment style.

Conclusion: Patient’s satisfaction was found to be a strong predictor of avoidance attachment style, while only chemotherapy and years from cancer diagnosis were influencing levels of satisfaction.

Abstract number: P317
Abstract type: Poster

Preferences for Breaking Bad News among General Population and Health Care Professionals: A Representative National Survey in the Czech Republic

Závadová I.
Mobil Hospice Cesta Domů, Prague, Czech Republic

Aim: The aim of this survey was to investigate the practices and preferences for breaking bad news (BBN) among general population and health care professionals (HCP) in the Czech Republic (CZ).

Study population: A representative sample of Czech population (N=1147) older than 15 years of age and purposive sample of HCP (N=883). The general population sample was weighted for age, gender, education and geographical region to achieve the representativeness for the whole population in CZ.
Methods: Respondents 15-50 years old were interviewed using the Computer Assisted Web Interviewing method and older respondents using the Computer Assisted Personnel Interviewing. Questions were focused on respondents’ preferences regarding delivering bad news (their preference to know or not, place, accompanying person, and time frame). Descriptive statistics were used to assess the associations between responses and various demographic variables.

Results: Only 6% of general population would not like to know the truth about their poor prognosis. In contrast, HCP indicated that 20% of their patients don’t want to know this information. Most respondents from general population (62%) would prefer to receive the bad news alone, 24% would like to have a family member with them. Both general population and HCP indicated that the time for BBN is too short (estimated 10 to 15 minutes). Both groups also agreed that BBN usually takes place at patient’s bed or in ambulance and that these are not the preferred places. More than half (57%) of HCP felt uneasy with BBN, even when they often take care of seriously ill people (51%).

Conclusion: There is a need for evaluation of time and place available for BBN in hospitals and other settings to ensure adequate quality of this highly important interaction. BBN should be an integral part of education for health care professionals in CZ at both pre- and post-gradual level.

Funding: Ministry of work and social affairs (grant No. S3MP3), STEM/MARK

Abstract number: P318
Abstract type: Poster

The ACTION Study Protocol: Advance Care Planning - An Innovative Palliative Care Intervention to Improve Quality of Life in Oncology A Multi-centre Cluster Randomized Clinical Trial

Rietjens J.1, Korfage I.1, van Delden J.2, Deliens L.3,4, Miccinesi G.5, Seymour J.6, Payne S.7, Lunder U.8, Groenvold M.9, van der Heide A.1, on behalf of the ACTION Consortium

1Erasmus MC, Public Health, Rotterdam, Netherlands, 2UMCU, Julius Centrum, Utrecht, Netherlands, 3Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 4VUmc, EMGO Institute, Amsterdam, Netherlands, 5Cancer Prevention and Research Institute, ISPO, Florence, Italy, 6University of Nottingham, Nottingham, United Kingdom, 7Lancaster University, Lancaster, United Kingdom, 8University Clinic Golnik, Golnik, Slovenia, 9University of Copenhagen, Copenhagen, Denmark

Background: Advanced cancer typically involves multiple symptoms and seriously affects patients’ quality of life. Anxiety and depression are common. Medical care for patients with advanced cancer should be aimed at symptom control and support. Patients’ preferences regarding care should be central. Open and respectful communication are of key importance, but have been found to be a challenge for health care professionals as well as patients and relatives. Advance care planning (ACP) is a formalised process of communication between patients, relatives and caregivers about patients’ care preferences. It raises awareness of the need to anticipate future deterioration of health.

Main research aim: To study the effects of formalized ACP on symptom burden and quality of life of patients with advanced cancer.

Study population: 1334 patients diagnosed with lung or stage IV colorectal cancer, from at least 20 hospitals in 6 countries.

Design and methods: A phase III multicentre cluster randomized controlled trial. Patients will be randomized to provide patients with advanced cancer with either ACP or ‘care as usual’. They will fill in questionnaires at inclusion, and at 2.5 and 4.5 months post-inclusion. A relative will fill in a questionnaire after the patient’s death. Use of medical care will be assessed through medical files. Primary endpoints are quality of life (QLQ-C30 emotional functioning) and symptoms at 2.5 months post-inclusion. Secondary endpoints are the extent to which care as received was in line with patients’ preferences, patients’ evaluation of the decision making process, quality of dying and cost-effectiveness of the intervention.

Conclusion: Our project will assess the impact of ACP on quality of life, and contribute to improving comfort and quality of care for patients with advanced cancer.

Funding: FP7-HEALTH-2013-INNOVATION-1

Abstract number: P319
Abstract type: Poster

Perceptions of the Nurse Practitioner Role in Facilitating the Implementation of an Onsite Pain Management Team in Long Term Care

Kaasalainen S.1, Brazil K.2

1McMaster University, Hamilton, ON, Canada, 2Queen’s University Belfast, School of Nursing and Midwifery, Belfast, United Kingdom

Background: One strategy to improve pain management in long term care (LTC) is to optimize the emerging role of the nurse practitioner (NP) in LTC. The purpose of this sub study was to learn about the NP role in implementing an onsite, interdisciplinary Pain Team in the LTC home setting.

Methods: We used a case study design that included two NPs who worked at separate LTC homes. Each of the NPs
Neuropathic Cancer Pain (NeuCP): Biological Predictors, Functional and Psychosocial Impact, and Therapeutic Interventions at Referral to a Cancer Pain (CP) Clinic

Pina P., Dalzell C., Sabri E., Lawlor P.G.

1Instituto Português de Oncologia de Lisboa, Portugal, 2Bruyere Research Institute, Palliative Medicine, Ottawa, ON, Canada, 3Ottawa Hospital Research Institute, Ottawa, ON, Canada, 4Bruyere Continuing Care, Division of Palliative Care, Dept of Medicine, Dept of Epidemiology and Community Medicine, University of Ottawa, Bruyere and Ottawa Hospital Research Institute, Ottawa, ON, Canada

Background: There are few literature data on NeuCP in Portuguese settings.

Aims: To determine at initial CP clinic referral: biological predictors; psychosocial impact; and characteristics of pre-referral management for NeuP.

Methods: Consecutive patient referrals to a specialist CP clinic had standard assessments and documentation: Brief Pain Intensity ratings (worst and average in last 7 days; and pain now) on a 0-10 scale; pain mechanism (using the DN4 tool to assess neuropathic pain); episodic pain; functional status; oral morphine equivalent daily dose (MEDD); Hospital Anxiety Depression and Emotional Thermometer scores; demographics; comorbidities; adjuvant analgesia, cancer diagnosis, metastases, treatment and pain duration. Using DN4 score ≥4 and < 4 categories to designate the presence or absence of a NeuCP component, respectively, as an outcome variable, bivariate and multivariate logistic regression models with were constructed to generate Odds Ratios (ORs) for a priori deemed, clinically meaningful sets of predictor variables: biological; psychosocial and functional impact; and pre-referral therapeutic interventions.

Results: 161/371 (43%) had a NeuCP component. In the bivariate logistic regression of biological variables, age >60; “palliative” designation status, surgery, chemotherapy, episodic breakthrough or incident pain were significant predictors (p< 0.05). In the multivariate model, “palliative” designation status, surgery, chemotherapy, had adjusted ORs (95% CIs) of 2.4 (1.4-4.1), 2.0 (1.2-3.4), and 3.6 (2.2-6.0), respectively, and gastrointestinal cancer emerged as a negative predictor, OR = 0.3 (0.1-0.9). In the other models, an independent association with NeuCP was demonstrated for “Worst” pain and use of antidepressants and steroids.

Conclusions: NeuCP was independently associated with “palliative” status, surgery, chemotherapy, head and neck cancer, higher “worst” pain scores and broader adjuvant analgesia use.

Abstract number: P320

Abstract type: Poster

The Impact of Supportive Care Interventions on the Severity of Patient Self-reported Depression among Advanced Cancer Outpatients

Rhondali W., Yennurajalingam S., Ferrer J., Chisholm G., Filbet M., Bruera E.

1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3MD Anderson Cancer Center, Biostatistics, Houston, TX, United States

Purpose: Advanced cancer patients often experience moderate to severe physical and emotional distress. One of the main components of emotional distress is depression. The objective of this study was to determine the impact of supportive care interventions on the severity of patient self-reported (PSR) depression among advanced cancer outpatients.

Methods: We included all the patients seen in the outpatient Supportive Care Center between February 2008 and February 2010 with one follow up visit. We used the Edmonton Symptom Assessment Scale (ESAS) to assess their symptom intensity. Clinical improvement of PSR depression was defined as an improvement of at least 30% between the initial visit and the first follow-up. We used logistic regression models to assess possible predictors of improvement in PSR depression.

Abstract number: P321

Abstract type: Poster

NPs tended to be most engaged in pain assessment and collaborated more with licensed nurses and personal support workers; less with pharmacists. NPs were more involved in organizational level activities, such as participating in committee work or assisting with the development of policies and procedures about pain. NPs created palliative care and pain service protocols; engaged in policy development, in-servicing, quality assurance and advocacy; and encouraged best practices. NPs were challenged with time constraints for pain management and balancing other role priorities and felt that increased scope of practice for them was needed.

Conclusions: The results of this study highlight how NPs implemented a Pain Team in LTC which may be helpful to others interested in implementing a similar strategy to reduce residents’ pain.

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1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3MD Anderson Cancer Center, Biostatistics, Houston, TX, United States

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Methods: We included all the patients seen in the outpatient Supportive Care Center between February 2008 and February 2010 with one follow up visit. We used the Edmonton Symptom Assessment Scale (ESAS) to assess their symptom intensity. Clinical improvement of PSR depression was defined as an improvement of at least 30% between the initial visit and the first follow-up. We used logistic regression models to assess possible predictors of improvement in PSR depression.
Results: 160/444 patients (36%) reported moderate/severe depression at baseline (ESAS item score ≥4/10). Higher baseline depression intensity was significantly related to anxiety (r=0.568; p=0.046), total symptom distress score (r=0.550; p<0.001) and personal history of depression (r=0.242; p<0.001). Ninety of the 160 (56%) patients with moderate/severe PSR depression at baseline showed a significant improvement at the follow-up visit (p=0.038). Improvement in anxiety, sedation, and feeling of well-being were associated with higher depression improvement. Antidepressant use was not associated with PSR depression improvement suggesting that this improvement was related to symptom management and psychosocial support rather than the pharmacological management of depression.

Conclusions: More than 50% patients with moderate/severe PSR depression improved after one single supportive/palliative care intervention. Improvements of anxiety and sedation were independently associated with depression improvement.

Abstract number: P322
Abstract type: Poster

High-flow Nasal Cannula Therapy (HFNC) for Patients with Severe Acute Respiratory Failure and Do Not Intubate Orders. Pilot Study
Brugger S.C., Rodríguez S., Domingo J., Gornaz P., Gavilan R., Iglesias S., Miralbes M., León M.
Hospital Universitario Arnau de Vilanova, Lleida, Spain

HFNC has an important role on severe acute respiratory failure treatment and it can improve work of breathing, dyspnoea and hypoxemia, as described in literature with no invasive mechanical ventilation. Also, by not requiring a facial mask, it allows coughing, verbal communication and is well tolerated without causing pressure skin injury.

Aims: To evaluate the efficacy, safety and outcomes of HFNC in ICU patients with acute respiratory failure, no response to conventional oxygen therapy and do not intubate orders.

Method: Prospective study with patients admitted to ICU from May-12 to August-13, who presented severe hypoxemia, potentially reversible etiology and low response to conventional oxygen therapy, for whom invasive ventilation was not indicated. Patients with severe hypercapnia were excluded. There were considered demographic and clinical data, as well as respiratory variables, at baseline and after initiated HFNC, and undesirable effects.

Result: 10 patients treated with HFNC had do not intubate orders. The average age was 70.1 years (48-79). 80% of the patients had APACHE II score equal to or greater than 15. There were 4 deaths. In all cases the device was considered useful by the doctors and/or patient, regarding gasometric improvement, dyspnoea and work of breathing. In two cases, however, the treatment seems to have only postponed death. There were few and transient undesirable effects.

Discussion: Although improvement of most patients, there was a high mortality in this series. It’s thought to be due to the high severity of the studied population, elderly and severe comorbidity. Eventhough cases with unfavourable outcomes, we believe HFNC was useful on end-of-life care: it early relieved dyspnoea, it allowed patient communication and it saved enough time for providing other comfort measures.

Conclusion: HFNC is an effective and well tolerated respiratory support for patients with severe hypoxemia and do not intubate orders.

Abstract number: P323
Abstract type: Poster

Connected Health: A Pilot Study of Cancer Symptom and Quality of Life Assessment with a Tablet Computer
Aktas A.1, Hullihen B.1, Shrotriya S.1, Thomas S.1, Walsh D.1, Estfan B.2
1Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Section of Palliative Medicine and Supportive Oncology, Cleveland, OH, United States, 2Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Cleveland, OH, United States

Introduction: Incorporation of tablet computers (TC) into patient assessment may facilitate safe and secure data collection. We aimed to evaluate the usefulness and acceptability of a TC as an electronic self-report symptom assessment instrument.

Methods: The study was conducted in a tertiary care academic cancer center outpatient clinic. Eleven subjects were recruited consecutively from a single medical oncologist physician appointment schedule. Eligible patients received a letter with study information >5 days in advance of their first visit. The day before that a telephone call by a researcher ensured they had received the letter. Those who then agreed to participate were invited to meet a research physician 20 minutes before their visit. We used a 3rd generation iPad TC for this study. REDCap web-based application supported data capture. The questionnaires were adapted from an international multicenter data collection project (EPCRC-CSA). Completed questionnaires were printed and given to the physician before the visit. Data was downloaded from REDCap to Microsoft Excel and descriptively analyzed with JMP.

Results: Most patients who received information participated. Completion rate was 100%. Most completed the survey without assistance. Six of the 11 surveyed had pain.
Signs of depression were evident in 2. The median global QoL was high for all. Based on ESAS the top 3 most common symptoms were tiredness, anxiety, and decreased well-being. In EORTC QLQ C-15-PAL, the 5 most frequently reported symptoms were weakness, tiredness, pain, trouble sleeping, and anorexia.

**Conclusions:** Studies with TC in busy outpatient clinics are practical. There was a 100% completion rate and it took on average just over ten minutes to complete. Clinic wait time can be usefully employed for this purpose. The information gathered prior to physician encounter was useful in clinical practice. Patient and physician acceptability for these quick and useful TC based surveys was excellent.

**Abstract number:** P324
**Abstract type:** Poster

**They Still Grieve - A Nationwide Follow up of Young Adults Two to Nine Years after Losing a Sibling to Cancer**

Sveen J.1, Eilegård A.2, Steineck G.3,4, Kreicbergs U.5,6

1Uppsala University, Uppsala, Sweden, 2Karolinska Institutet, Stockholm, Sweden, 3Karolinska Institutet, Department of Oncology and Pathology, Stockholm, Sweden, 4Gothenburg University, The Sahlgrenska Academy, Department of Oncology, Gothenburg, Sweden, 5Karolinska Institutet, Department of Women’s and Children’s Health, Stockholm, Sweden, 6Sophiahemmet University College, Stockholm, Sweden

**Aim:** The aim of the study was to assess the prevalence of unresolved grief in bereaved young adult siblings.

**Methods:** The study was a Swedish population-based study of young adults who had lost a brother or sister to cancer, two to nine years earlier. Of 240 eligible siblings, 174 (73%) completed a study-specific questionnaire. This study focused on whether the respondents had worked through their grief over the sibling’s death, and to what extent.

**Results:** Thirteen (7%) of 174 bereaved siblings reported that they had not worked through their grief at all, and 79 (45%) reported that they had worked through their grief to some extent.

**Conclusion:** The results suggest that even two to nine years after the loss of a sibling to cancer, more than half of the bereaved young adults had not worked through their grief. This may be an indication that young adult sibling’s grieving process is prolonged.

**Abstract number:** P325
**Abstract type:** Poster

**Do you Have a Daughter? Patient Characteristics and Location of Death in a Community-based Palliative Care Practice in Ontario (Canada)**

Klinger C.A.1, Aldridge L.2, Thompson B.E.3

1University of Ottawa, Department of Medicine, Division of Palliative Care, Ottawa, ON, Canada, 2Family Physician in Palliative Care, Ottawa, ON, Canada, 3University of Ottawa, Department of Family Medicine, Ottawa, ON, Canada

**Aim:** Family physicians play a crucial role in community-based palliative care. With further emphasis on home care/a home death and in line with Andersen’s behavioural model of health care utilization, predisposing, enabling and need factors for patients’ access to service/their location of death are hypothesized.

**Population:** All deceased palliative care cohort patients (as defined by the Gold Standards Framework and Ontario Health Insurance Plan palliative care billing codes) cared for by an Ontario-based physician practice during the 2012 calendar year (N = 98).

**Design:** Exploratory study employing a retrospective chart review. Linkage to 2006 Census Tract Profiles and a previous, local neighbourhood survey in the public domain for socio-economic status profiles.

**Analysis:** Frequency analysis of demographic data from the physician practice’s charts.

**Results:** Patients (male: 52%, female: 48%) with an average age of 71 years (range: 36 - 92) and an average Palliative Performance Scale score of 53 at admission (range: 10 - 80) spent an average of 67 days (range: 1 - 637) under the practice’s care. Most (93%) had a cancer diagnosis (mainly lung and gastro-intestinal) with non-cancer diagnoses the remainder. With the majority of patients having one (39%) or more (43%) caregivers - many being daughters - about 41% died at home, 19% on a dedicated palliative care unit, 17% in residential hospice, 16% in hospital and 7% in a retirement home.

**Conclusion:** Bivariate (chi-square and Fisher’s exact test for low cell count) and multivariate logistic regression analyses to determine significance and to assess determinants of place of death are ongoing. The study is set to fill a gap in the literature and to enhance community-based service provision in order to better meet the complex needs of community palliative care populations.

**Funding:** This study is supported by a 2013 Janus Research Grant from the Research and Education Foundation of the College of Family Physicians of Canada.

**Abstract number:** P326
**Abstract type:** Poster

**“FEAR OF DYING”: Conceptual Proposal for Improving Nursing Care at the End of Life.**

**Preliminary Results**

Fernández-Donaire L.1, Monforte-Royo C.2, Aradilla-Herrero A.1, Edo-Gual M.1, Fernández-Narváez P.1, Maté-Méndez J.1, Tomás-Sábado J.1
**Abstract number:** P327  
**Abstract type:** Poster  

**Prospective Multicentre Comparative Study of Syringe Driver Practices within Palliative Care Service Providers in New South Wales, Australia**

Moore H.M.,1,2 Daniels B.1,4, Chye R.1,2  
1Sacred Heart Health Service, St Vincent’s Hospital, Palliative Care, Sydney, Australia, 2St Vincent’s Clinical School, University of New South Wales, Sydney, Australia, 1Translational Cancer Research Network, Sydney, Australia, 4Prince of Wales Clinical School, University of New South Wales, Sydney, Australia

**Introduction:** Syringe drivers are considered a safe and convenient method of drug delivery. Single and multiple drugs can be continuously infused, usually over 24 hours, into subcutaneous tissue (arm/chest/abdomen/thigh). Indications include the inability to take oral medication and symptom control.

**Aim:** To validate the diagnostic label Fear of the dying process, its definition, defining characteristics (DC) and related factors (RF), for inclusion in the taxonomy of the North American Nursing Diagnosis Association (NANDA), and validate nursing activities related to the label.

**Methods:** The validation process was conducted in three phases. In the first phase through the Delphi method, a questionnaire was administered to a group of experts with the intention of reaching a consensus for the definition, DC and RF of the label; the proposal was submitted to NANDA. In the second, we conducted a Nominal Group twice to design and agree on nursing activities related to the label. Finally, we administered a questionnaire to a group of experts to validate the usefulness in clinical practice of the selected activities through a new Delphi method. The results were statistically analyzed using SPSS 20.0 for Windows.

**Results:** The initial questionnaire contained 16 DC and 17 RF. After successive evaluations of the first expert panel, data was retained with a median >3 and suggestions were added, resulting in a total of 15 DC and 19 RF. The resulting 44 nursing activities Nominal Group were categorized into five labels; 11 incorporating aspects of “assessment”, 11 reflected “therapeutic interventions”, 8 were related to the “information and/or health education”, 10 referred to the “environment” and 4 impinged on the “effectiveness evaluation”. The results of the last phase are being analyzed.

**Conclusions:** We have obtained nursing care proposal for patients at the end of life using Delphi and Nominal Group technique. We will obtain consensus on nursing activities for patient care on the human response to the “Fear of dying”.

**Abstract number:** P328  
**Abstract type:** Poster  

**Use of Chemotherapy and Target Therapy in the Last Weeks of Life**


Oncology Institute of Ljubljana, Medical Oncology, Ljubljana, Slovenia

**Introduction:** Overuse of chemotherapy and target therapy (Cht) is one of identified indicators of aggressive care near the end of life. In analyze completed in 2009, results have revealed high percentage of patients (pts) with advanced cancer receiving Cht in their last 4 and 2 weeks of life in our hospital. Since then several presentation and educational events were organized to guide
oncologist in decision making about appropriately timed cessation of ChT.

**Aim:** To evaluate trend of ChT use in our hospital nowadays and compare results with previous analyze in 2009.

**Methods:** We have reviewed charts of pts treated with ChT who have died in our hospital during 2012. We have analyzed use of ChT during last 4 or 2 weeks of life, admittance to intensive care unit (ICU) or palliative care unit (PCU). The results were compared between 2009 and 2012.

**Results:** There were 361 pts treated with chemotherapy (Ch) who died in our hospital in 2012. 91 pts (25.2%) have received Ch in their last 4 weeks of life, 34 (9.4%) also in last 2 weeks. Additionally there were 39 pts (10.8%) who received target therapy (T) during last 4 weeks of life, 21 (5.8%) also in last 2 weeks of life, as mono-therapy or as part of combined therapy. In 52 pts (14.4%) new ChT was started during last 4 weeks of life. Still, in comparison with 2009, there was less ChT use in last weeks of life in 2012: during last 4 weeks 39% (2009) vs. 31% (2012) and in last 2 weeks of life 23% (2009) and 14% (2012). In 2012 there were 32 pts (8.8%) admitted to ICU during last 4 weeks of life (in 2009 5.9%). For 63 pts (17.5%) in 2012 there were palliative care consultation done or they were admitted to PCU (in 2009 only 6.3%).

**Conclusion:** Although we can notice a trend to lower use of ChT in a group of pts with advanced cancer during last weeks of life in our hospital, there is still a very high proportion of pts receiving ineffective and toxic treatments that can lead to poor quality of end of life.

**Abstract number:** P329

**Abstract type:** Poster

**Characteristics of People with Physical and Mental Disease Committing Suicide**

**Kraus S.**¹, **Fegg M.J.**², **Bausewein C.**³

¹Ludwig-Maximilians University Munich, Department of Forensic Medicine, Munich, Germany, ²Munich University Hospital, Department of Palliative Medicine, Munich, Germany

**Aims:** To compare characteristics and risk factors of people committing suicide with physical and mental diseases as underlying cause.

**Method:** Descriptive Analyses of suicide case notes (including police information and suicide notes) and autopsies of cases admitted to the Institute of Forensic Medicine between 2009 and 2011. Differences between groups were calculated using Chi2-tests.

**Results:** Of 1069 cases, 552 suffered from physical disease (PD; n=202) or mental disorders (MD; n=350). 63.9% (353) were male, mean age 56.1 years (range 16-97), people with PD were significantly older than those with MD (68.8 vs. 48.7 years; p< 0.001). Of the 220 people with PD, 30.7% (n=62) suffered from cancer, 28.7% (n=58) from chronic pain syndromes and 12.4% (n=25) from lung disease. People with cancer (qui-square test 23.15, p< 0.001) had a higher risk of committing suicide compared to lung disease (qui-square test 0.004, p=0.95) and chronic pain (qui-square test 4.47, p=0.034). More people with MD had attempted suicide before (chi-square test 18.56, p < 0.001). The number of physical disease (more then two) was also significant (chi-square test 9.69, p=0.02). There were no differences between the groups regarding suicide methods (including intoxication).

**Conclusion:** A considerable proportion of people committing suicide suffer from physical disease, especially cancer. Older age, number of physical disease and suicide attempts in the past are risk factors for committing suicide. Professionals in palliative care should be aware of this and explore suicidal ideation in patients at risk.

**Abstract number:** P330

**Abstract type:** Poster

**Dignity Models in Healthcare. A Review of the Literature**

**Errasti-Ibarondo B.**, **Carvajal Varcancel A.**, **Martinez García M.**, **Arantzamendi Solabarrieta M.**

¹University of Navarra, Pamplona, Spain, ²Clinica Universidad de Navarra, Pamplona, Spain

**Introduction:** The persons’ dignity is a fundamental aspect of the end of life care for healthcare professionals and patients. Nowadays some meanings of dignity extend their exclusive attachment to the idea that it is an intrinsic quality of the human beings.

**Objective:** To know different dignity models elaborated in different healthcare contexts and to identify the essential aspects that may influence in the patients’ personal sense of dignity.

**Method:** A review of the literature was carried out in CINAHL, Pubmed and PsycINFO databases, introducing “Dignity Model” as keyword.

**Results:** Five empiric models of dignity elaborated from different contexts and with different perspectives were identified: The model of how nurses maintain patients’ dignity; the model of patients’ perspectives of dignity in care; Model of dignity in illness; the model of how patients’ dignity is promoted or threatened in hospital; Model of Dignity. All of them consider dignity as an intrinsic trait of the human being, but at the same time they take into account a subjective dimension of the dignity that depends on the persons’ experience. The essential aspects that influence the personal sense of dignity are: the view of the persons about themselves, the effects that the illness has on them, the organizational context and the behavior of healthcare professionals.
**Conclusions:** All the models included in this review provide to healthcare professional a starting point to reflect and to incorporate practices that may preserve the dignity of terminally ill patients. The essential aspects identified in the models could be applied to the care of the persons that are at the end of life.

**Abstract number:** P331  
**Abstract type:** Poster

**Audit: Medical Record Documentation among Advanced Cancer Patients**

Chirac A.1, Perceau E.1, Rhondali W.1,2, Ruer M.1, Chabloz C.1, Filbet M.1  
1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3Hospices Civils de Lyon, Lyon, France

**Background:** Medical record documentation of cancer inpatients is a core component of continuity of care. The main goal of this study was an assessment of medical record documentation in a Palliative Care Unit (PCU) using a targeted clinical audit based on deceased inpatients’ charts.

**Methods:** Stage 1 (2010): A clinical audit of medical record documentation assessed by a list of 6 items (diagnosis, prognosis, treatment, power of attorney directive, advance directives). Stage 2 (2011): Corrective measures, with theoretical training regarding legislation and medical record documentation (1h) for the nurses and physicians. Stage 3 (2012): re-assessment with the same items’ list after 6 month.

**Results:** Forty cases were investigated during stage 1 and 3. After the corrective measures, inpatient’s 10 medical record documentation was significantly improved, including for diagnosis (p=0.01), 11 diseases extension and treatment (p<0.001). Our results highlighted the persistence of a weak 12 rate of medical record documentation for advanced directives (p=0.145).

**Conclusion:** Our results encourages us to continue this work to improve medical record documentation. It would be interesting to extend this research in oncology units, but also to other specialties, especially for the most vulnerable populations in order to improve the transmission of information to patients and their families.

**Abstract number:** P332  
**Abstract type:** Poster

**A Baseline Review of the Use of Instant Release Fentanyl Products in a Major Cancer Centre**

Parewal G., Hayle C., Barker C., Berman R.  
The Christie NHS Foundation Trust, Palliative Care, Manchester, United Kingdom

**Background:** As the management of background pain has improved there has become an increased awareness of the phenomenon of breakthrough cancer pain (BtCP), which alongside the development of transmucosal fentanyl preparations for BtCP, has led to a growing interest into this phenomenon.

**Aims:** To assess the initiation and titration of immediate release fentanyl (IRF) preparations for BtCP by the Hospice Palliative Care and Symptom Control Team (PCSCT).

**Method:** Retrospective case note review of 25 inpatients for whom the PCSCT initiated IRF preparation. Data collection and analysis done using Microsoft Excel.

**Results:** 1 case was omitted from analysis as the IRF was not initiated as an inpatient. Mean patient age was 55 years. 78% had metastatic malignancy. There was a documented pain history in 92% of the patient’s notes with an assessment of opioid responsiveness in 83%. Typical duration of pain episodes was not documented in 75% of patients. The most common product prescribed was Abstral (67%). 8% of patient notes had documented evidence of verbal or written advice given. 8% patients had a documented plan for titration in the casenotes, with 17% of patients having a range prescribed on the drug kardex. In the latter case, the nursing staff administered the higher dose prior to medical assessment in 13% cases. The PCSCT reviewed 22 patients (92%) at least once following initiation of the IRF to assess response. 79% were assessed twice, 33% three times and 13% four times. Appropriate actions were then taken.

**Conclusion:** The PCSCT play a major role in assessing and managing patient’s BtCP including their suitably for IRF. The results highlighted areas for improvements in the use of IRF preparations, upon which recommendations have been made. These include improved education regarding IRF, producing an information leaflet for patients, improving documentation in casenotes and examining the most effective, yet safe method of prescribing IRF products.

**Abstract number:** P333  
**Abstract type:** Poster

**Parenteral Nutrition Survey - Personal Views Influence Prescribing Modalities**

Šimaneck R.1, Nestor K.2, Bozetti F.3, Chasen M.4, Fearon K.5, Jatoi A.6, Lundström S.7, Muscaritoli M.8, Orreval Y.9, Watzke H.9, Strasser F.2  
1Hietzing Hospital, 5th Medical Dept. with Oncology, Vienna, Austria, 2Kanton Hospital St. Gallen, Department of Internal Medicine and Palliative Care Center, St. Gallen, Switzerland, 3University of Milan, Faculty of Medicine, Milan, Italy, 4University of Ottawa, Division of Palliative Care, Ottawa, ON, Canada, 5University of Edinburgh, Department of Clinical Surgery, Edinburgh, United Kingdom, 6Mayo Clinic, Department of...
Background: Communication and shared decision making are vital in the management of deteriorating patients. The AMBER care bundle is a systematic approach to managing patients identified as deteriorating, with uncertain recovery and at risk of dying in the next 1-2 months.

Aim: To understand which patients are more likely to be supported by the AMBER bundle, and how this is affected by illness trajectory in the last hospital admission.

Methods: We investigated factors associated with the use of AMBER in all patients who died over 11 months on 5 inpatient wards where the AMBER bundle was being implemented. Two reviewers undertook retrospective review of electronic patient records.

Results: Our sample (N = 149) had a median age of 80, interquartile range (IQR) 72 - 87. Main admission problem was cancer in 25%, non-cancer in 31% and multiple medical problems in 44%. 38% of patients were supported by the AMBER bundle. Trajectory of final illness was defined a priori as ‘predictable and gradual’ (40%), ‘predictable rapid’ (22%), ‘unpredictable’ (21%) or ‘sudden death’ (17%) using definitions agreed by the research team. Patients who died from a ‘predictable and gradual’ deterioration (by definition >7 days) were more likely to be supported by AMBER than other trajectories (62% vs. 21%, \(\chi^2 = 24.8, p < 0.001\)). Patients supported by AMBER had a longer admission (median 20 days vs. 11 days, \(p < 0.001\)) and longer terminal phase (14 days vs. 7 days, \(p = 0.001\)). 62% of patients with cancer were supported by AMBER compared to 30% with non-cancer diagnoses (\(\chi^2 = 12.7, p = 0.001\)).

Conclusion: These data show that use of AMBER is affected by duration and predictability of deterioration as well as diagnosis. A longer period of predictable deterioration facilitates utilisation of tools such as the AMBER care bundle. More work is needed for earlier identification of predictors of deterioration in patients with a rapid or unpredictable course. These results will be used to refine practice.

Abstract number: P335
Abstract type: Poster

Current Approaches to General Palliative Care in a Danish Hospital - Preliminary Results

Bergenholtz H.1, Hølge-Hazelton B.2,3, Jarlbæk L.4

1Regional Research Unit, Region Zealand, Roskilde/Koaze Sygehus, Roskilde, Denmark, 2Regional Research

Abstract number: P334
Abstract type: Poster

No Time for AMBER? Investigating the Use of a Care Bundle for Patients with Uncertain Recovery

Etkind S.N.1, Karno J.2, Bristowe K.1, Koffman J.1, Carey I.2, Edmonds P.M.2, Murtagh F.E.M.1

1King’s College London, Cicely Saunders Institute, Dept. of Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Kings College Hospital NHS Foundation Trust, London, United Kingdom, 3Guy’s and St Thomas’ NHS Foundation Trust, London, United Kingdom

Aims: The role of parenteral nutrition (PN) in patients with incurable cancer and malignant bowel obstruction remains controversial. We aim to investigate current practice of PN by survey selected groups from ESMO, MASCC, ESPEN and EAPC.

Methods: Internet-based survey investigating decisions on PN in patients with malignant bowel obstruction based on two case-vignettes. We categorized participants into 3 groups:

- group 1: recommendation of PN in both cases,
- group 2: recommendation of PN in 1 case and
- group 3: no recommendation. For statistical analysis we assembled group 1 and 2 and compared them with group 3. Statistical analysis was performed with chi-square test, http://quantpsy.org.

Results: Eighty-one participants completed the survey. Nine (11%) recommended PN in both cases, 37 (46%) in one case and 35 (43%) did not in any case. Contrary to a higher amount of clinical work (>75%: 44%, 57% and 60%) and number of incurable patients (>75%: 11%, 22% and 23%) the impact of PN in routine care decreased in group 1, 2 and 3 (very important: 56%, 22% and 0%; important: 22%, 19% and 11%). Cachexia stage (case 1: cachexia, case 2: refractory cachexia) was estimated correctly by 11%, 54% and 11%, cachexia classified routinely by 44%, 35% and 23%, By comparing group 1 and 2 (n=46 (57%)) with group 3, in group 1 and 2 there was a lower amount of oncologists (26% vs. 51%, \(p=0.019\)) and palliative care specialists (13% vs. 32%, \(p=0.023\)), a lower number of participants who would recommend PN in refractory cachexia (17% vs. 49%, \(p=0.003\)) and a higher number who would recommend PN in pre-cachexia (57 vs. 6%, \(p=0.000\)). A Karnofsky index >70% was presupposed by 26% compared to 49% in group 3 (\(p=0.036\)).

Conclusion: A large heterogeneity of views, attitudes and understanding of cachexia affects prescribing modalities of experienced clinicians.
Aims: To select a minimal but still comprehensive set of quality indicators for palliative home and hospital care in Belgium.

Methods: The 80 previously established quality indicators (with description of nominator, denominator and measurement question) were presented at a panel of palliative experts. In a home assignment, they had to score the indicators for ‘priority’ to be included in the minimal set on a scale from 0 (least prior) to 9 (most prior), as prescribed by the RAND/UCLA method, and to indicate the 8 most prior indicators per respondent type. Indicators with a median score of 6 or less were discarded; indicators with a median score of 7 or higher were retained. High scoring indicators not reaching consensus (ie 2 or more panel members scored the indicator 3 or less) and indicated by no more than 6 panel members as most prior, were discussed during an expert meeting.

Results: Before the meeting, 39 indicators were discarded; 19 indicators were selected for the minimal indicator set; 22 indicators were discussed. Twelve of these 22 indicators were selected, leading to a minimal set consisting of 5 indicators about physical aspects of care, 6 indicators about the psychosocial aspects of care, 13 indicators about information, communication and care planning, 5 indicators about type of care and 2 indicators about continuity of care.

Conclusion: A minimal set consisting of 31 indicators reflecting all important issues in palliative care was created to assess quality of care in a quick and efficient manner. The remaining 49 indicators were placed within optional modules usable to thoroughly assess the quality of palliative care for patients and their families.

Abstract type: Poster

Development of a Method of Diagnosing Complexity in Palliative Care. (In Spanish: IDC-Pal: Instrumento Diagnostico de la Complejidad en Cuidados Paliativos)
Construction of a Palliative Care Complexity Diagnostic tool, defining what characteristics and circumstances confer complexity to end of life care and in what degree.

**Methods:** A conceptual framework was made from literature review and focus group to identify dimensions and items, constructing IDC-Pal V.0. The first field test of IDC-Pal V.0 was performed by Andalusian doctors and healthcare professionals, content and criterion validity being the main objectives. In the second field test, IDC-Pal V.1 was evaluated by Andalusian doctors assessing mainly criterion validity and reliability. Finally, IDC-Pal V.2 was field tested by doctors at national level, analysing essentially feasibility. Construct validity was supported by factorial analysis; content validity by content analysis with Atlas.ti; criterion validity by considering the participating experts’ criteria; an imperfect gold standard, as there was no other measure for comparison and X² analysis. The standard error of the mean was measured for reliability.

**Results:** IDC-Pal V.0: 9 dimensions, 55 items, 3 degree complexity item classification (5 minimum; 19 medium, 31 maximum); tested by 81 professionals (46 doctors), 309 cases. 93.5% identified correctly the case’s complexity degree. 55.8% agreed with case’s complexity degree assigned by the tool. IDC-Pal V.1: 5 dimensions, 40 items included a glossary, 3 degree complexity item classification; tested by 96 doctors, 180 cases. Agreement on degree of complexity assigned to 20 items was achieved. No items considered of minimum complexity degree. IDC-Pal V.2: 3 dimensions, 36 items, glossary, 2 degrees of complexity (22 items Complex and 14 items Highly complex); tested by 147 doctors, 317 cases. Complexity degree is linked to number of items and high complexity degree to clinical items.

**Conclusions:** IDC-Pal is a reliable and valid tool for diagnosing and classifying Complexity in Palliative Care, feasible and quickly completed, useful in research and/or practice.
Context: Identifying the end-of-life (EOL) preferences of older, vulnerable populations, is vital to quality and equitable EOL care.
Aims: To compare EOL preferences of older Latinos with advanced cancer to those of their contemporaries and determine concordance between patients’ treatment and decision-making preferences and their actual experiences.
Methods: Older Latinos with advanced cancer and a comparison group without cancer were interviewed to identify their preferences for palliative vs. life-extending treatments, decision-making, place of death, artificial nutrition and hydration, advance directives and prognostic disclosure. Chi-square tests were conducted to compare the preferences of those with and without cancer and patient concordance values were calculated.
Results: Sixty baseline interviews with patients and 68 with controls were completed. Fifty percent of patients vs. 73% of controls preferred a palliative approach (P=0.01). Thirty-one percent of patients vs. 14% of controls wanted life-prolonging drugs (P=0.029). Preference rates for palliative drugs were similarly high among patients (78%) and controls (70%) (P=0.41). Similar rates across groups were identified for preferences for shared decision-making (=60%); mechanical ventilation (=23%); artificial nutrition (=40%); hydration (57%); and full disclosure (≈80%). Advance directives rates were limited in both groups (=38%). Concordance between current treatment and decision-making preferences and practices was 73% and 63% respectively.
Conclusion: Preferences may vary within and across groups of older Latinos, yet palliative preferences are strongly prevalent in both groups. Older cancer patients may desire palliative and life-prolonging treatments simultaneously. Better concordance between preferences and practices could lead to improved patient outcomes. More research with vulnerable older adults is needed to tailor programs/interventions to meet their needs.

Abstract number: P340
Abstract type: Poster
Place of Death in Populations that Could Benefit from Palliative Care: A Population-based Study in 14 Countries
¹Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, ²Observatorio National de la Fin de Vie, Paris, France, ³University of Southampton, Faculty of Health Sciences, Southampton, United Kingdom, ⁴Cancer Prevention and Research Institute, ISPO, Clinical and Descriptive Epidemiology Unit, Florence, Italy, ⁵The University of Texas MD Anderson Cancer Center, Houston, TX, United States, ⁶VU University Medical Center, EMGO Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, Netherlands, ⁷Hospice Waikato, Hamilton, New Zealand, ⁸Servicio de Información y Evaluación en Consejería de Salud, Junta de Andalucía, Seville, Spain, ⁹Hasselt University, Department of Behavior, Communication and Linguistics, Diepenbeek, Belgium, ¹⁰University of Alberta, Faculty of Nursing, Edmonton, AB, Canada, ¹¹International Observatory on End of Life Care, Lancaster University, Lancaster, United Kingdom, ¹²University of Pecs Medical School (UP), Institute of Family Medicine, Pecs, Hungary, ¹³Dongduk Women’s University, Department of Health Science, School of Natural Science, Seoul, Korea, Republic of, ¹⁴Brown University, Providence, RI, United States

Aims: A majority of patients dying from chronic life-limiting diseases prefer to die at home, yet many still die in hospital. Comparing place of death cross-nationally can indicate margins for improvement and policy suggestions. We aimed to compare the place of death of people who could have benefited from palliative care in nine European and five non-European countries, and examine to what extent country-variation in place of death is related to socio-demographic, clinical and healthcare factors.
Methods: Death certificate data for all 2008 deaths in Belgium, England, Wales, France, Italy, Mexico, Netherlands, New Zealand, Canada, Czech Republic, Hungary, South Korea, USA and Spain (Andalusia) with an underlying cause of death corresponding to the minimal palliative care subset (Rosenwax et al. 2005) linked with regional healthcare statistics (N=2,220,997). Descriptive statistics and multivariable logistic regression analyses were used.
Results: People who could have benefited from palliative care died at home in 13% (Canada) to 51% (Mexico) of cases, in hospital in 25% (Netherlands) to 85% (South Korea) of cases, and in nursing home in 1% (South Korea) to 35% (Netherlands) of cases. The large differences across countries in the proportion of people dying at home and elsewhere were only partly explained by differences in age, sex, marital status, cause of death, and availability of hospital beds, long-term care beds and general practitioners.
Conclusion: Country differences in place of death in a palliative care eligible population are only partly explained by differences in healthcare provision and socio-demographic and clinical differences and are thus likely attributable to different palliative and end-of-life care policies, strategies and practices. Our findings facilitate a further identification of policies and practices that can enable people to die
in their place of choice within particular cultural, political and economic contexts.

Abstract number: P341
Abstract type: Poster

Comparison of Patients and their Care in Urban and Rural Specialized Palliative Home Care - A Single Service Analysis

Heckel M.1, Stiel S.1, Frauendorf T.1, Hanke R.M.2, Ostgathe C.1

1University Hospital Erlangen, Department of Palliative Medicine, Erlangen, Germany, 2Specialized Outpatient Palliative Care (SAPV) Team, Fürth, Germany

Background: Specialized outpatient palliative care teams (in Germany called SAPV) aim to ensure best possible end-of-life care for outpatients with complex needs. Information on the influence of living areas (rural vs. urban) on patient and care related aspects are rare. This study aims to explore differences between palliative care patients in urban and rural dwelling concerning their nursing and service characteristics.

Methods: A retrospective data analysis of documentary data for 502 patients supplied by SAPV team from December 2009 to June 2012 was conducted. Patients and care characteristics were investigated by frequency analysis and were compared for both groups of urban and rural dwelling patients (T-Test, Chi², Fisher’s exact test p< 0.05).

Results: 387 complete data sets could be included. Urban (n=197) and rural (n=190) dwelling patients were almost even groups. The mean age of the whole sample was 74.5 years, 55.3% were female. Most patients were diagnosed with cancer (76.8%). No significant differences in urban and rural dwelling patients concerning most demographic, care, disease and service related aspects of palliative home care could be detected. Except the rate of re-admittance to hospital is higher for rural dwelling patients (Fisher’s exact test p=0.022).

Conclusions: Although predominantly presumed the single service analysis shows except re-admittance rate to hospital no considerable differences between palliative care patients regarding their living area. Findings indicate patients cared for in rural and urban settings have similar needs and impose similar requirements on palliative care teams.

Abstract number: P342
Abstract type: Poster

Trends in Specialized Palliative Care for Non-cancer Patients in Germany - Data from the National Hospice and Palliative Care Evaluation (HOPE)

Stiel S.1, Hess S.1, Hofmann S.1, Klein C.1, Lindena G.2, Ostgathe C.1

1University Hospital Erlangen, Department of Palliative Medicine, Erlangen, Germany, 2Clinical Analysis, Research and Application (CLARA), Kleinmachnow, Germany

Introduction: The need for specialized palliative care (SPC) for non-cancer patients (NCP) is increasingly discussed. Nevertheless, little is known about their specific problems, unmet needs and whether improvements in care have taken place so far. This investigation focuses on developments seen in NCP management concerning SPC in Germany.

Methods: The German Hospice and Palliative Care Evaluation (HOPE) is a national long-term quality assurance project. For this study aggregated data from yearly evaluation periods of inpatient PC units between 2007 and 2011 (T2) are used to investigate differences between NC patients documented from 2002 to 2005 (T1) in symptoms, treatment and general condition.

Results: Data from overall 11036 patients could be analyzed (T1: 4182; T2: 6854). The proportion of NCP patients compared to all patients rose from 3.5% (n=147) to 8.1% (n=558). NC patients are now referred to SPC services at a younger age (T1: 75.0, T2: 73.8 years), with lower needs of nursing care support (T1: 40.1%, T2: 42.7%) and a lesser tendency to die during inpatient hospital stay (T1: 57.2%, T2: 41.0%). They are admitted with a greater variety of diagnoses and suffer from a minor complexity in symptoms and problems.

Conclusions: Despite the continuously growing number of patients with non-malignant diseases, their presence in SPC facilities is still under-represented in Germany. However our study shows that steps in the right direction seem to be made as it can be assumed that in the population under review SPC was integrated earlier in the trajectory. The need to improve quality of life of NCP during the final stages of their diseases will continue to challenge the health care system in terms of workload, need of more staff and further training of medical professionals dealing with NCP in the future.
Background: End-of-life care is often provided in primary care settings.

Aim: To describe and compare GP end-of-life care for Dutch patients who died from 'cancer', 'organ failure' and 'old-age or dementia'.

Design and methods: A cross-sectional, retrospective survey was conducted within a sentinel network of GPs. GPs recorded the end-of-life care of all patients who died (01/01/2009 to 31/12/2011) using a standardised form. Differences in care between patient groups were analysed using multivariable logistic regressions.

Study population: A total of 42 GP practices (63 GPs), covering 0.8% of the population, participated.

Results: The end-of-life care of 688 patients (453 cancer, 162 organ failure and 73 old-age/dementia) was recorded. GPs personally provided palliative care for 75% of cancer, 64% of old-age/dementia and 38% of organ failure patients. In the week before death, 89% of cancer and 86% of old-age/dementia patients received palliative treatments, compared with 77% of organ failure patients. Cancer patients had the most end-of-life communication and anticipatory decision making, whereas old-age/dementia patients had the least (e.g. life expectation was discussed with 84% of cancer, 46% of old-age/dementia and 55% of organ failure patients).

Interpretation: GPs may have difficulty recognising organ failure patients' palliative care needs or, in practice, GPs’ care for this group may be more aligned with an earlier model of palliative care than the current WHO model. Furthermore, the patient group most likely to lose decision-making capacity, old-age/dementia patients, received the least end-of-life communication and anticipatory decision-making, even though GPs seemed to consider palliative care approaches appropriate for them.

Abstract number: P344
Abstract type: Poster

Tolerability and Efficacy of Subcutaneous Levetiracetam in Palliative Care Patients with Symptomatic Epilepsy - A Case Series

Steigleder T.1,2, Ostgathe C.1

1University Hospital Erlangen, Department of Palliative Medicine, Erlangen, Germany, 2University Hospital Erlangen, Department of Neurology, Erlangen, Germany

Background: Two thirds of patients with intracranial tumors suffer from symptomatic epilepsy; every second patient will have seizures in the last weeks before death. Antiepileptic therapy with levetiracetam (LEV) is well tolerated and safe. The drug is licensed for intravenous or oral routes. For many other drugs in palliative care subcutaneous (s.c.) administration is often favored as safe, easy to use and feasible in particular in the dying phase. Data on tolerability and efficacy of subcutaneous application of LEV is scarce. Here we report on a case-series of five patients, who received off-label LEV s.c.

Method and patients: We treated five in-patients with secondary epilepsy with LEV s.c. All patients were previously treated with oral LEV. The mean dosage was 1700mg/day. Last seizure was reported 3 to 19 days prior to admission. When oral or intravenous application was not applicable any more, all patients received a subcutaneous indwelling cannula. To continue treatment a LEV solution was prepared (2,5mg/ml in NaCl0,9%) and administered twice daily. LEV dosage was continued.

Results:
Safety and feasibility: In the five patients no local or systemic complications / side effects were found. Administration was well tolerated and easily applicable. Efficacy: for the duration of the treatment no seizures occurred. Two patients received an EEG (10-20-system, 30min duration) which showed no epileptic activity. In one patient we examined plasma levels of LEV after four days of subcutaneous treatment and found it to be therapeutic (10,6ng/ml).

Conclusion: This pilot data suggest that - off label - subcutaneous application of LEV may be safe, feasible and effective posing a possible option in treating epilepsy in palliative care situations. Further investigations are urgently needed.

Abstract number: P345
Abstract type: Poster

An Analytic Framework for Delirium Research in Palliative Care Settings: Integrated Epidemiological, Clinician-researcher and Knowledge User Perspectives


1Bruyere Continuing Care, Division of Palliative Care, Dept of Medicine, Dept of Epidemiology and Community Medicine, University of Ottawa, Bruyere and Ottawa Hospital Research Institutes, Ottawa, ON, Canada, 2University of Cambridge, Cambridge, United Kingdom, 3Ottawa Hospital Research Institute, Palliative Medicine, Ottawa, ON, Canada, 4University of Notre Dame, Sydney, Australia, 5Ottawa Hospital Research Institute, Ottawa, ON, Canada, 6Bruyère Continuing Care - Palliative Care Unit, Division of Palliative Care, University of Ottawa, Bruyere Research
Institute, Ottawa, ON, Canada, 7University of Alberta, Edmonton, AB, Canada, 8Flinders University, Adelaide, Australia, 9Université Laval, Quebec, QC, Canada, 10MD Anderson Cancer Center, Houston, TX, United States, 11University of Limerick, Limerick, Ireland, 12University of Amsterdam, Amsterdam, Netherlands, 13Research and Academic Institute of Athens, Athens, Greece, 14Istituto Nazionale Dei Tumori, Milan, Italy, 15Elisabeth Bruyère, Ottawa, ON, Canada, 16Ottawa Hospital, Medical Oncology, Ottawa, ON, Canada

Context: Delirium frequently presents difficult management challenges in the context of goals of care in Palliative Care (PC) settings.

Aims: To formulate an analytic framework (AF) for further research on delirium in PC settings.

Methods: We obtained multidisciplinary input from delirium researchers and knowledge users at the SUNDIPS (studies to understand delirium in palliative settings) international 2-day delirium study planning meeting, performed literature searches, and subsequently availed of epidemiological expertise in developing an AF for delirium research in PC settings.

Results: We formulated an AF to represent the full clinical care pathway of delirium in PC settings. We identified 18 specific questions, forming 3 main groups: the 1st predominantly epidemiological, includes delirium occurrence rates, risk factor evaluation, prevention, screening and diagnosis; the 2nd covers pragmatic management questions; the 3rd relates to the development of predictive models for delirium outcomes. Many questions arise at pivotal decision points in the clinical care pathway where, in the absence of evidence, there are substantive reported differences in management, or where clinical equipoise exists in relation to the choice between alternative management options, for example, outcomes based on current standard management compared to those with management directed by a risk prediction model. We also pre-specified a select number of outcomes that are considered important for decision making, including incremental cost effectiveness and resource utilization.

Conclusions: Using an AF, we identified multiple knowledge gaps in relation to the occurrence rates, assessment, management and outcome prediction of delirium in this population. The knowledge synthesis generated from adequately powered, multicentre studies to answer the framework’s research questions will inform decision-making and policy development regarding delirium detection and management in PC settings.

Abstract number: P346
Abstract type: Poster

Quality Indicators of Structure in Portuguese Palliative Care Services: Evaluation

Capelas M.L.1, Nabal M.2, Coelho S.P.3, Rosa F.C.1
1Catholic University of Portugal, Institute of Health Sciences, Lisboa, Portugal, 2Hospital Universitario Arnaud de Vilanova, UFISS, Lleida, Spain, 3Catholic University of Portugal, Institute of Health Sciences, Porto, Portugal

Introduction: The quality indicators are simple, valid, reliable and useful tools to monitor the quality of care, allowing the identification of improvement areas, and, thereby creating conditions to promote the quality of care. The quality indicators of structure are the first step of these tools and really important to achieve the quality of process and results.

Aim: To evaluate the level of achievement of the Quality Indicators of Structure in Portuguese Palliative Care Services.

Methods: First, we defined the Quality Indicators of Structure through a Delphi Method, conducted in 3 phases with 71 experts. After that an online survey with 17 quality indicators was designed and all the Portuguese palliative care teams were invited to participate in the study.

Results: Only a total of 19 in 37 teams answered to the survey. The level of achievement of these quality indicators ranges between 16 (“provide home care”) and 84% (have the service organization chart, identifying the leaders, describing the hierarchy of elements and their functions) of teams depending of the indicator.

Conclusions: We found in all of these quality indicator areas of clear necessity of improvement, which should be given attention by the teams in order to they can meet the requirements for a quality processes and results.

Abstract number: P347
Abstract type: Poster

Opioid Use in the Last 24 Hours of Life. A Large-scale Retrospective Survey among Belgian Physicians

Chambaere K.1, De Maeseneer D.2, Rottey S.2, Cohen J.1, Van Belle S.1,2, Vander Stichele R.1,3, Deliens L.1,4
1Vrije Universiteit Brussel (VUB) & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Ghent University Hospital, Department of Medical Oncology, Ghent, Belgium, 3Ghent University Hospital, Heymans Institute of Pharmacology, Ghent, Belgium, 4VU University Medical Center, EMGO Institute for Health and Care Research, Amsterdam, Netherlands

Background: Opioids are first choice treatment of severe pain, dyspnea and cough at the end of life. The rate and characteristics of opioid use seem to vary between patient groups and care settings, and administration is often restricted for concerns of respiratory depression and hastened death. Though the double effect principle allows physicians to adequately treat symptoms even when life
shortening can be expected, terminal pain may remain undertreated. This study reports the rate and characteristics of physicians’ use of opioids in patients at the end of life in Flanders, Belgium in 2007.

**Methods:** We performed a postal questionnaire survey among anonymous physicians certifying a large representative sample of Flemish deaths in 2007 (n=6927). Items on opioid use pertained to dose, route, time of initiation, intention and estimated degree of life shortening, if any. Patient and clinical data (age, sex, cause and place of death) were derived from the death certificates.

**Results:** Response rate was 58%. Opioids were administered in the last 24 hours in 62% of non-sudden deaths, most often in younger patients, cancer patients and in hospital. In patients experiencing severe pain the rate was 92% and lowest for patients dying at home and non-cancer patients who were also treated for shorter periods than cancer patients, with lower and steadier doses of mostly short-acting IV opioids. A life shortening intention with opioid use was reported in 20% of cases and was associated with a rise in dosage in the last days of life. Physicians estimated an actual life shortening effect of opioids in 55% of cases.

**Discussion:** This study identified older, non-cancer and out-of-hospital patients as being at higher risk of suboptimal symptom relief at the end of life. Despite evidence to the contrary, life shortening effects of opioids were still expected by physicians, leading to underuse. Palliative care programs should focus on improving knowledge about opioid treatment.

**Abstract number:** P348

**Abstract type:** Poster

**Respecting ‘Significant Others’; End of Life Care and Quality of Dying for Lesbian, Gay, Bisexual and Trans (LGBT) People**

**Patterson A.E., Makita M., Almack K., Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care**

University of Nottingham, School of Health Sciences, Nottingham, United Kingdom

**Aims:** This paper reports interim findings of a study funded by Marie Curie Cancer Care under a call for research into ‘variations in end of life care’. It is capturing experiences of older LGBT people regarding end of life care (EoLC) and quality of dying. In various healthcare settings the presence of ‘significant others’ and access to information, is often managed by staff using ‘next-of-kin’ (NoK) principles. Though widely used, NoK lacks clear definition. Common misunderstandings include that it refers to and needs to be someone related by blood or marriage which can lead to the exclusion of LGBT partners or friends.

**Method:** Using surveys (n=300) and interviews (n=60) it reports interim findings about older LGBT people’s experiences as ‘significant others’ of someone ill or dying.

**Results:** Preliminary analyses suggest that key people in the lives of LGBT people are not consistently included in key decisions; practice around EoLC and quality of dying is variable. NoK issues are being debated within and with the LGBT community but there remains a need for consistency across services so that ‘significant others’ are not sidelined at the very point when their presence is most required and desired. The paper outlines strategies recommended to be used by partners and significant others to navigate difficulties arising in illness or dying. Some people are assertive ensuring that they are recognised as a ‘significant other’; some allow staff to make assumptions about their relationship, talking of “getting away” with being seen as mother and daughter; others felt at the behest of staff for their inclusion.

**Conclusions:** Findings speak to important matters of policy and practice that significantly affect EoLC and quality of dying for LGBT people; highlighting a need to ensure respect and recognition for a wider range of relationships (including friends and same-sex partners) when someone is dying; so moving beyond definitions of ‘kin’ restricted to ties of blood or marriage.

**Abstract number:** P349

**Abstract type:** Poster

**The Experience of the Family of a Child and Teenager Requiring Palliative Care: Fluctuating between Hope and Hopelessness in a World Transformed by Loss**

**Misko M.D., Bousson R.S., Santos M.R.**

University of São Paulo, São Paulo, Brazil

The needs of families and children with life-limiting and life-threatening conditions are unique. The present study aimed to understand the experience of the family of a child and adolescent requiring palliative care. This is a qualitative study using the Symbolic Interactionism and Grounded Theory as theoretical and methodological frameworks, respectively. The study was conducted at the Pain and Palliative Care Outpatient Clinic of a tertiary teaching and research hospital in the city of São Paulo/Brazil. A total of fifteen families of children requiring palliative care took part in the protocol and data were obtained by means of participant observation, semi-structured interviews. The experience is made up of four sub-processes: “Having their lives shattered”; “Dealing with the new situation”; “Recognizing palliative care” and “Learning to live again”, which are continuously interrelated throughout the experience and are the challenges the family has to act upon and devise strategies in order to overcome them. Articulation among these sub-processes allowed the identification of the core
Perceived Role of the Family Physician in Early Palliative Home Care for Patients with a Chronic Life-limiting Disease: A Qualitative Study with Family Physicians, Community Nurses and Patients

Beernaert K.1, Van den Block L.1, Van Thienen K.2, Devroey D.3, Pardon K.1,4, Deliens L.1,4, Cohen J.1

1Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Vrije Universiteit Brussel, Brussels, Belgium, 3Vrije Universiteit Brussel, Department of Family Medicine, Brussels, Belgium, 4Hasselt University, Department of Behavior, Communication and Linguistics, Hasselt, Belgium, 5EMGO Institute for Health and Care Research and Expertise Center for Palliative Care, Department of Public and Occupational Health, VU Medical Center, Amsterdam, Netherlands

Background: Patients with a life-limiting illness may experience palliative care needs. While palliative care (PC) has been mostly regarded as a health care service for the final phase of life, usually provided by specialized health professionals, it is now assumed to be relevant in earlier stages and an important role is assigned to family physicians (FPs). However, the delineation of their role in (early) PC remains vague.

Aim: To explore views from FPs, community nurses and patients about the roles and tasks of the FP in PC for patients with a life-limiting disease from diagnosis onward.

Methods: We performed 18 interviews with patients with cancer, organ failure or dementia and 6 focus groups (4 with FPs and 2 with community nurses). Data were recorded, transcribed and thematic analysis was performed.

Findings: We found four roles for FPs in PC applicable throughout the disease trajectory of their patients:

1) health promoter,
2) care coordinator,
3) communicator and
4) scholar committed to improve PC competencies.

Important tasks were attributed to FPs at different stages:

(1) at diagnosis the FP needs to clarify the specialist’s explanation about the disease and treatments;
(2) during treatment the FP should survey the patient’s body functions and medication use so as to check whether the patient needs further psychosocial, practical, existential care or the family needs support. FPs should start arranging advance directives;
(3) After exacerbations the FP should check if additional home care is needed;
(4) In the terminal phase, the FP should inform the patient and family about the impending death.

The collaboration with palliative home care teams can be initiated by the FP.

Conclusion: FPs, community nurses and patients perceive specific roles and tasks for the FP in PC. Our results help to define the professional competencies needed for early PC, but also help building an integrated model of family practice, hospital practice and PC.

“With these Symptoms You Don’t Expect a Long Life-expectancy”- The Views of Nurses Regarding Life-expectancy as a Prerequisite for Palliative Sedation

Lokker M.E.1,2, Swart S.J.1, Rietjens J.A.C.1, van Zuylen L.2, Perez R.S.G.M.1, van der Heide A.1

1Erasmus Medical Centre, Public Health, Rotterdam, Netherlands, 2Erasmus Medical Centre, Medical Oncology, Rotterdam, Netherlands, 3VU University Medical Centre, Anesthesiology, Amsterdam, Netherlands

Background: Palliative sedation (PS) is, according to the Dutch National Guideline (2009), ‘the intentional lowering of consciousness of a patient in the last phase of life’. The guideline states two criteria for the use of PS: the presence of refractory symptoms leading to unbearable suffering and a life-expectancy that does not exceed one or two weeks. Nurses play an important role in the observations leading to the initiation of PS by physicians, but it is however unclear how they address the life-expectancy criterion.

Aim: The aim of this study is to explore the views of nurses regarding the limited life-expectancy criterion for PS.
Methods: Qualitative interviews were conducted with a sample of nurses with experience with PS from different care settings. Interviews were analysed using the constant comparative method.

Results: Thirty-eight nurses, mostly women, with a mean age of 45 were interviewed. Because nurses usually see patients more often than physicians, they tend to recognize patients’ limited life expectancy before physicians do. A limited life-expectancy was judged as being intrinsically connected to the presence of refractory symptoms. Although nurses stated that PS is not performed in patients with a life-expectancy of more than two weeks, they indicated that when symptoms are so severe that they become refractory a longer life-expectancy should not be a major barrier. Achieving comfort for the patient is key. Initiating PS when life-expectancy is really more than two weeks was however judged as very burdensome for patients and relatives and therefore not a justifiable practice. Concerning the potential life-shortening effect of PS most nurses indicated that they thought PS, by bringing calmness to the patient, actually lengthens life to some extent.

Conclusions: Although a limited life-expectancy is an important prerequisite for the use of PS in The Netherlands, nurses find this criterion secondary to the need to alleviate severe suffering.

Abstract number: P352
Abstract type: Poster

Systematic Review to Develop a Framework for Regional Palliative Care Services

Fassbender K.1, Oleszczuk M.2, Potapov A.2, Fraser M.P.3, Jajszczok M.3

1University of Alberta, Department of Oncology, Edmonton, AB, Canada, 2University of Alberta, Edmonton, AB, Canada, 3Alberta Health Services, Edmonton, AB, Canada

Aims: Interaction between patients in period of hospitalization, despite its importance, is often neglected. The study examines the roles hospitalized patients with cancer play for each other.

Methods: A qualitative study using semi structured in-depth individual interview and purposive sampling was carried out in different wards of a large cancer hospital in Tehran, Iran. The interviews were continued until data saturation. The all interviews were recorded and transcribed verbatim. Then the data were coded and categorized based on subjects and areas using a thematic variable-oriented analysis.

Results: As a total, 12 patients with cancer were interviewed. The study findings indicated 5 themes including causing/ increasing stress (with 9 categories, like death of other patients, amputation regarding other patients because of treatment, other patients’ anxiety, recurrence in other patients, other patients’ words (e.g., telling stories about patients with poor prognosis or occurrence of divorce for patients with breast cancer after performing mastectomy), causing sadness (with the categories of being/ becoming unwell regarding other patients), decreasing stress (with
9 categories, like acting as a source of support, reasoning, joking, telling stories about patients with good prognosis, and so on), giving information to each other (with 3 categories, including giving information on treatment methods, decreasing side effects of applied treatment, and physicians’ knowledge, skills, and practice), and supporting each other spiritually (with 3 categories, including praying for each other, teaching some ways to communicate with God, and emphasizing the importance of having/ relying on religious beliefs).

Conclusion: The study findings indicate that patients with cancer play different roles for each other in hospitalization period, some of which are positive and some negative, roles that sometimes arise due to failure of medical team members to play their roles.

Abstract number: P354
Abstract type: Poster

I, they and we: A Qualitative Study on how Cancer Patients Experience their Illness Trajectory vis-à-vis their Older Parents

Van Humbeeck L.1, Dillen L.2,3, Piers R.4, Verhaeghe S.5, Grypdonck M.4, Van Den Noortgate N.1

1Ghent University Hospital, Department of Geriatrics, Ghent, Belgium, 2Ghent University Hospital, Oncology Centre, Ghent, Belgium, 3Federation of Palliative Care Flanders, Vilvoorde, Belgium, 4Ghent University, Department of Social Health and Nursing Sciences, Ghent, Belgium

Background: In 2011 almost 25,000 Belgians between 40 and 60 years were diagnosed with cancer. With increasing life expectancy the chance augments that these patients still have parents alive. This implies that care for these patients should also take into account the impact cancer may have on (the relationship with) their parents, an often neglected topic. This study therefore wanted to gain insight in how these patients experience cancer vis-à-vis their parents (and environment).

Methods: Interviews with 10 cancer patients between 40 and 60 years were analyzed using the constant comparative method as proposed by Grounded Theory. The analytic process was supported by NVivo 10 and driven by multidisciplinary researcher triangulation.

Results: Within the stories three perspectives emerged with regard to how patients relate to their family members, and their older parents in particular. The we-perspective is characterized by a higher sense of closeness, mutual support, a willingness of both actors to communicate about difficult topics with a sense of humor and pleasure. Such a way of relating led to feeling recognized as person and as patient. In the they-perspective the overall tendency of the patient is to protect his environment, in particular his parents. This mindset is typified by seeing the other as too fragile and by withholding information, leaving both parties on their own. The I-perspective is marked by a patient’s quest for recognition of his everyday struggle with cancer. The patient is highly self-absorbed as his environment either fails to appreciate the impact of the illness or reduces the patient to his sick role.

Conclusion: The data induced a fine-grained understanding of how an adult cancer patient relates to his environment. Depending on the situation, the time frame and the person the patient is talking about, he oscillates between the three perspectives. These insights challenge the often short-sighted and narrow interpretation of family-oriented care.

Abstract number: P355
Abstract type: Poster

Indwelling Pleural Catheter for Ambulatory Care in Patients with Malignant Pleural Effusion

Bielsa S., Torres M., Palma R.M., Porcel J.M.

Arnau de Vilanova University Hospital, Internal Medicine, Lleida, Spain

Background: Indwelling pleural catheters (IPC) offer effective control of malignant pleural effusion (MPE) symptoms. We aim to describe the experience with IPC in our centre, including the satisfaction degree of patients and caregivers.

Methods: Eight consecutive patients (6 males) with MPE treated by the insertion of an IPC in the last year were enrolled in the study. Questioning regarding caregiver’s satisfaction as well as dyspnea and quality of life’s scales were done by telephone interviews.

Results: Six patients with lung adenocarcinomas, 1 breast cancer and 1 renal cell carcinoma, with a mean age of 67 (standard deviation [SD] 13) years were included. Three patients died 78, 39 and 11 days after IPC insertion, while 5 patients are still alive (range 12 to 105 days). The only recorded complication was one case of exit site infection. Only one IPC could be removed in the breast cancer patient after 100 days, when spontaneous pleurodesis was confirmed. Dyspnea relief was complete in 3 and partial in 4 patients. One patient did not reported improvement in their quality of life evaluated by Quality of Life Index (QLI)-Spitzer Index. The median of Spitzer index was 4.6 (SD 0.7) before and 6.6 (SD 1.8) after IPC. Treatment was entirely accomplished at home. Four of the caregivers did not feel confident enough to manage the IPC and, therefore, the primary care nurse did it at home. Four patient’s relatives, who were in charge of IPC care, reported to be well-informed and feel safe, so that they would like to share their experience with other patients or caregivers.

Conclusions: IPC was an effective treatment in improving symptoms and quality of life. Half of the family caregivers accepted to take IPC care, and they feel safe and satisfied.
Abstract number: P356
Abstract type: Poster

Dealing with Issues Faced by Children Suffering with Life Limiting Conditions and their Caregivers: Assessment of Needs and Planning the Interventions

Talawadekar P.P.

Indian Association of Palliative Care, Children’s Palliative Care Project, Mumbai, India

Introduction: The life limiting conditions bring with them pain, discomfort, hospitalizations and emotional, psychological and social challenges for children and also for their families as they cope with taking care of the sick children and coming to terms with their own feelings like sadness, helplessness and anxiety. Children suffering with life limiting conditions have various issues. Assessment of these issues helps in planning the interventions.

Objectives: To evaluate the needs and concerns of Children and caregivers to plan the intervention.

Methods: Around 515 children have been registered in the Children’s Palliative Care Project which has been initiated since 2010 in Maharashtra, India. Most of the children are with conditions other than Cancer. Complete assessment of needs of children and their caregivers are recorded in the case record forms. Focus Group Discussions are held periodically with the caregivers and children with different life limiting conditions to evaluate their concerns and needs. Expert Pediatricians and child psychologists are consulted for planning the interventions. The interventions range from providing individual counseling to rehabilitative aids to children.

Results: The analysis of the need assessment shows that children and the caregivers need on-going counselling, information about the disease and the prognosis, rehabilitation, income generation and spiritual support. The interventions are being planned to provide ‘Quality Care’ in collaboration with a Multidisciplinary team and networking with various agencies and the community.

Conclusions: Assessing the needs of the children and caregivers helps in planning the intervention. The needs differ as per the disease trajectory. Different models of care may be necessary for different needs.

Abstract number: P357
Abstract type: Poster

Measuring Intensity of Care at the End-of-Life: A Systematic Review

Luta X.1 Busato A.2, Stuck A.3, Schoenenberger A.3, Maessen M.2

1University Bern, Bern, Switzerland, 2University Bern, ISPM, Bern, Switzerland, 3University Hospital Bern, Geriatrics, Bern, Switzerland

Research shows that the last months of patient’s lives are often associated with an increased utilization of health services. However, this does not necessarily reflect the most appropriate use of health care for these patients. An increasing number of publications have focused in this field of research. These studies had to take the intensity of the care into account to make valuable comparison in end of life (EOL) care utilisation between diseases groups or between decedents and survivors. The measures of intensity of care are very heterogenetic. Therefore, we performed a systematic review to identify intensity of care measures which are used in EOL care research, assess their frequency of use in journal publications and summarize their features in order to qualitatively assess their validity. We performed a comprehensive search in OVID Medline, Embase and The Cochrane Library of Systematic Reviews to identify all the literature published up to the end of March 2013. The searches included a combination of MeSH terms, text words and synonyms for end of life care and treatment intensity: e.g., ‘end of life care’, ‘terminal illnesses’, ‘aggressiveness of care’, ‘intensity of treatment’ and ‘quantity of care’. We found 26 papers that reported on more than 22 different EOL intensity of care measures. Most studies originated from the USA, studied general or cancer populations and were all except one retrospective cohort studies. These measures can be categorized as: measures based on use of general health services (e.g. number of hospitalizations, days spent in the intensive care, emergency department visits (ER) visits, and hospice days) and procedure-based measures (e.g. intubation or mechanical ventilation). Eight studies provided information of the validity. The available measures should be chosen for research with great care as they are not always validated.

Abstract number: P358
Abstract type: Poster

The Palliative Care Rehabilitation Survey (PCRS), an Instrument to Evaluate the Rehabilitation Priorities in Palliative Care Patients: Italian Validation

Vacchero M., Bocini S., Valle A., Veronese S.

Fondazione FARO Onlus, Torino, Italy

The role of physiotherapy in palliative care is clearly established, but tools to assess its impact on the palliative care outcomes are still lacking. The Italian Palliative Care Association (SICP) recognized the lack of validated tool available in the Italian language. The Palliative Care Rehabilitation Survey (PCRS) was developed and validated in Canada to evaluate the rehabilitation priorities in palliative care patients and seemed a good tool to be adapted in the Italian contest.

Methods: A process of forward-backward translation (Italian-English), content validation, face validity of the PCRS
were undertaken and construct validity is now ongoing in a multicenter prospective study in three specialist palliative care teams (SPCT) in Italy. The whole process followed the recommendations proposed and codified by EORTC.

**Preliminary results:** The translation process was successful and the final version was approved by the original Canadian authors. An independent team of experts (a physiatrist, a palliative care physician and a physiotherapist) provided a positive opinion on the relevance and importance of the items of the PCRS (content validation), verifying that the items cover the entire theoretical definition of the construct, capturing the most important aspects. Face validity was carried on enrolling 12 cancer patients cared by the SPCT that were receiving physiotherapy. Participants reported that the items were clear, understandable, acceptable and not offensive.

The next step of the construct validity has now started. 200 patients in charge of 3 different Italian SPCT are being enrolled. The Italian PCRS is administered to patients receiving palliative physiotherapy in three different sessions together with the Palliative Outcome Score (POS) a validated questionnaire used in the Italian palliative care setting. The results of this phase will be presented at the EAPC conference in Lleida.

**Abstract number:** P359  
**Abstract type:** Poster  
**You Are what you Wear - A Longitudinal Narrative Study of the Experiences of Palliative Caregiving for a Spouse with Dementia in a Nursing Home**  
**Hennings J., Froggatt K., Payne S.**

Lancaster University, Division of Health Research, Lancaster, United Kingdom

**Background:** The natural course of dementia is often protracted and unpredictable, with progressive physical and cognitive decline over many months and years. As a result, a large proportion of people with dementia spend at least the last year of their lives in a long term care setting/nursing home. Placement of one’s spouse into a nursing home marks a change in the caregiving role. Spouse caregivers find their role and status are brought into question towards the preservation of personal identity of the spouse with dementia and the relationship between them.

**Aim:** To explore the caregiving experiences of spouse carers of people with advanced dementia living in nursing homes.

**Study population:** Spouse caregivers (7 women & 3 men) of people with dementia nearing the end of life were recruited from nursing homes in Northern England.

**Design and methods:** Longitudinal narrative study using three sequential interviews and diary accounts.

**Results:** The findings presented here focus on one caregiving activity: attention to the appearance of the spouse. Spouse caregivers work hard to support and maintain the social identity of their partners by paying particular attention to their presentation and bodily appearance. Features of this maintenance work include selection and provision of clothing and grooming equipment. Items are labelled to ensure that they are traceable and worn only by the owner. Maintenance of the ‘usual appearance’ of the person with dementia is a vehicle through which person centred care can be delivered, biographical continuity is maintained and the relationship between spouses is supported.

**Conclusions:** Caregivers’ attention to the appearance of their spouse is one aspect of caregiving which contributes towards the preservation of personal identity of the spouse with dementia and the relationship between them.

**Source of funding:** This work was carried out as part of a project supported by The BUPA Foundation (grant number TBF-PPW09-024).

**Abstract number:** P360  
**Abstract type:** Poster  
**A Nationalwide Survey of the Structure and Activity of Hospital Palliative Care Teams in Japan: Results of the Registration of Japanese Society for Palliative Medicine**  
**Koyama F.1, Abe K.2, Tamura S.3, Komiya S.4, Ogawa A.1, Hama T.6, Tomiyasu S.7, Hashizume T.8**

1Kinki University Hospital Faculty of Medicine, Nursing, Cancer Center, Osakasayama City, Japan, 2Chiba Prefectural University of Health Science, Chiba, Japan, 3Higashi Sapporo Hospital, Sapporo, Japan, 4Yokohama City University Hospital, Yokohama, Japan, 5National Cancer Center Hospital East, Kashiwa City, Japan, 6Osaka Medical Center for Cancer and Cardiovascular Diseases, Osaka, Japan, 7Nagasaki Municipal Hospital, Nagasaki, Japan, 8Hashizume Clinic, Akita, Japan

The Japanese Society for Palliative Medicine (JSPM) started the hospital palliative care team (PCT) registration to clarify the structure and activity in Japan. We present the results of the registration in 2012.

**Methods:** PCT was tentatively defined as a team consisting of palliative care physicians (at least one full-time physician), a nurse and other professionals providing consultation for physical, psychosocial, and spiritual pain of inpatients. The data was collected by the online registration of the JSPM.

**Results:** 485 PCTs were registered in 2012. They were in 378 general hospitals (78%), 84 University hospitals (17%), and 23 cancer care hospitals (5%). The placements of the PCT members were physician (99%), nurse exclusively for PCT (64%), psychiatrist (78%), medical social worker (78%), dietitian (69%), physiotherapist (63%), clinical psychologist (55%) and dentist/dental hygienist...
(13%). 62,217 inpatients (cancer 97%, non-cancer 3%) were consulted. The reasons for the consultation were pain (60%), symptoms (42%), psychological symptoms (33%), family problems (12%), region cooperation (12%), and ethical issues (2%). The performance statuses of the cancer patients were PS0 (5%), PS1 (17%), PS2 (22%), PS3 (30%) and PS4 (26%). The cancer treatment statuses were under pre-treatment (5%), treatment (41%) and post-treatment (54%). The outcomes of the cancer patients were discharge home (35%), hospital death (33%), completion of intervention (9%), transfer to palliative care unit (11%) and transfer to other medical institution (7%).

Conclusion: An advance in the structure and activity of PCTs was observed in the results. We need to improve the quality of PCTs and continue to monitor the national data.

Abstract number: P361
Abstract type: Poster

Patterns of Care and Place of Death of Patients with Metastatic Non-small Cell Lung Cancer

Philip J.1, Hudson P.1, Bostanci A.2, Sundararajan V.3, Palliative Care Research Network of Victoria

1University of Melbourne, Centre for Palliative Care Education & Research, Fitzroy, Australia, 2St Vincent’s Hospital Melbourne, Centre for Palliative Care, Fitzroy, Australia, 3University of Melbourne, Department of Medicine, Melbourne, Australia

Despite improvements in survival with emerging therapies, the development of metastatic non-small cell lung cancer (NSCLC) is associated with a median survival of less than 12 months. Attention to symptoms and quality of life concerns therefore form the mainstay of care for most patients. The early introduction of palliative care consultation for those with metastatic NSCLC has been associated with improved quality of life and reduced depression, and therefore recommended as standard care by institutional cancer bodies for this patient group.

Aims: We sought to describe the care patterns, in particular the receipt of palliative care, and the place of death of this diagnostic group in Victoria.

Methods: Retrospective cohort analysis was undertaken using linked registry and administrative case-mix datasets for a cohort of Victorian patients with NSCLC from diagnosis of metastatic disease until death between 1 July 2003 to 30 June 2010.

Results: 8624 incident metastatic NSCLC and 64% were male. Median survival from diagnosis of metastases was 72 days, with 75% surviving at least 25 days and 25% nearly 7 months or more. Receipt of supportive care declined over the trajectory from 60% at diagnosis to 46% during the death admission; palliative care consultation increased from 26% to 56%, and use of a hospice bed from 14% to 38%. Thirty percent did not have a palliative care consultation. Only 17% of patients died outside of hospital, 38% in a palliative care bed/hospice setting and 45% in an acute hospital bed.

Conclusions: Despite a poor overall survival, palliative and supportive care are not universally accessed by patients with metastatic NSCLC.

Abstract number: P362
Abstract type: Poster

Prevalence of Symptoms among Patients with Cancer in Yemen

Aklan N.A.1, Al-Alimi K.A.1, Alsirafy S.A.2

1National Oncology Center, Sana’a, Yemen, 2Kasr Al-Ainy School of Medicine, Palliative Medicine Unit, Kasr Al-Ainy Center of Clinical Oncology & Nuclear Medicine, Cairo, Egypt

Introduction: The majority of cancer patients in Yemen present in an advanced stage. For them, palliative care (PC) and cancer pain relief are considered a realistic treatment. However, regarding PC development, Yemen is in the stage of “No known activity”. Similarly, cancer pain is not adequately controlled as indicated by the very low opioid consumption figures. Research to explore the PC needs of Yemeni cancer patients is needed.

Methods: We prospectively assessed the prevalence and severity of symptoms in 50 cancer patients using two methods. First, we asked the patients an open question about the symptoms they have. Second, we systematically assessed 20 physical symptoms commonly encountered in cancer patients.

Results: The median number of symptoms per patient was 1 (range: 0-4) in response to the open question and 7 (range: 0-16) in response to systematic assessment. The number of symptom entries was 81 (74% of them moderate-severe) in response to the open question and was 371 (57% of them moderate-severe) in response to systematic assessment. Pain was the most common (56%) symptom in response to the open question, the most common (42%) symptom to be reported as most distressing, and the least symptom to be under-reported on systematic assessment. In 70% of patients with pain, it was of moderate/severe degree. The most common symptoms with systematic assessment were fatigue/weakness (78%), weight loss (62%) and pain (60%). The most common symptoms not reported in response to the open question and found on systematic assessment were weight loss (62%), taste changes (52%), early satiety (28%) and constipation (28%).

Conclusion: This is the first study to illustrate the high symptom burden among Yemeni cancer patients. There is an urgent need to develop PC and to improve cancer pain control in order to relieve the suffering of cancer patients.
in Yemen. An open question is not enough to detect many symptoms and systematic assessment of symptoms is needed.

Abstract number: P363
Abstract type: Poster

Comparison of Topics Raised by Service Commissioners, Providers and Users in a Health Technology Assessment of Palliative Care in Six European Countries


1University of Sheffield, SchHARR, Sheffield, United Kingdom, 2University of Sheffield, School of Nursing and Midwifery, Sheffield, United Kingdom, 3University of Auckland, School of Nursing, Auckland, New Zealand, 4Radboud University Medical Centre, Department of Primary and Community Care, Nijmegen, Netherlands, 5ECORYS Nederland B.V., Health Unit, Rotterdam, Netherlands, 6University of Bremen, Department of Health Services Research, Bremen, Germany, 7University of Oslo, Institute for Health and Society, Oslo, Norway, 8Università Cattolica del Sacro Cuore, Institute of Bioethics, Rome, Italy, 9Poznan University of Medical Sciences, Department of Palliative Medicine, Poznan, Poland

Background: Many people with life-limiting illnesses benefit from palliative care but services vary widely across Europe. An EU-funded project focused on developing new Health Technology Assessment (HTA) methods for assessing complex health technologies has been established using a palliative care as a case study.

Aims: To compare topics for the scope identified by stakeholders in palliative care systems across six European countries.

Methods: Stakeholders (service commissioners, providers and users) in six countries (England, Germany, Italy, Netherlands, Norway and Poland) were invited to contribute either using either a qualitative research approach or seeking stakeholder views as research partners. Using a qualitative approach, 40 individual, face-face interviews were conducted and analysed thematically. As research partners, an adapted version of the EUnetHTA core model guided 60 face-face discussions. Thematic analysis and conceptual mapping were used to identify key topics.

Findings: Although specific problems relating to common topics differ for each country, most stakeholders raised concerns about the availability and accessibility of palliative care services and resources. Additional concerns exist about palliative care provision for non-malignant diseases, over treatment at the end of life and the costs of palliative care. Ethical concerns about autonomy, whole truth telling to patients and decision making were also identified. Social awareness of palliative care is also a concern.

Discussion: Despite complex differences in the context and provision of palliative care across Europe, common topics relating to palliative care were identified. However, the nature and manifestation of some topics are country-specific.

Conclusions: Despite differences in palliative care provision across Europe, common topics for an HTA exist. Stakeholder involvement to identify both country-specific and common topics enhances the cultural sensitivity of the project scope.

Abstract number: P364
Abstract type: Poster

Identification of the Psychosocial Needs of End-of-life Patients: Developing the ENP-E Tool

Limonero J.T.1, Mateo D.2, Maté-Méndez J.3, González-Barboteo J.4, Barbero E.5, Martínez M.5, Beas E.2, Buisan M.6, de Pascual V.5, Gómez-Battiste X.2

1Universitat Autònoma de Barcelona, Stress and Health Research Group, Faculty of Psychology, Bellaterra (Cerdanyola del Vallès), Spain, 2The ‘Qualy’ Observatory, WHO Collaborating Centre for Public Health Palliative Care Programmes, Institut Catalá d’ Oncologia, Chair of Palliative Care, University of Vic, L’Hospitalet de Llobregat, Spain, 3Hospital Duran i Reynals, Institut Catalá d’ Oncologia, Psycho-Oncology Unit, Stress and Health Research Group, Faculty of Psychology, Universitat Autònoma de Barcelona, L’Hospitalet de Llobregat, Spain, 4Palliative Care Service, Institut Catalá Oncologia, Bellvitge Biomedical Research Institute (IDIBELL), L’Hospitalet de Llobregat, Spain, 5Hospital Duran i Reynals, Institut Catalá d’ Oncologia, Psycho-Oncology Unit, L’Hospitalet de Llobregat, Spain, 6La Caixa’ Foundation, Barcelona, Spain

Background: To provide palliative care (PC) to end-of-life patients (EoLP) is necessary to know which aspects of psychosocial nature can contribute to well-being of these patients, and for this, we must have reliable assessment tools, simple and specific for use in this area. This project is developed within the programme for the comprehensive care of persons with advanced diseases in Spain.

Aim: To develop an instrument for assessing the psychosocial needs of EoLP (ENP-E) in PC units and to analyze the content validity.

Methods: Development of the instrument. Expert panel revision. Instrument developed has been evaluated by a logical-rational process, the clarity and acceptability of
Is Incorporation of Workshops in Medical Simulation Center for the Teaching of the Palliative Medicine Subject in the Degree of Medicine

Martínez M.1, Urdiroz J.1, Larumbe A.1, Vaquero J.1, Mañeru G.1, Centeno C.1,3

1Unidad de Medicina Paliativa, Clínica Universidad de Navarra, Pamplona, Spain, 2Universidad de Navarra, Pamplona, Spain, 3Universidad de Navarra, ICS Instituto Cultura y Sociedad, Pamplona, Spain

Background: Palliative medicine (PM) education requires appropriate methods to teach new skills and attitudes that a physician should incorporate. At the University of Navarra PM is mandatory subject. As innovation educational experience we have designed two workshops in the medical simulation centre incorporating to our PM course their technical and architectural advantages: clinical scenarios, audio video system and closed circuit, multiple rooms that accept different configurations connected, etc. We present results of the first year of teaching.

Methodology: Narrative of the teaching experience of the two workshop and descriptive statistical analysis of the evaluation survey were completed at the end of the workshops. The tool has 11 closed questions to rate objectives, teachers, difficulty of the practice and utility of the seminars (numerical scale 0-5) and an additional open question asking suggestions.

Results: The workshops were on “communication skills” (COM) and “subcutaneous use of medication in PC” (SC) and were attended by 180 students of the sixth year. Each workshop was repeated three times with 60 students each, divided in 4 groups coordinated by facilitators. Scenarios were: information on the progression of the disease and difficult questions for COM, subcutaneous elysis, subcutaneous hydration, and use of different drugs by sc way for SC. The response rate of survey was of 63% for COM and 64% for SC. The overall satisfaction was 4.6/5 for COM and 4.2/5 for SC. The knowledge and attitude of teachers were rated over 4.5. Students appreciated the appropriateness of the teaching methods and the importance of what they have learned. They find the experience useful, and they would like to have the opportunity to practice more.

Discussion: This pilot experience was positive. The chances of use medical simulation centre could improve teaching of PM.

Background: Palliative Medicine Education in European Universities. A Proposal for Ranking Status

Centeno C.1, Carrasco J.M.1, Garralda E.1, Filbet M.2, Ellershaw J.3, Lynch T.1, Elsner F.4

1University of Navarra, Institute for Culture and Society, Pamplona, Spain, 2University of Lyon, Lyon, France, 3University of Liverpool, Liverpool, United Kingdom, 4Aachen University, Aachen, Germany

Background: Palliative Medicine (PM) has arisen generally outside the medical school curriculums, but it seems that something is changing in recent years.

Aim: To propose a ranking of the PM teaching status in the university, throughout the European WHO region (53 countries), using data from the EAPC Atlas in 2013.

Method: National experts reviewed the data of the Atlas with a fine-tuning on-line process. Three indicators were defined to assess the status of PM teaching in each country: proportion of medical schools with some PM teaching (MS), degree of obligation (DO), number of professors in PM (NP). Through a nominal group (method for consensus), 6 members of the EAPC Task Force on the Development of PC in Europe and Physician Training granted weights to each indicator. Their relevance was voted in a 0-10 scale in two rounds, and a score 0-100 points (pt) was defined. The resultant score was applied to each country in order to obtain a rank.
Implementation of Liverpool Care Pathway for the Dying Patient (LCP) in Primary Health Care in Norway

Driller B.1, Karlsen L.2, Winsjansen B.3, Strømskag K.E.4, Research Group. Care and Treatment of Critically Ill and Dying Patients, Møre og Romsdal HF, Molde University College

1Møre og Romsdal HF, Cancer Department, Ålesund, Norway, 2Eide Municipality, Care Home, Eide, Norway, 3Fræna Municipality, Home Care Service, Elnesvågen, Norway, 4Norwegian University of Science and Technology, Faculty of Medicine, Trondheim, Norway

Background: The Liverpool care pathway (LCP) provides evidence-based guidance on comfort measures, anticipatory prescribing of medication, discontinuation of inappropriate interventions, psychological and spiritual care and family support in end-of-life care.

Aims: We explored the benefits and barriers to the implementation of LCP in primary health care with focus on documentation of care and end-of-life care specific educational needs.

Methods: The communities Eide, Fræna and Sunndal in Møre og Romsdal have four care homes with short-term and long-term wards and three home care services involved in end-of-life care. Before implementing the LCP we made a base review of the documentation of 66 patients that died between October 2010 and March 2012. The LCP was implemented with training for the nurses and general practitioners in May and June 2012. After the first 5-10 deaths with LCP there was another round with training including an assessment of experiences the professional caregivers had with LCP. In March 2013 we reviewed the documentation of all patient deaths (n=39) between September 2012 and February 2013 whether or not with LCP and assessed the caregiver experiences by interviews.

Results: 77% died within LCP. 62% of them were non-cancer patients. The documentation was more comprehensive. The majority of the staff felt that the LCP structured patient care better, supported problem anticipation, encouraged security by better advance care and enhanced multidisciplinary communication and care of relatives.

Discussion: The LCP facilitates comprehensive documentation. High-quality documentation provides practice examples for education and further professionalization. Ongoing education on the use of LCP is important.

Conclusion: An interprofessional, multidisciplinary approach towards education and communication at all levels of care is needed to meet the complex needs of the dying patient and to improve staff confidence in delivering end-of-life care with LCP.
secure relationship to help families to deal with their loss. Knowledge about the effect of family relationships with nurses in end of life situations of children in palliative care can help health professionals to hone and refine programs and services for these children and their families, thereby improving the quality of care they receive and the elaboration of mourning.

Abstract number: P369
Abstract type: Poster

The Benefits of Hospital Admissions for Patients with Palliative Care Needs in New Zealand

Robinson J.1, Gott M.1, Gardiner C.1, Ingleton C.2
1University of Auckland, Faculty of Medical and Health Sciences, Auckland, New Zealand, 2University of Sheffield, School of Nursing, Sheffield, United Kingdom

Aim: To explore the benefits of hospital admissions for patients with palliative care needs in New Zealand.

Study population: Adult patients admitted to an acute hospital who meet one of the Gold Standards Framework Prognostic Indicators for palliative care need.

Methods: Data was collected using semi structured interviews. Participants were interviewed twice. The initial interview was carried out on the ward within two days of admission to explore reasons for admission and participants expectations of care. A further interview was completed within a week of discharge at the participant’s place of residence or place of care. A process of thematic analysis was used to examine interview data.

Results: Preliminary analyses of the data have identified several emerging themes. Although participants discussed negative aspects of their hospital admission, all were able to identify positive dimensions and when asked about their preference for care many participants preferred to come to hospital rather than receive the necessary care at home. Benefits of the admission included gaining a better understanding of their illness, feeling ‘safe’ and achieving relief from intractable symptoms. Participants also felt that family members became anxious when they become unwell at home and expressed ‘relief’ when they were admitted to hospital.

Conclusion: These findings suggest that while many patients with palliative care needs continue to experience a certain sense of burden during an admission to hospital, this is often tempered with perceptions of benefit for both the patient and family. Further research exploring the experiences of palliative care in an acute hospital setting is needed to inform policy and practice and to ensure that patients with palliative care needs are able to access appropriate and timely hospital care.

Abstract number: P370
Abstract type: Poster

Hip Fractures: An Indicator of Serious Illness among Older Adults

Ritchie C.S.1,2, Kelley A.3, Cenzer I.4, Wallhagen M.4, Smith A.1,2, Covinsky K.2,4
1University of California San Francisco, Medicine, San Francisco, CA, United States, 2San Francisco VA Medical Center, San Francisco, CA, United States, 3Mount Sinai School of Medicine, Brookdale Department of Geriatrics and Palliative Medicine, New York, NY, United States, 4University of California San Francisco, San Francisco, CA, United States

Background: Over 1.6 million older adults sustain hip fractures annually. Hip fractures contribute to accelerated functional decline and increased mortality. While we understand the negative impact of hip fractures once they have occurred, the proportion with high levels of morbidity prior to experiencing hip fracture is less well understood.

Methods: We used data from the Health and Retirement Study, a longitudinal survey of older adults, linked to Medicare claims to characterize a representative cohort of older adults with hip fracture (January 1992 through December 2008). Characteristics of the population prior to hip fracture were drawn from the interview before hip fracture (mean 13 months, range 0-30 months). Features used to indicate serious illness included functional vulnerability (dependence in instrumental or basic activities of daily living [IADLs and ADLs, respectively], NH residence, caregiver use) and medical vulnerability (multimorbidity, moderate to severe pain, high health care utilization and mortality risk).

Results: 800 older adults experienced a hip fracture during the study period. Prior to hip fracture, 9 percent already resided in a nursing home. Of those living at home, over 1/2 had difficulty with 1 or more IADLs, 21% were dependent in 1 or more ADLs, and 15% required > 8 hours/day of assistance. About 1/4 screened positive for depression, 27% reported moderate or severe pain and 36% had 3 or more chronic conditions. Twenty one percent had at least 2 or more hospitalizations in the previous 12 months, and 31% had a high mortality risk score.

Conclusion: Most models of hip fracture care emphasize a curative or rehabilitative approach. A significant proportion of older adults have evidence of functional and medical vulnerability prior to hip fracture. For these individuals, integration of palliative care services into post-hip fracture care will be important for optimizing quality of life and addressing their high levels of morbidity.
Advancing the Concept of Supportive Care for Frail Older People in Acute Care Settings

Nicholson C.1, Morrow E.2, Hicks A.3, Fitzpatrick J.3

1King’s College London, National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, London, United Kingdom, 2Formerly King’s College London, National Nursing Research Unit, Florence Nightingale School of Nursing and Midwifery, London, United Kingdom, 3King’s College London, Florence Nightingale School of Nursing and Midwifery, London, United Kingdom

This paper reports findings from Phase One of a four-phased mixed methods study to establish the Supportive Care (SC) needs of frail elders and to develop an intervention within UK hospitals. Primarily developed within cancer services, SC assists patients and carers to maximize quality of life throughout a life-limiting illness. Despite the evident limits to their lives, the relevance of SC to frail elders is not often recognized.

Aim: Phase One establishes with stakeholders including patients, carers, and clinicians, the key components of SC for frail elders in hospital.

Design: A concept advancement of SC to frail elders using a thematic literature review and in-depth interviews was carried out over 10 months. The literature search drew on Penrod and Hupcey’s (2006) principle-based concept analysis. Searches covered over 26,000 articles, including duplicates - 42 were retained. This built an understanding of the concept through an iterative process of exploration, evidence gathering, cross checking and interpretation. To strengthen the consistency and coherence of the concept of SC in relation to the care of frail elders, in-depth interviews were carried with a purposive sample of 18 clinicians and academics interested in Supportive Care for frail elders. These interviews were subject to independent coding by two researchers prior to thematic analysis. The focus was practice at ward level. The resultant findings are currently subject to a modified Delphi study.

Results and interpretation: Ten components of Supportive Care, illuminating the multi-faced and uncertain nature of frailty, were identified and have been used to devise a working model of SC. The SC model offers a focus on outcomes and processes of care for frail elders living and dying over time often outside prognostic categories. The model aims to provide a helpful context to support both quality of life and quality of care in acute settings.

Funding: The study is funded through a NIHR PD Fellowship.
Background: Fatigue is one of the most common adverse effects of sunitinib treatment for renal cell carcinoma (RCC) and may potentially be reflected by associated changes in the motor cortex (M1). Transcranial Magnetic Stimulation (TMS) is a noninvasive method to study maps of muscles in M1. The aim was to assess whether sunitinib-induced fatigue was associated with changes in the map of a hand muscle in M1.

Methods: Patients treated with sunitinib for metastatic RCC were enrolled and were tested before and after 4 weeks of treatment with sunitinib 50mg QD. Strength was measured as maximum voluntary contraction (MVC) of the muscle. Fatigue was recorded with Brief Fatigue Inventory (BFI), and as duration that patient could sustain contraction up to 30% MVC. TMS was applied in a 7x5 grid (1 cm resolution) while electromyography was collected from the muscle. Variables included:

1) area of map in M1, no. of sites evoking muscle response,
2) map excitability, sum of normalized responses, and
3) center of Gravity (CoG), locus of response-weighted center of map.

Results: Six patients have been analyzed. Average BFI score increased (p = .043), while MVC significantly decreased for 5 subjects who reported worsened fatigue on BFI (p=.043), and did not decrease for the one subject without fatigue. There was no significant change in duration of sustaining contraction. Area of map decreased (p=.07), but excitability did not. Center of gravity shifted antero-medially (p=.028).

Conclusion: Four weeks of sunitinib treatment increases perception of fatigue and reduces muscle strength. These changes occur in parallel with reorganization of the muscle’s map in M1. The location of the map shifted antero-medially, suggesting spread to higher motor regions in order to maintain cortical output to muscle. Future studies could image connectivity of M1 with higher motor and prefrontal regions to elucidate comprehensive correlates of sunitinib-related fatigue.
Lung cancer is an unforgiving illness with most patients diagnosed in the advanced stages of disease. Little is known about the range or challenges of end-of-life care decisions such patients encounter.

This study aims to identify and explore the main influences on decision-making by patients diagnosed with advanced lung cancer across one area of Northern Ireland.

Qualitative data were obtained during two individual interviews (4 weeks apart) lasting 28-72 minutes (mean 48 minutes) with 12 patients (6 male, 6 female) diagnosed with primary lung cancer and known to community palliative care. The Llewellyn-Thomas (1995) decision-making framework informed data collection. Data were analysed using Interpretative Phenomenological Analysis (Smith et al., 2009) and narrative analysis (Frank, 1995).

Emergent themes mirrored the illness journey and Frank’s narrative analysis:

1. Beginnings: There’s something not right, receiving/breaking bad news, emotional responses and no way back;
2. Middles: Treatment decision-making, impact of treatment on quality of life, impact of illness on self, impact of illness on social relations and impact on engagement with the physical world;
3. Endings: Preferred priorities for care, a good death, legacy, coping patterns and funeral wishes.

Three cross-cutting themes were common to all patients: preciousness of time regarding diagnosis, treatment and prognosis; importance of skilful communication, offering protection and using appropriate language; and maintenance of hope. This study offers insight into patients’ experiences of living with advanced lung cancer, their daily navigation of decisions that surpassed our assumptions, and patient expectations of professionals. Despite knowing their inevitable fate, findings highlighted the importance of maintaining hope and exploring futures. Messages may inform end-of-life care policy initiatives and professional practice within palliative and end-of-life care. Irish Hospice Foundation funded.

**Abstract number:** P376

**Abstract type:** Poster

**Social Inequality in GPs’ End-of-Life Care among Cancer Patients?**

**Neergaard M.A.,** 1 Olesen F., 2 Sondergaard J., 3 Jensen A.B. 4

1Aarhus University Hospital, Palliative Team, Aarhus, Denmark, 2Aarhus University, Research Unit for General Practice, Aarhus, Denmark, 3University of Southern Denmark, Research Unit for General Practice, Odense, Denmark, 4Aarhus University Hospital, Department of Onkology, Aarhus, Denmark

**Background:** Involvement and contact with general practitioners (GPs) in end-of-life seems to facilitate fulfilment of patients’ preferences for dying at home. Equality in care is seen as important, but little is known about whether GPs’ contact patterns in end-of-life care is socio-economically equal.

**Aim:** To analyse associations between GP contact patterns in end-of-life care and socio-economic characteristics of Danish cancer patients.

**Method:** A population-based, cross-sectional register study comprising 599 adults who had died of cancer from 1 March to 30 November 2006 in Aarhus County, Denmark. Based on unique personal identifier numbers, register data were retrieved on socio-economic characteristics and GPs’ services. Data were analysed using Generalised linear regression models.

**Results:** The study showed that having low income (Prevalence Ratio (PR): 1.18 (95% CI: 1.03;1.35)) or being immigrants or descendent of such (PR: 1.17 (95% CI: 1.02;1.35)) were positively associated with GP face-to-face contacts (including both seeing the patient in the consultation and at home) in the last 90 days of the patients’ lives. Furthermore, patients living in large communities (≥ 100,000 inhabitants) had a lower likelihood of having GP face-to-face contacts in all (PR: 0.85 (95% CI: 0.77;0.95)) than patients living in small communities (< 10,000 inhabitants).

**Conclusion:** The study indicates favouritism towards economically deprived patients and positive discrimination toward immigrants/descendants concerning GP contacts. Furthermore, the study indicates cultural differences concerning the GPs’ contacts with their patients depending on the size of the community. To determine the underlying reason for these differences further research is needed where the actual needs of the individual patients is taken into account. Needs that are so far is not yet documented in health care registers.

**Abstract number:** P377

**Abstract type:** Poster

**Development and Testing of a Dignity Care Intervention for Use by Community Nurses to Deliver an Evidence Based Approach to Providing Person Centred Dignity Conserving, Palliative Care to Patients and their Families Receiving End-of-Life Care at Home**

**Johnston B.M.,** 1, 2 Buchanan D., 2 Andrew J., 2 Papadopoulou C., 1 Ostlund U. 4

1University of Nottingham, Sue Ryder Care Centre Research Group, Nottingham, United Kingdom, 2NHS Tayside, Palliative Care, Dundee, United Kingdom, 3University of Dundee, School of Nursing and Midwifery, 4Karolinska Institutet, Nursing, Stockholm, Sweden
Background: This study has developed, implemented and tested a complex intervention, the Dignity Care Intervention (DCI), providing an evidence based approach to providing person centred dignity conserving, palliative care to patients and their families receiving end-of-life care at home by community nurses (CNs). 

Aims: The primary aim was to explore the feasibility and acceptability of the DCI from the patients’ and carers’ perspectives. A secondary aim was to explore the ability of the DCI to allow individual dignity related needs to be assessed and subsequently met, by community nurses.

Methods: A qualitative, evaluation design underpinned by the philosophy of Merlau-Ponty was employed for the evaluation of the DCI. Data collection included focus groups with CNs (39) at the beginning and end of the study; individual interviews with patients (30); informal carers (4). Interview data were analysed using framework analysis.

Results: The intervention enabled nurses to assess key concerns, and deliver evidence based care actions. Analysis of the interviews resulted in four theme categories; Experience of DCP; responding to my illness concerns, how illness affects me as a person and how illness concerns affect my relationships. Patients and family members identified that the use of the DCI gave them the opportunity to discuss concerns that might have not been raised otherwise.

Conclusions: The DCI helps CNs deliver psychosocial care, previously identified as a difficult area for CNs in practice. CNs use of the DCI helps patients receive individualised care, which directly relates to the issues they have identified as most distressing and/or important and their preferred measures to address these issues, allowing increased information and support to carers. The use of the Patient Dignity Inventory to assess key concerns facilitated patients communication of their dignity-related needs to community nurses.

Abstract number: P378
Abstract type: Poster

Evaluating the Impact of a Volunteer Delivered Befriending Network for People with Life Limiting Conditions: A Qualitative Study

Gardiner C.1, Barnes S.2

1University of Auckland, School of Nursing, Auckland, New Zealand, 2The University of Sheffield, School of Health & Related Research (ScHARR), Sheffield, United Kingdom

Background: Volunteer services are under-utilised in end of life care, despite their significant capacity for reducing statutory resource use and improving patient outcomes. A befriending service is a volunteer delivered companionship service, co-ordinated by a central agency. This study describes the evaluation of a Befriending Network for people with life limiting conditions in the UK, co-ordinated and funded by Age UK Oxfordshire.

Aim: To explore the experience of befriending recipients and their informal carers regarding use of the Befriending Network, and their satisfaction with the network.

Methods: Qualitative semi-structured interviews were held with a purposively selected sample of 12 befriending recipients and family carers. Recipients had a range of life limiting conditions, and varying life expectancy. Interviews were recorded and analysed using the principles of thematic analysis.

Results: All the befriending recipients interviewed were satisfied with the service and felt that it impacted positively on their quality of life, with the impact often felt across the wider family. For many befriending recipients, the network was described as a ‘life-line’. The findings also suggested that in some instances, the presence of a befriending volunteer reduced the need for other services such as social services, formal psychological support, or respite care.

Conclusion: Volunteer delivered Befriending Networks offer a valuable friendship service, in addition volunteers can provide significant emotional, psychological, practical, and social support. The impact of Befriending Networks on resource spend in other areas of the health and social care sector may be substantial, and further research is warranted to explore this further.

Funding: This evaluation was funded by Age UK Oxfordshire

Abstract number: P379
Abstract type: Poster

What Are the Psychosocial Effects of Moving to a New Hospice Building?

Murray J.1, Armour K.2, Meystre C.J.N.2

1Marie Curie Hospice Solihull, Cancer Care, Birmingham, United Kingdom, 2Marie Curie Hospice Solihull, Birmingham, United Kingdom

Aim: To investigate psychosocial aspects of relocating hospice using attachment theory (AT).

Background: Mental representations of self and other are formed by our primary relationship and inform subsequent relationships and responses to life events. Attachment style (AS) is predictive for staff responses to change of work relocation, a stress on layout and functional delivery in palliative care where memories matter. AT links place to identity, providing insight into the stress of moving. Our 17 bedded hospice with daycare and community services relocated to a new unit from a building occupied for 50 years. Project planning managed practical issues but psychosocial aspects were undefined.
Methodology: After ethics review hospice personnel were invited to anonymously complete a modified adult attachment questionnaire with mixed methods quantitative and semi-structured qualitative elements. Gender was not recorded. Staff and volunteer views had no statistical differences or conflicting themes and are reported together.

Results: 42 questionnaires (31%) were returned: 34 staff, 8 volunteers. Median service 6.2 years; (range <1 to 23). Most had secure AS. Neither anxiety nor avoidance scores related to length of service. Higher anxiety scores correlated with grieving (p< 0.003) and feeling it was wrong to sell the old hospice (p< 0.05). Those staff with high anxiety and avoidance scores were less likely to want to move (p< 0.05). Thematic analysis revealed major themes: memories and remembrance; atmosphere of care; experiences with patients, families and colleagues; positivity about new environment; anticipatory grief; need of a fitting end.

Conclusions: Attachment style is stable despite hospice work. Higher staff anxiety scores had more negative emotional responses of anticipatory grief over memories not attachment to the building. Mixed method studies are powerful for complex phenomena. The study captured a unique event. Relocation plans should address psychosocial responses.

Abstract number: P380
Abstract type: Poster
Prescribing for Palliative Care Patients with Renal Impairment

Marie Curie Palliative Care Institute Liverpool (MCPcil), Dept of Molecular & Clinical Cancer Medicine, Liverpool, United Kingdom

Aims: Renal impairment is an increasingly common problem within the palliative care population. The symptom burden in this group of patients is high, with associated increased morbidity and mortality.

A re-audit was undertaken of existing regional guidelines concerning prescribing in renal impairment, with two additional surveys of healthcare professionals (HCPs) working within palliative care and renal specialists to evaluate perceptions of practice.

Methods: The audit consisted of three parts a) a web-based survey determining HCPs perceptions of practice, b) a case note audit determining actual practice, c) a web-based survey of perceptions of practice amongst renal specialists.

Results:

a) 83 professionals completed the survey of practice. In moderate to severe renal impairment oxycodone was the most commonly chosen first line PRN opiate for opiate naïve patients. There was variability in choice of background opiate in patients with renal impairment.

b) 51 professionals completed the case note audit. 60% of patients included in the survey had CKD, with a mean urea of 17mmol/l and mean creatinine of 239µmol/l. 86% of patients were prescribed a PRN opiate, of which 72% were prescribed oxycodone and 22% were prescribed morphine.

c) 11 renal specialists completed the survey of practice. Morphine was chosen as a first line PRN opiate more commonly than amongst palliative care HCPs.

Conclusion: There remains a lack of robust evidence regarding the use of palliative care drugs such as opiates in patients with renal impairment. In addition there is variability in prescribing practice both within palliative care HCPs as a group, and also renal specialists. Confidence is low amongst palliative care HCPs particularly when prescribing for patients undergoing renal replacement therapy.

Following the results of the audit, regional guidelines for prescribing in renal impairment have subsequently been revised.
nurses for 83 beds. Only 83 NH had a night nurse. The total number of death among all the nursing home was 8573 for 2011, with a mean number of 19 deaths by NH. The main cause of death was dementia 41%, whereas cancer related death was only 13%. Mostly deaths occur in the nursing home (14/19; 74%).

The majority of NH has access to a specialist palliative care support team 319 (69%). The respondent declared using a pain assessment tool for 422 (91%), and only 174 (37%) were able to provide the opioid consumption. We found that 299 (64%) provide systematic information to patient and their family regarding advances directives. The factor significantly associated with death in the nursing home, was the night nurse: 27 deaths occurs in NH if there is a night nurse versus 12 (p < 0,001).

**Conclusion:** The location of the frail elderly death is a major health issue needed to be addressed. Our results suggest that one nurse at night could decrease the number of death in the hospital.

**Abstract number:** P382
**Abstract type:** Poster

**Preparation in the Event of Terminal Haemorrhage in Head and Neck Cancer Units in the UK - Questionnaire Study**

**O’Brien A.L.**, **Husbands E.**, **Perkins P.**

1Gloucestershire Hospitals NHS Trust, Palliative Care, Gloucester, United Kingdom, 2Gloucestershire Hospitals NHS Foundation Trust, Palliative Care, Gloucester, United Kingdom, 3Sue Ryder Leckhampton Court Hospice, Cheltenham, United Kingdom

**Aim:** To understand how Head and Neck multidisciplinary teams across the UK prepare for the possibility of terminal haemorrhage.

**Method:** Online questionnaire with reminders sent to Head and Neck Oncology Nurses in the UK registered with BAHNON.

**Results:** The questionnaire response rate was 42% representing 25 head and neck centres across the UK. There was considerable variation in annual case load between 40 - 650 patients per centre. 282 patients identified were at risk of terminal haemorrhage and there 58 actual events, representing a 20% event rate. 25% of terminal haemorrhages that occurred were not predicted, 59% of events occurred in hospital, 27% at home, 9% in a hospice. 80% of centres proactively identify risk and offer information, 8% do neither. The perceived likelihood of outcome is the most cited factor in prompting discussion surrounding preparation. The majority of discussions are led by specialist head and neck cancer nurses. 21% of centres have no formal guidelines in place for preparation in the event of terminal haemorrhage.

**Conclusion:** There is a significant variation between centres in their preparation for terminal haemorrhage, with no clear adherence to local guidelines in some centres, or the absence of local guidelines entirely. That numbers of patients predicted to be at risk varies significantly and is not proportional to centre size suggesting significant differences in frequency or method of risk stratification. Our data suggests a higher frequency of terminal haemorrhage than previously thought. This work provides significant new information as to how UK centres prepare for the event of terminal haemorrhage from the point of view of the health professional, as well as providing guidance on the numbers of patients that this potentially affects.

**Abstract number:** P383
**Abstract type:** Poster

**Transition from Children’s to Adult Services for Young People with Life-limiting Conditions: Findings from a Questionnaire Survey in Northern Ireland**

**Kerr H.**, **O’Halloran P.**, **Nicholl H.**, **Price J.**

1Queen’s University, School of Nursing and Midwifery, Belfast, United Kingdom, 2Trinity College Dublin, School of Nursing and Midwifery, Dublin, Ireland

**Research aims:** To describe service provision for the transition from children’s to adult services for young people with life-limiting conditions in Northern Ireland, and to identify organisational factors that promote or inhibit effective transition.

**Study population:** Health, social, educational and charitable organisations providing transition services to young people with life-limiting conditions in Northern Ireland.

**Study design and methods:** A questionnaire has been developed by the research team drawing on examples from the literature and the advice of an expert advisory group. The questionnaire was piloted with clinicians, academics and researchers in June 2013. The questionnaire focuses on components of practice which may promote continuity in the transition from child to adult care for young people with a life-limiting condition. The survey will be distributed throughout Northern Ireland to an estimated 75 organisations, following the Dillman total design survey method. Numerical data will be analysed using PASW Statistical software to generate descriptive statistics along with a thematic analysis of data generated by open-ended questions.

**Results and interpretations:** The survey will provide a description of services, transition policies, approaches to managing transition, categories of service users, the ages at which transition starts and completes, experiences with minority ethnic groups, the input of service users to the process, organisational factors promoting or hindering effective transition, links between services, and service
providers’ recommendations for improvements in services. The outcomes will be an overview of the transition services currently provided in Northern Ireland identifying models of good practice and the key factors influencing the quality, safety and continuity of care. Survey results are due early in 2014.

Abstract number: P384
Abstract type: Poster

A Pilot Evaluation of the Palliative Performance Scale in Long Term Care: Tips for Success
Kaasalainen S.1, Brazil K.2, Kelley M.L.3
1McMaster University, Hamilton, ON, Canada, 2Queen’s University Belfast, School of Nursing and Midwifery, Belfast, United Kingdom, 3Lakehead University, Thunder Bay, ON, Canada

Aims: Palliative care in long-term care (LTC) homes is an area of growing concern. Little work has been done to explore innovative ways to identify and care for residents who become palliative. The purpose of this intervention study was to evaluate the implementation of the Palliative Performance Scale (PPS) in LTC. Specifically we explored staff perceptions about implementing the PPS and how it cued staff to initiate palliative care discussion with residents and family when a resident’s health declined.

Methods: This study utilized a qualitative descriptive design that included data from four separate sources: journals of three ‘champions’ who were responsible for leading the implementation of the PPS; staff evaluations of three educational training sessions; minutes from meetings; and 11 interviews from key staff who were involved in the implementation process. Data were analyzed using thematic content analysis.

Results: Staff generally felt positively about using the PPS in LTC and stated that it increased awareness of palliative care and helped identify those residents who were nearing the end of life. There were some barriers to implementing it, such as staff resistance and lack of time to complete it. The importance of having a designated ‘champion’ and effective interdisciplinary communication in addition to widespread training, were identified as successful strategies to facilitate the implementation process.

Conclusion: These study findings support the use of the PPS in LTC and offer some perspective about ways to implement it successfully. Future work is needed to evaluate the PPS in LTC using more rigorous designs.

Abstract number: P385
Abstract type: Poster

Elderly Patients in a Palliative Care in an University Hospital in Brazil
De Carlo M.M.R.d.P.1,2, Carvalho R.C.2, Lima N.K.C.3, Laboratório de Investigação sobre a Atividade Humana - LIATH
1School of Medicine of Ribeirão Preto - University of São Paulo, Department of Neuroscience and Behavioral Sciences, Division of Occupational Therapy, Ribeirão Preto, Brazil, 2School of Nursing of Ribeirão Preto - University of São Paulo, Postgraduate Program in Public Health Nursing, Ribeirão Preto, Brazil, 3School of Medicine of Ribeirão Preto - University of São Paulo, General and Geriatric Medical Clinic, Ribeirão Preto, Brazil

Introduction: With the changing epidemiology and population aging, health professionals have faced the need to consider the specific demands imposed by the care of the elderly in palliative care and their families.

Methods: Descriptive-analytical study based on the database of patients seen by the Palliative Care Group of a public university hospital of high complexity. The study period is from August 2010 and June 2013. The functional capacity was evaluated by the Karnofsky Performance Status Scale (KPS) and symptoms were assessed by the Edmonton Symptom Assessment System (ESAS).

Results: A total of 893 patients were attended in this period and 541 were 60 years-old or older (61%). To this study was selected 178 older individuals (33% of all elderly patients), non-random sample, for convenience of complete data. There was 50% of patients with age between 60 and 70 years, with a average of 71 years. Male gender was prevalent (62.4%), with a low educational level (54.5% with one to seven years of schooling and 18% were illiterate). 60.1% were outpatients, 30.3% were admitted to the hospital and 9.6% were attended by home care. 170 subjects (96% of the sample) had a cancer diagnosis. 40 individuals (22.5%) had the KPS score of 40% at the first evaluation. Fatigue was considered moderate for 95 subjects (53.4%) and pain was considered moderate (4-7 points) for 72 subjects (40.4%).

Conclusion: Elderly patients that were referred to palliative care in this hospital had the cancer diagnosis. The majority was referred for care in advanced disease or terminal illness. It is necessary to improve the education of the health staff to indicate palliative care to non-oncology patients and in an early phase of the disease. Patients need to be cared for by multidisciplinary team care programs in palliative care, with emphasis on promoting quality of life and well-being and prevention of suffering due to illness that threatens the continuity of life.

Abstract number: P386
Abstract type: Poster

Factors Related to Emotional Distress at End of Life
Nabal M.1, Sarret C.2, Castro S.3, Caceres M.3, Abella F.2

1School of Medicine, Hamilton, ON, Canada, 2Laboratório de Investigação sobre a Atividade Humana - LIATH, 3School of Nursing, Ribeirão Preto, Brazil, 2School of Medicine of Ribeirão Preto - University of São Paulo, General and Geriatric Medical Clinic, Ribeirão Preto, Brazil
Aim: To analyze which variables are related to the presence of emotional distress in patients receiving palliative care.

Methods: Prospective inferential study. Inclusion criteria: Older than 18, advanced disease receiving inpatient palliative care, acceptance of psychological interview. Exclusion criteria: performance status lower than 30 (KPS scale), poor symptom control, cognitive impairment (Pfeiffer>2 errors), psychological assessment rejection.

Variables: Age, Gender, Diagnosis, Time since diagnosis, Psychopathological background, Level of information, Pain, Spiritual resources, Conspiracy of Silence, Place of discharge and Presence of emotional distress.

Statistics: Descriptive analysis with frequencies and central tendency measures. Comparative analysis by t Student and Chi square test (α of 5%, a level 95 % and p < 0.05). Statistical analysis was performed using SPSS® v. 17.

Results: From the total of 70 patients included in we detect emotional distress (by using specific Spanish validate test (DME) or by the psychological interview) in 45. There was no statistically significant relationship between psychopathological background, time form diagnosis, or patient’s expectations about the outcome. More than half of patients with emotional distress had pain, but the difference with those without emotional distress and pain (40%) was not significant. (p=0.15). No significant relationship was found between the place of discharge and emotional distress (P=0.62). The presence of conspiracy of silent was 46.7% in patients with emotional distress but 44% in those with no emotional distress detected. (p=0.83). Significant relationships between spiritual resources and emotional distress was detected (p=0.005).

Conclusion: Spiritual concerns play an important role in emotional distress. Further research is need to corroborate and clarify our findings with a with a bigger and multicultural sample of patients.

Abstract number: P387
Abstract type: Poster

Symptom Severity and Sustained Attention: What is the Impact on Patients with Advanced Cancer?

Matuoka J.Y.1, Kurita G.P.2, Sjøgren P.3, Pimenta C.A.M.1

1University of São Paulo, School of Nursing, Medical Surgical Nursing, São Paulo, Brazil; 2Rigshospitalet, Section of Palliative Medicine, Multidisciplinary Pain Centre, Copenhagen, Denmark; 3Rigshospitalet, Section of Palliative Medicine, Copenhagen, Denmark

Aims: Symptoms, comorbidities and low physical performance status may interfere with the ability to concentrate and answer adequately to stimuli. Therefore, the aim of this study was to analyze the impact of severe symptoms in patients with advanced cancer on sustained attention.

Method: 178 outpatient with advanced cancer receiving palliative chemotherapy underwent sustained attention assessment (Continuous Reaction Time test - CRT) and answered a questionnaire regarding social and clinical status. Symptoms like pain, sleep, fatigue, depression, anxiety and performance Status (Karnofsky - KPS) were assessed. They were considered severe if pain and sleep scores were ≥ 7 (Visual Numeric Scale; 0-10), fatigue scores ≥ 4 (Fatigue Pictogram; 1-5), anxiety and depression scores ≥ 13 (HADS) and performance status ≤ 70% (KPS 10-100%). Correlations were analyzed by SPSS® v. 15.0.

Results: There was no correlation between severe scores of pain, sleep, fatigue, anxiety, depression, performance status and CRT (p>0.05). In addition, no correlation was observed either in patients with weak or absence of those symptoms.

Conclusion: In the present study, no correlation between the severe symptoms and CRT was observed. These results might be due to low sensibility and specificity of the instrument to detect sustained attention impairment in advanced cancer patients or maybe these patients adapted themselves to these changes, although it is not a strong hypothesis. Considering the impact that impaired attention has on quality of life, further investigation is required.

Abstract number: P388
Abstract type: Poster

Examine the Acceptability of a Discharge Report Form When a Patient is Referred to the Palliative Night Nursing Community Service

Ferns M.

Irish Cancer Society, Nursing, Dublin, Ireland

Aim of the Study: The aim of the study was to examine three aspects of patient discharge. One to examine information transfer between hospital personnel and the night nurse, two to identify deficits in drug prescriptions and medications and three to identify if essential equipment is given to the patient on discharge.

Methodology: Quantitative, closed self-completing questionnaire.

Sample: 124 Night Nurses.

Analysis: Microsoft Excel.

Results: Information Transfer: 67% of the nurses were always or usually informed that the diagnosis had been discussed with the patient with 32% being informed less frequently. 47% of nurses always or usually had a nursing
and medical written handover with 52% less frequently and 17% of respondents reporting never having a written report.

**Prescriptions on discharge:** 81% of nurses always or usually had a written prescription for regular medication administration with 18% reporting less frequently. 58% of nurses always or usually found that PRN medication was prescribed with a time interval with 42% reporting less frequently which includes 9% who never had a time interval prescribed. 67% were always or usually informed when the last dose of analgesia was given leaving 33% informed less frequently.

Prescribing for symptom relief was good for pain management with 91% of nurses reporting there was always or usually a prescription in place. This compares to an average of 82% for chest secretions, agitation/restlessness and nausea and vomiting.

**Medications on discharge:** 89% of nurses reported the patient was always or usually discharged with medication for pain relief. 68% reported medication for excessive chest secretions, agitation/restlessness and nausea and vomiting.

**Equipment on discharge:** 75% of nurses reported no aprons and gloves given to the patient and 49% of nurses reported no Sharps Bins.

**Conclusion:** The results indicated a need for a discharge report form when patients are referred to the Night Nursing Service.

**Abstract number:** P389
**Abstract type:** Poster

**Preparedness to Care in Advanced COPD: How Prepared Are Informal Carers of Patients with Advanced COPD and what Are their Support Needs?**

**Baseline Data from an Ongoing Longitudinal Study**

_Farguhar M.C.授课, Ewing G.授课, Moore C.授课, Gardener C.授课, Holt Butcher H.授课, White P.授课, Grande G.授课, Living with Breathlessness Study Team_

1University of Cambridge, Public Health & Primary Care, Cambridge, United Kingdom, 2University of Cambridge, Centre for Family Research, Cambridge, United Kingdom, 3King’s College London, London, United Kingdom, 4University of Manchester, Manchester, United Kingdom

**Background:** Chronic obstructive pulmonary disease (COPD) is a chronic progressive condition which, when advanced, can lead to high carer-burden. We lack good research evidence on the needs of informal carers of patients with advanced non-malignant disease and how best to support them; in particular the lack of longitudinal carer research has been noted.

**Aims:** To describe the preparedness to care among informal carers of patients with advanced COPD and their support needs at the baseline of an ongoing longitudinal study.

**Methods:** Mixed method baseline interviews with a cohort of approximately 100 informal carers of patients recruited from a primary care population base in the East of England. The cohort forms part of the Living with Breathlessness study and, as such, is being followed over time in a mixed-method 18-month Longitudinal Interview Study involving 3-monthly semi-structured interviews with flexible methodology to capture changing patient function and service access, and carer need and support. Quantitative carer measures include Preparedness for Caregiving Tool and Carers Support Needs Assessment Tool analysed using descriptive statistics. Purposively sampled qualitative data will be analysed using a framework approach and multiple-perspective case study methodology.

**Results:** At the time of abstract submission baseline data collection is ongoing but due for completion by the end of November 2013. The results will describe the preparedness of informal carers to care and the relationship between preparedness and carer support needs when caring for patients with advanced COPD.

**Conclusions:** The Living with Breathlessness study aims to provide new evidence on the trajectories of health and social care needs and service access of patients with advanced COPD and their informal carers to inform a new framework for care and support in advanced non-malignant disease.

**Abstract number:** P390
**Abstract type:** Poster

**Life Threatening Illness in Popular Movies - A First Descriptive Analysis**

_Drukarczyk L., Klein C., Ostgathe C., Stiel S._

University Hospital Erlangen, Department of Palliative Medicine, Erlangen, Germany

**Background:** In the last two decades the public attention as well as the peoples’ perspective towards dying and death has changed, possibly supported by the dynamic transformation of hospice and palliative care. So far, it is not clear how the change in public awareness influences the presentation of dying and death in media. The study investigated the presentation of different entities of terminal illnesses in popular movies and illustrates the discrepancy to clinical results.

**Methods:** A systematic film search was conducted in 2011-2012 to identify movies from 1991-2011 dealing with incurable diseases. Finally 35 out of 4200 movies were analyzed with means of a data extraction tool containing different elements of presentation of the patients’ lives such as symptoms, therapy and end-of-life.

**Results:** The total number of movies with focus on terminal illness, dying and death has increased since 1991.
(1 movie per year) till 2011 (6 movies per year). In the first timeframe considered in this investigation (1991 to 2010), cancer (67%) and Aids/HIV (33%) were the only terminal illnesses portrayed in films popular in Germany. During the following decade, cancer remained the primary terminal illness portrayed (45%), and was again followed by Aids/HIV also in a dropped percentage (15%). At least one symptom referring to the terminal illness is shown in 89% of movies. The terms “palliative and hospice care” were not mentioned even once.

**Conclusions:** The number movies dealing with terminal illnesses increases and a considerable audience seems to be interested in these films. A presentation containing more true-to-life elements for the picturing of dying and death could be a major public educational resource.

**Abstract number:** P391  
**Abstract type:** Poster  
**Differences between Cancer and Non-cancer Patients Attended by a Palliative Care Support Unit in Southern Spain**  

Hospital Universitario Virgen del Rocío, Internal Medicine, Seville, Spain

**Objectives:** To compare and determine the main healthcare features between cancer and non-cancer patients who were attended by a hospital-based, specialised, palliative care unit (“palliative care support unit”).

**Methods:** Cross-sectional study. Recruited patients were those attended by a palliative care specialised unit within Internal Medicine Department of a university hospital in Southern Spain, between January 2011 and March 2012. Patients with incomplete data were excluded for analysis. Analysed variables were: age, main carer profile, main disease, Barthel index (BI), Karnofsky index (KI), Palliative Performance Scale (PPS), number of physician/nurse visits, and discharge cause. Analysed variables were compared through Chi-squared (qualitative) or Mann-Whitney’s U test (qualitative).

**Results:** A total of 597 patients were included. A 86.6% was terminally ill (n=518), and a 63.5% were cancer patients (CP, n=379). 49.1% were women (CP 41.4% vs. NCP 36.2%; P<0.000). Main carer profile: woman 87% (86.2% vs 88.5%; P=0.262), wife/husband 30.6% (36% vs 19.1%; P=0.000), daughter/son 49.4% (44.2% vs 58.5%; P=0.000). A 13.7% fulfilled criteria of polypathological patient (1.5% vs 36.9%; P=0.000), mostly having advanced heart failure. Mean age was 72.58±12.38 years vs. 79.53±13.57 years, BI 21.32±26.72 vs 35.87±28.55 (P=0.000), KI 13.42±17.17 vs. 40±15.08, PPS 33.22±19.08 vs 41.88±15.85, number of physician visits/patient-episode 4.15±5.18 vs 6.48±7.04 (P=0.000 for all above), and number of nurse visits 1.36±2.44 vs. 2.38±4.27 (P=0.014) for CP vs. NCP respectively.

Death rate was 47.7% (n=285), CP 52% vs. NCP 39.5% (P=0.000). A 3.4% (both equal) was admitted on a hospital ward through emergency department and 13.6% (17.6% vs 5.9%; P=0.029) through planned transfer from home to ward.

**Conclusions:** Non-cancer patients were frail disabled elders, thus requiring more number of visits, suggesting they are a more demanding population, possibly as they lived longer during follow-up.

**Abstract number:** P392  
**Abstract type:** Poster  
**Te Pâkeketanga: Living and Dying in Advanced Age in New Zealand**  
Gott M., Moeke-Maxwell T., Williams L., Black S., Gardiner C., Trussardi G.

University of Auckland, Auckland, New Zealand

**Research aims:** To explore the end-of-life circumstances of Māori and non-Māori in New Zealand dying >85 years and the experiences of their whānau and family during the end-of-life period and after bereavement.

**Study population:** Approximately 60 bereaved whānau/family groups (n=150 total participants).

**Study design and methods:** 575 Māori and non-Māori participants aged >85 years participating in the LiLACS New Zealand longitudinal study of ageing have completed questions specifying their preferences for end-of-life care and nominated a whānau/family member to be interviewed after their death. Interviews (incorporating an interviewer-administered questionnaire) are currently being conducted with bereaved whānau and family participants 4–6 months following the death of the older LiLACS NZ participant to explore the extent to which their care preferences were met and the wider end of life experiences of their family/whānau carers. A health promoting palliative care framework is informing the project.

**Analysis:** Analyses are informed by a narrative gerontology framework and a Kaupapa Māori research methodology.

**Results and interpretation:** Preliminary analyses indicate that, in New Zealand, the oldest old and their family and whānau carers face a number of challenges at the end of life, including fragmentation of care and gaps in statutory and non-statutory service provision. Initial findings indicate family/whānau carers lacked access to palliative care information and resources to support their caregiving activities. Conducting multiple interviews within one family/whānau group has also illuminated tensions within
families regarding end of life care management. The need to contextualise the end of life period within a person’s wider experiences of ageing and earlier life course events is apparent.

Funding: Health Research Council of New Zealand grant number13/293 ($1.1 million; 01/09/13 - 01/09/16).

Abstract number: P393
Abstract type: Poster

Hospital Admissions in the Last Year of Life for People who Died from Liver Disease in England, 2007-2011

Hinga A., Pring A., Verne J.
Public Health England, Knowledge and Intelligence South West, Bristol, United Kingdom

Research aims: To determine the number and type of hospital admissions in the last year of life for people dying from liver disease.

Study population: People who died in England with a liver disease as underlying /contributory cause of death.

Methods: Retrospective study using the national Hospital Episodes Statistics (HES) database linked to the Office for National Statistics (ONS) mortality file. All people who died from a liver disease with at least one hospital admission in the last year of life.

Results: Compared with other diseases, a higher percentage of people dying from liver disease have a hospital admission during the last year of life: Liver (89%) Cancer (88%) all causes (76%). 87% of all admissions were as emergencies. On average, each person dying from liver disease had three admissions during the last year of life, lasting on average 11 days. Hospital is the most common place of death for liver disease. People dying from viral liver disease had the longest final admissions and were admitted close to death.

Conclusions: Most liver diseases are chronic but patients are admitted into hospital very close to death as an emergency and die there. Better planning for end of life care is needed.

Abstract number: P394
Abstract type: Poster

How Does the Environment of a UK Hospice Impact on the Social Wellbeing of Older Inpatients? An Ethnographic Study

Rigby J.S.1, Milligan C.2, Payne S.3

1Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 2Lancaster University, Centre for Ageing Research, Lancaster, United Kingdom

Background: Little is known about how to design inpatient hospice buildings to maximise the wellbeing of the growing number of patients aged 65yrs or over.

Aim: To investigate the impact of a hospice environment on the social wellbeing of older inpatients.

Method: Interviews were conducted with10 staff, 2 visitors and 7 older in-patients at a UK hospice with 8 single and one 4-bed rooms, to elicit their views on the building, and 120 hours of non-participant observation, to find how space was used. Field notes and interview transcripts were subject to thematic analysis using NVivo X, using concepts derived from therapeutic landscapes theory.

Results:

1) Supervision and independence -The building was constructed around a long blind-ended corridor, with a nurses’ station near the entrance. Those who were terminally ill or restless were allocated to single rooms near the nurses’ station. Frequent room transfers occurred in response to changing needs, and older patients disliked these. Room doors were kept open during the day, enabling staff to monitor occupants as they walked along the corridor. There were several complaints of loneliness from those in rooms at the end of the corridor, as staff visited less often.

2) Private and public space - Older patients spent most of their time in their rooms, usually seeing visitors at the bedside. Of the available social spaces, the hospice garden was the most visited, and older patients enjoyed contact with nature. They rarely entered the two patient lounges and conservatory, which were often occupied by staff for meetings, family conferences and meal breaks.

Conclusions: To maximise older inpatients’ social wellbeing, the hospice environment should be designed to balance the need for supervision and independence, and for private and public space. Staff working practices should ensure that the use of the environment is patient-centred.

Abstract number: P395
Abstract type: Poster

Experiences and Barriers in End-of-Life Management in Nursing Homes: A Focus Groups Study with Professionals


1University of Granada, Nursing, Granada, Spain, 2Servicio Andaluz de Salud, Granada, Spain, 3Servicio Andaluz de Salud, Loja, Spain, 4Servicio Andaluz de Salud, Cullar Vega, Spain, 5University of Granada, Granada, Spain
Aim: Explore the perception of nursing homes health professionals about how end-of-life is managed, in this kind of institutions.

Study population: Professionals involved in end-of-life care in nursing homes of Granada (Spain).

Study design and methods: 15 professionals were recruited and interviewed in three Focus Groups. In order to promote discussion in the focus groups, researchers take into account heterogeneity criteria to conform the different groups.

Method of analysis: An inductive-deductive analysis, inspired in Strauss-Corbin’s grounded theory, was conducted.

Results and interpretation: Five categories emerged from professionals’ speech; Experience of working in a nursing home, end-of-life needs management, Relationships with families. End-of-life decisions, and Coordination with other institutions. Professionals feel emotionally involved with nursing home residents and they feel more likely to identify with the persons who are close to end of life, and think about their own death. Although nursing homes are perceived such as an institution that provides holistic and warm end-of-life care, professionals require more specific training in palliative care skills, and better resources for caring end-of-life elderly. Professionals feel very distress when they have to make difficult decisions related to end-of-life. Difficulties with family’s emotional support and coordination with other institutions are also highlighted.

Conclusion: Nursing homes could be a good alternative to provide palliative care in Spain. Some problems like scarce resources and coordination should be addressed. Professionals should receive more training in palliative care, especially in emotional support to families.

Funding: This research has received funding from Consejeria de Salud de la Junta de Andalucia (PI-0619-2011).

Abstract number: P396
Abstract type: Poster

Experience-based Knowledge in the Care of Homeless People with Severe Illness and Complex Care Needs

Håkanson C.1, Christiansen M.2, Ekstedt M.1,3, Sandberg J.1,4, Kenne Sarennalm E.1,5, Ohlen J.1,6

1Ersta Sköndal University College, Palliative Research Centre, Stockholm, Sweden, 2Karolinska Institutet, Neurobiology, Care Science and Society, Dept. of Nursing, Stockholm, Sweden, 3KTH School of Technology and Health, Stockholm, Sweden, 4Jönköping University, School of Health Sciences, Sweden, 5Research and Development Centre, Skaraborg Hospital, Sweden, 6Gothenburg University, The Sahlgrenska Academy, Institute of Health and Care Sciences, Gothenburg, Sweden

Background: The number of homeless people in Sweden amounts to approximately 34 000. Of those about 4500 live in streets or shelters. The mortality rate among homeless people outnumbers other groups in the society. Often they have severe, multiple mental and physical illnesses, drug abuse and a variety of complex care needs, including palliative. From an international perspective, research related to care for homeless people with severe illness and complex care needs is very sparse (no Swedish studies have been identified). Among the few that have been found, challenges related to the homeless situation and the illness panorama are reported. From the perspective of the homeless persons themselves, studies report stigmatisation, lack of respect and competence among health-care professionals, and insufficient organisation of health care.

Aim: The aim of this study is to explore the development of experience-based knowledge among health care professionals and social workers in a unique setting, in which advanced inpatient health- and social care, including palliative care is provided to homeless people.

Methods: In this on-going qualitative case-study, clinically relevant and applicable knowledge is focused. Repeated focus group discussions and coupled thematic interviews were performed with staff (physicians, social workers, mental carers, nurses). Analysis is performed with an interpretive descriptive method.

Results and implication: The results, which are currently being processed, will present staffs’ experiences of identification and assessment of individual care needs, specific knowledge development and requirement in relation to palliative care and homelessness, and challenges, obstacles and opportunities for meeting the needs of severely ill and dying homeless people. The results will provide knowledge of importance for the development of care for severely ill homeless persons.

Abstract number: P397
Abstract type: Poster

Development of a Decision Support Tool for Clinical End-users of POS: Findings from a Programme to Enhance Routine Clinical Outcome Tool Implementation

van Vliet L.M.1, Harding R.1, Bausewein C.2, Payne S.3, Higginson I.1, EURO IMPACT

1King’s College London, Cicely Saunders Institute, Department of Palliative Care and Rehabilitation, London, United Kingdom, 2Munich University Hospital, Department of Palliative Medicine, Munich, Germany, 3Lancaster University, International Observatory on End of Life Care, Division of Health Research, Faculty of Health and Medicine, Lancaster, United Kingdom
Aims: Routine clinical use of Patient Reported Outcome Measures (PROMs) such as the Palliative care Outcome Scale (POS) seems inhibited by a lack of guidance on how to respond to reported problems. The aim of this work was twofold; i) to determine for which POS items such guidance is needed, and ii) to set up a Delphi study which will produce a decision support tool (DST) on the use of these POS items in clinical care.

Methods: For stage

i) participants of a POS training day completed a questionnaire on their need for clinical guidance in using - specific - POS items. For stage

ii) a teleconference with international experts (clinicians, researchers and patient representatives) was held to determine the audience and format of the DST.

On selected POS items a systematic search for guidelines and reviews was conducted, and selected key experts assisted in creating recommendations on how to respond to scores on these items.

Results: Ninety per cent of 38 trainees needed guidance in the use of POS in clinical care. Most help was needed for the items depression (n=8)/feels good about yourself (n=10), information given (n=7), and family worries (n=4). Key experts (n=3) stated guidance was also needed on breathlessness. Experts (n=19) agreed that the DST should support different levels of expertise and should be produced in different formats, e.g. a web-based tool. Using evidence from clinical guidelines, systematic reviews and key experts recommendations were created on how to respond to different levels of POS items ‘information needs’, ‘family anxiety’, ‘depression’, and ‘breathlessness’, to be tested in a Delphi study.

Conclusion: As PROMs are increasingly used to improve quality in healthcare, our project is a novel example of how implementation can be enhanced. Involving users, experts and the literature can inform the creation of an evidence-based yet clinically useful DST. Future work will test the recommendations and create various formats of the DST.

Abstract number: P398
Abstract type: Poster

Can Symptom Scores in End-stage Kidney Disease Help with Timing of Anticipatory Care Planning?

Lovell N.1, Bristowe K.1, Shepherd K.2, Brown H.1, Matthews B.1, O’Donoghue D.1, Vinen K.2, Murtagh F.1

1King’s College London, Cicely Saunders Institute, London, United Kingdom, 2King’s College Hospital NHS Foundation Trust, London, United Kingdom, 3Guy’s and St Thomas’ NHS Foundation Trust, London, United Kingdom, 4NHS England, NHS Improving

Research quality, London, United Kingdom, 4NHS England, NHS Improving

Aims: Patients with end stage kidney disease report high fatigue (weighted mean prevalence 71%) and up to 58% experience depression. Good symptom management and being prepared are patient priorities but professionals find timing of discussions challenging. We aimed to identify if routine symptom assessment had potential to inform timing.

Methods: Mixed-methods study, including experience survey and symptom assessment (validated renal Palliative care Outcome Scale). 3 questions concerned anticipatory care planning (ACP): Q1) Have you thought about where you would like to be cared for if you were not able to get better? Q2) Have you thought about who would you like to be involved in decisions about your medical care? Q3) When you raise concerns do you feel they are taken seriously?

Results: 91 dialysis patients, 64.4% male, 30% aged 75 and above. 49.5% white. Fatigue and depression showed significant differences in question response: Q1: 19.1%(95% CI 11.5-28.8) ’yes’, 15.7%(95% CI 8.9-25.0) ’to some extent’, 58.4%(95% CI 47.5-68.8) ’no’, and 6.7%(95% CI 2.5-14.1) ’don’t know’. Patients with high depression scores more often considered future care options (χ²=8.569;p=0.036;n=87). Q2: 55.6%(95% CI 44.7-66.0) ’yes’, 21.1%(95% CI 13.2-31.0) ’to some extent’, 20.0%(95% CI 12.3-30.0) ’no’, and 3.3%(95% CI 0.7-9.4) ’don’t know’. Patients with high fatigue more often considered who they wanted involved in decisions (χ²=9.798;p=0.02;n=85). Q3: 53.5%(95% CI 42.4-64.3) ’yes’, 32.6%(95% CI 22.8-43.5) ’to some extent’, 8.1%(95% CI 3.3-16.1) ’no’, and 5.8%(95% CI 1.9-13.0) ’not applicable’. Patients with high fatigue felt less sure concerns were taken seriously (χ²=8.799;p=0.032;n=81).

Conclusions: These results highlight need to consider symptoms when timing ACP discussion. Routine regular symptom assessment may help inform readiness of patients, particularly if reporting fatigue/depression.

This work is a key component in a project led by NHS Kidney Care.

Abstract number: P399
Abstract type: Poster

End-of-Life Treatment in the Intensive Care Unit

Badia M., Domingo J., Gormaz P., Gavilan R., Iglesias S., Trujillano J.

Hospital Universitario Arnau de Vilanova, Intensive Care, Lleida, Spain

Introduction: End-of-Life Care is part of the health care work of the intensivist physician.
Objective: To determine the clinical characteristics of patients who die in Intensive Care Unit (ICU) and determine whether the death was associated with the treatment-limiting decisions.

Material and method: Prospective observational study conducted in a mixed ICU. We studied all consecutive ICU patients who died from March to August in 2013. Collected data included demographic variables, diagnostic group, chronic diseases, severity scoring system APACHE II, modified Rankin scale, invasive procedures (mechanical ventilation, renal dialysis, vasoactive drugs), length of stay and the kind of limitation of life-sustaining therapy (withholding or withdrawing).

Results: 43 deaths patients were studied with an average age of 67±12 years, 60.5% were male, with an APACHE II score of 22±8 at admission. Of study patients, 30.2% received full support, 46.5% died after withholding of life-sustaining therapy and 23.3% after withdrawing treatment. 76.5% of patients with withholding of life-sustaining therapy had higher score on Rankin scale with moderate-severe disability. However, 80% of patients in which withdrawing treatment was performed showed a mild score on Rankin scale (p = 0.026). There were no differences regarding with other variables. The factors associated with the decision of limitation were chronic diseases (p = 0.004), group diagnostic (p = 0.002), therapeutic futility (p< 0.001) and multiorgan dysfunction (p = 0.018). There was no relation to age or previous autonomy. The limited treatment consisted in vasoactive drugs and mechanical ventilation. In no case there was knowledge of advance directives.

Conclusion: Almost three-quarters of patients who die in the ICU have received some kind of treatment limitation. The withdrawal of support measures is performed in very few cases. In our area there is no knowledge of specific advance directives.

Abstract number: P400
Abstract type: Poster

Symptoms & Problem Clusters in Cancer and Non-cancer Patients in Specialized Palliative Care - Is there a Difference?

Stiel S.1, Matthies D.M.K.1, Seuß D.2, Walsh D.3, Linden A.4, Ostgathe C.4

1University Hospital Erlangen, Department of Palliative Medicine, Erlangen, Germany, 2Faculty Information Systems and Applied Computer Science, University of Bamberg, Bamberg, Cognitive Systems Group, Bamberg, Germany, 3Cleveland Clinic Taussig Cancer Center, Cleveland, OH, USA, The Harry R. Horvitz Center for Palliative Medicine, Cleveland, OH, United States, 4Clinical Analysis, Research and Application (CLARA), Kleinmachnow, Germany

Background: Although symptoms of patients should be considered individually, single symptoms may not only be seen as isolated problems, but integrated into systematic groups of symptoms, the so-called clusters. These clusters may have consequences for symptom management. Facing a growing number of non-cancer patients in palliative care, this study aims to differentiate their symptom clusters from those of cancer patients.

Methods: Data from inpatients from the German Hospice and Palliative Care Evaluation (HOPE) between 2007 and 2011 were used for a cluster analysis of a 16-item symptom and problem checklist. An agglomerative hierarchical method was chosen. Coefficients from distance matrix ranging between 0-1 were calculated to indicate the interrelationship of clustered symptoms.

Results: Data of 6181 cancer and 560 non-cancer patients documented in HOPE at the time of admission to inpatient palliative care units were included in this analysis. The analysis identified five clusters in non-cancer patients: (1) nausea and vomiting (d = .000); (2) anxiety, tension and feeling depressed (d = .166); (3) organization of care and overburdening of family (d = .187); (4) weakness and assistance with ADL and loss of appetite (d = .182).

Comparable five clusters were identified in cancer patients:

1) nausea and vomiting (d = .000);
2) anxiety, tension and feeling depressed (d = .125);
3) wound care and disorientation/ confusion (d = .229);
4) organization of care and overburdening of family (d = .202);
5) weakness, tiredness, assistance with ADL and loss of appetite (d = .207).

Conclusions: As symptom clusters do not significantly differ between cancer and non-cancer patients, more specific and frequent symptoms in non-cancer patients should be assessed. In general, the identification of symptom clusters may help to recognize symptom and problem issues and to target treatment accurately.

Abstract number: P401
Abstract type: Poster

Distress in Cancer Patients

Albuquerque K.A.1,2, Pimenta C.A.M.2

1University Federal of Pernambuco, Department of Nursing, Recife, Brazil, 2University of São Paulo, School of Nursing, São Paulo, Brazil

The distress may be answer to cancer and its treatment and be associated with several factors. The purpose was
to assess the distress and associated factors in cancer patients. A cross-sectional study was conducted from July to October 2013 with 136 patients with gastrointestinal tumors, aged between 18 and 65 years old, at least 6 years of schooling and KPS ≥ 60%. The Distress Thermometer was used. Data were analyzed by Chi-square, Student’s t, Mann-Whitney and ANOVA test for logistic regression. Most were male (59.6%), average age of 53.1 years (SD=0.8, CI=51.5-54.7). Then types of cancer prevalent were rectal (28.9%), stomach (21.5%) and bowel (17.0%), without metastasis (69.1%), with an average diagnosis 19 months (SD=1.32, CI=16.3-21.6) and without any current treatment (65.9%). Most had KPS≥80 (88.2%), mild pain (X=2.6, SD=0.2), fatigue (X=2.1, SD=0.2), depression (X=1.5, SD=0.2), anxiety (X=3.6, SD=0.3) and sleep disorders (X=2.4, SD=0.3). Fifty-eight patients self-assessment with distress. The regression model showed a positive association (p< 0.05) of distress with weight loss, nervousness, sadness, fatigue, limited walking and sexual problems. Distress, the sixth vital sign in oncology, is poorly considered in the routine assessment. Actions to control distress and to prevent the events and triggering stimuli can contribute to improving the care and quality of life of cancer patients.

Abstract number: P402
Abstract type: Poster

Friend or Foe? The Impact of Using Electronic Records on Professionals

Garcia-Baquero Merino M.T1, Pinedo F.2, Monleon Just M.1, Lobete Cardeñoso M.1, Ruiz Lopez D.1

1Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 2Subdirección General de Servicios de Sistemas de Información, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 3Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain

Background: Patient Electronic Registers (PERs) can help identify palliative care needs homogenous and unambiguously, they are becoming widely used by clinicians to enhance continuity of quality care. Professionals find technology both a challenge and a priority. Providing staff with IT competence and training delivery is crucial.

Aim: To formally evaluate MPER from the professional user view point before consolidating our electronic tool. Informal feedback both from patients and family and professionals was available but any tool is only as good as those who use it, we needed to hear professionals’ views to engage them in the process.

Methodology: 8 item 10 point Likert scale and 4 free text questions, sent by e-mail to all been given IT access to the Regional Electronic Palliative Care Records System. Replies were anonymous.

Results: We had a 22% response survey; 79% from females and 21% from males; 47.15% of which were doctors and 52.85% nurses. Median age of participants was 43; 45.07% worked in Hospital; 30.64% in Home Care Team; 11.26% in the 24 hour service and 4.22% in the independent sector. With reference to usefulness 65.3% rated it 5 or above and 11.1% rated it 2 or below As to the Overall value of the tool 66.6% rated it 5 or above and 8.3% 2 or below. Advantages: Improved accessibility to clinical data; improved coordination and enhanced continuity of care. Disadvantages Time consuming; scarce protocol completion; Suggestions electronic integration, requests for complete uploaded clinical information and Comments use for homecare and its value as homogenous system.

Conclusion: The tool needs improving. It is already seen as useful to allow access to relevant information. End of Life care can be underpinned by good (IT) communication to improve safety and delivery of quality care and data management. Further work will make protocols easier and quicker to complete and integrate it existing other resources.

Abstract number: P403
Abstract type: Poster

Accuracy of Clinician Estimates of Prognosis in Palliative Care Patients in a London Hospital

Stevens J.H.1, Stone P.C.2, Rudd L.3
1St George’s, University of London, London, United Kingdom, 2St George’s, University of London, Palliative Medicine, London, United Kingdom, 3St George’s, University of London, Palliative Care, London, United Kingdom

Aims: A clinician’s prediction of survival is an important part of palliative care to enable patients to plan for death and to inform decisions on care. Research has suggested clinicians are more likely to overestimate than underestimate a patient’s prognosis and variables such as diagnosis and a clinician’s level of experience can influence the accuracy of predictions. The purpose of this study is to review clinical prediction of survival (CPS) by a palliative care team and compare with actual survival time (AS) to provide insight into accuracy of prognosis.

Methods: A retrospective service evaluation was carried out on 851 anonymised, routinely collected, palliative patient notes, from April 2012- March 2013. The audit was registered with an audit committee. CPS made by members of a hospital palliative care team were compared with AS. CPS was recorded as ‘days’; < 14 days; ‘weeks’; < 8 weeks or ‘months’; 8 weeks+. AS was calculated from a date of death or evidence that the patient was alive at
the time of the audit; this was then compared with original CPS. Records with no recorded CPS or incomplete data were eliminated. The records were further categorised according to diagnosis (cancer vs non-cancer) and age.

**Results:** Final analysis of 596 records showed CPS was 65% accurate (overestimated=26%, underestimated=9%). CPS was most likely to be accurate if CPS was ‘days’ (90% accurate). Sensitivity and specificity were higher for non-cancer than cancer diagnoses for all CPS categories (‘days’, ‘weeks’ and ‘months’). Positive predictive value (PPV) was highest when CPS was ‘days’ in non-cancer patients (0.97). Accuracy was highest for 90+ yrs (75% accurate) and lowest for 50-60yrs (51% accurate).

**Conclusion:** Clinicians predict 65% of survival times accurately; if inaccurate they are more likely to overestimate than underestimate. Accuracy is highest for elderly patients, non-cancer diagnoses and when estimated survival time is shorter (< 14 days).

**Abstract number:** P404
**Abstract type:** Poster

**The Rhetoric and Practice of Palliative Care: A Qualitative Study of the Patient Journey**

Fox J.1, Yates P.1, Windsor C.2, Connell S.1

1Queensland University of Technology, Institute of Health and Biomedical Innovation, Brisbane, Australia, 2Queensland University of Technology, Brisbane, Australia

**Aims:** Palliative care has been recognised as an essential component of good cancer care; however health professionals appear reluctant to practice early referral of patients to this specialty. Limited research exists around the implications for patients in the late referral from curative treatment to palliative care. We sought to understand this transition process within a metastatic melanoma environment.

**Methods:** Purposive sampling was used to recruit 16 patients diagnosed with metastatic melanoma and their carers and 14 health professionals. The semi-structured interview was the method of data collection. Interviews were transcribed verbatim and analysed using constructivist grounded theory methods.

**Results:** The analysis identified tensions between the theory and practice of palliative care at the individual, organisational and structural levels. There were distinct differences across groups in approach to the transition to palliative care. At the individual level there appeared an ideological divide where some health professionals identified palliative care with medicalisation. At the organisational level while the concept of a multi-disciplinary team was dominant in language, roles remained clearly bound. Palliative care has also struggled to position itself within a system that espouses integration but values distinct specialties. In this context patients and carers worked hard to make sense of a health system where the trajectory of care was obscure.

**Conclusions:** Tensions exist between the theory and practice of palliative care. In identifying structural, social and cultural factors underpinning this tension, our study advances knowledge in the understanding of the complex process of transition to palliative care. This understanding contributes to the knowledge base enabling more appropriate support for patients in the transition process.

**Abstract number:** P405
**Abstract type:** Poster

**Process Quality of Dying in a Cohort of Patients Treated by a Team of Palliative Care Household Support (ESDCP)**

Galindo Ocaña J., Aguilera González C., Calle Cruz L.F., Fernandez Lopez A., González León R., Cia Ramos R.

Hospital Universitario Virgen del Rocío, Sevilla, Spain

Knowing the quality of the dying process in terminal patients based on the caregivers’ informed experience can help us to identify which are the most important aspects of this process, in order to improve interventions for an integrated care.

**Objectives:** Describe relevant variables in terminal ill patients deceased at home. Analyze the quality of the dying process of these patients and the related factors that allow the assessing of the health care indirectly.

**Methodology:** Descriptive study of cohort of terminal patients who died at home and who were attended by ESDCP during the first half of 2013. Variables: age, sex, type terminal illness, sedation frequency, and reasons which motivated it. It was made a phone survey to caregivers applying: the Questionnaire of Dying Process Quality and Death (QODD). It includes: sociodemographic characteristics, symptoms, preparation for death, the moment of it, stay with their families, treatment preferences and concern about the whole person. Statistical analysis: SPPS. V 14.0

**Results:** 571 patients were treated, 161 died at home. The average age: 75.17 years and a 52.1% were women. The caregivers were: 42.2% children and husband / wife in a 38.5%. The cancer was 67.7 % (lung: 23%, Colon:12.8% compared with non-cancer to 32.2% ( heart deficiency: 25%, dementia: 25 %). 60.2% required sedation (72.1% were oncology and a 27.8% non-oncology). The reason to sedate was the agony in 81.4%, followed by dyspnea (37.1%) and delirium (27.8%). The 62% of sedated patients had more than one refractory symptom.

The results of the survey are still under development, although it guarantees a better quality of death at home, if there are enough resources.
Conclusion: There is a High frequency of sedation at home. The most common cause is the agony. In high percentage refractory symptoms that motivate sedation were more than one. The more detailed conclusions on the questionnaire will be discussed subsequently.

Abstract number: P406
Abstract type: Poster
Policy Analysis: Palliative Care in Ireland

May P.1, Hynes G.2, McCallion P.2,3, Payne S.2,4, Larkin P.5, McCarron M.2
1Trinity College Dublin, Centre for Health Policy and Management, Dublin, Ireland, 2Trinity College Dublin, School of Nursing & Midwifery, Dublin, Ireland, 3University at Albany, State University of New York, School of Social Work, New York, NY, United States, 4Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 5University College Dublin, School of Nursing, Midwifery and Health Systems, Dublin, Ireland

Aims: In 2001 Ireland became one of the first nations to publish a dedicated national palliative care policy. This paper analyses the Irish experience and in particular the impact on service availability. In so doing it aims to inform the ongoing development of palliative care services in Ireland and internationally at a time when many nations are in the process of forming and/or implementing their own national plans.

Methods: A documentary and content analysis addressed all relevant policy and service documents to 2011. The findings were organised according to the ‘policy analysis triangle’ framework, examining what the policy entailed, where the key ideas originated, why the policy process was activated, who were the key actors, and what were the main consequences.

Results: Palliative care provision expanded following publication and patients in all regions of Ireland benefited. However, priorities on the national policy agenda were unaddressed or not fully embraced. Key policy goals could not be realised given the large resource commitments required; the competition for resources from other, better-established healthcare sectors; and challenges in expanding workforce and capacity. Additionally, the inherently cross-sectoral nature of palliative care complicated the co-ordination of support for the policy.

Conclusion: As other nations look to develop their own dedicated policy responses in palliative and hospice care, the Irish experience emphasises the importance of feasibility and evidence in compiling a plan. Palliative care remains a relatively new field with limited capacity for rapid expansion and challenges in competing for resources with more established areas of a health care system. Further, this is an inherently complex field requiring careful stakeholder management to establish broad support for policy goals.

Abstract number: P407
Abstract type: Poster
Patients with Cancer: Information Sources and Obstacles to Receiving Information from Medical Team Members

Omidvari S.
Health Metric Research Center, Iranian Institute for Health Sciences Research, ACECR, Mental Health Research Group, Tehran, Iran, Islamic Republic of

Aims: Responding to patients’ information needs is so important and depending on the sources who respond to the needs, it may affect patients’ health. This study examines information sources of patients with cancer and obstacles to receiving information from medical team members.

Methods: A qualitative study using semi structured in-depth individual interview and purposive sampling was carried out in a major cancer hospital in Tehran, Iran.

The interviews were continued until data saturation. The all interviews were recorded and transcribed verbatim. Then the data were coded and categorized based on subjects and areas using a thematic variable-oriented analysis.

Results: In all, 13 patients with cancer were interviewed. The study findings indicated that patients used professional and unprofessional sources to meet their information needs, including “other hospitalized patients”, “other patients’ relatives”, “physicians”, “nurses”, “non-medical personnel”, “physicians’ words when talking with each other professionally at the bedside”, “patient’s medical record”, “evidences in the environment”, “media”, “patient’s knowledge about the fate of the other patients”, and “patient’s friends and relatives”. Patients received information on the diagnosis of the disease which had afflicted them, different treatment methods, side effects of various treatment methods, considerations after surgery, treatment costs, prognosis, survival rate, and so on.

Despite the fact that in patients’ opinions medical team members were the best source to receive information, but they found some barriers to receive the needed information and raise their questions including “lack of access to the attend”, “behavioral manner of medical team members”, “their lack of time”, and so on.

Conclusion: The study findings show that patients with cancer receive a part of their information needs from unprofessional sources which may provide incorrect information to them and damage their health.
A Comprehensive Palliative Care Program at a Tertiary Cancer Center in Jordan

Shamieh O.1, Hui D.2

1King Hussein Cancer Center, Palliative Care, Amman, Jordan, 2MD Anderson Cancer Center, Palliative Care and Rehabilitation, Houston, TX, United States

Context: Palliative care is an emerging specialty in Arab countries and only available in a few cancer centers. In Jordan, cancer is the second leading cause of death, after cardiovascular diseases. In 2010, 6,820 patients were newly diagnosed with cancer. More than 50% of cancers presented in advanced stage. The palliative care program in King Hussein Cancer Center (KHCC), located in Amman the capital city of Jordan, is a leading cancer center in the region, has been growing rapidly to serve the needs of cancer patients and their families.

Objective: To describe the KHCC palliative care program and its integration into the oncology setting to optimize care delivery for cancer patients.

Methods: Descriptive review of palliative care program at KHCC.

Results: Cancer patients at KHCC have access to an interprofessional palliative care team in the inpatient, outpatient and community setting. In 2012, the inpatient consultation team saw 400 consultations. 979 patients were admitted to the KHCC palliative care unit and boarding service: 602 already under the direct care of our palliative care team and 377 newly transferred from oncology services. The median length of stay under palliative care was 11 days. The outpatient clinic had a total of 1,133 patient visits, with an average of 8 patients per day. The home care program enrolled 658 patients and provided a total of 1,501 visits, consisting of 177 initial visits, 1031 routine follow-up visits, 156 crisis visits, and 137 bereavement visits. Our program is World Health Organization-designated regional center for palliative care education and training, and actively conducts research.

Conclusion: Palliative care program at KHCC has a large patient volume. This program may be a model for successful delivery of comprehensive cancer care in the Middle East.

Keywords: KHCC: King Hussein Cancer Center; Palliative Care; Supportive Care; Middle East

Author Disclosure Statement: No competing financial interests exist.

Abstract number: P409

Using the Pain Management Index (PMI) to Assess the Adequacy and Outcomes of Cancer Pain Management at Referral to a Cancer Pain (CP) Clinic

Pina P.1, Dalzell C.2, Sabri E.3, Lawlor P.G.4

1Instituto Português de Oncologia de Lisboa, Lisbon, Portugal, 2Bruyere Research Institute, Ottawa, ON, Canada, 3Ottawa Hospital Research Institute, Ottawa, ON, Canada, 4Bruyere Continuing Care, Division of Palliative Care, Dept of Medicine, Dept of Epidemiology and Community Medicine, University of Ottawa, Bruyere and Ottawa Hospital Research Institute, Ottawa, ON, Canada

Background: There are few literature data on the adequacy of CP management in Portugal.

Aims: To determine (1) the adequacy of CP management (PMI status) and its predictors at CP clinic referral, (2) the associated psychosocial impact and therapeutic interventions.

Methods: Consecutive patient referrals to a specialist CP clinic had standard assessments and documentation: Brief Pain Intensity (BPI) ratings (worst and average in last 7 days; and pain now) on a 0-10 scale; pain mechanism; episodic pain; functional status; oral morphine equivalent daily dose (MEDD); psychosocial distress; demographics; comorbidities; adjuvant analgesia; cancer diagnosis, metastases, treatment and pain duration. The BPI average pain at referral was categorized as none (0), mild (1-3), moderate (4-6), and severe (7-10), generating a corresponding PMI pain score of 0, 1, 2, and 3 for each patient. PMI treatment scores of 0, 1, 2, and 3 reflected use of none, non-opioid, mild, and strong opioid, respectively. The PMI pain score was subtracted from the PMI treatment score to give the actual PMI. A -ve PMI reflects inadequate treatment. Predictors of a -ve PMI were examined in logistic regression models, generating Odds Ratios (ORs) for predictor variables. Impact and interventional variables for PMI -ve vs +ve groups were compared using the Chi-square test and t-test, as appropriate.

Results: 95/371 (25.6%) had a -ve PMI. BPI mean % pain relief was 30.4 ± 31.5 in the PMI -ve group versus 49.6 ± 26.6 in the PMI +ve (p< 0.001).

Conclusions: One in four patients had under treatment of their CP based on their PMI and this was corroborated by patients’ subjective sense of pain relief.

Abstract number: P410

Validation of ‘Cancer Dyspnoea Scale’ for Advanced Cancer Patients in a Tertiary Cancer Centre in India

Damani A., Ghoshal A., Muckaden M.

Tata Memorial Hospital, Palliative Medicine, Mumbai, India

Background: Dyspnea is difficult symptom to measure because of its subjective nature and multi-dimensionality.
12-point multidimensional scale, Cancer Dyspnoea Scale (CDS), was developed in Japan by Tanaka et al for measurement of dyspnea in cancer patients. This is self rating easy to administer scale for measuring the physiological and psychological distress due to dyspnea. It is validated in Japanese, English and Swedish only.

**Aim:** Study aims to describe validity and reliability testing of CDS in local population of advanced cancer in tertiary cancer care centre.

**Methods:** English version of CDS was translated to Hindi and Marathi using standard forward-backward translation procedure and feasibility study for new version was carried out in 10 patients. Study was approved by IRB and HEC. Total of 120 patients, newly registered with department of Palliative Medicine, who fit into selection criteria, 60 for Hindi and 60 for Marathi translated questionnaires were chosen. After obtaining informed consent, patients were asked to fill a set of questionnaires including CDS(translated version), Visual Analogue Scale-Dyspnoea. Only baseline measures were used.

**Results:** Results were analysed using following statistical considerations for Hindi and Marathi versions separately:

- Construct validity was evaluated by factor analysis.
- Intersubscale correlation was evaluated by calculating Pearson’s correlations.
- Convergent validity was assessed by Pearson’s correlations with VAS for dyspnea completed at same time.
- Internal consistency of multiple item scales was evaluated by calculating Cronbach’s alpha coefficient.

**Conclusion:** This study established validity of translated versions of CDS in Hindi and Marathi. Validation will allow use of this tool as a multidimensional and subjective measure of dyspnea in other studies involving measurement of dyspnea in local cancer population. So, this study will benefit the further research on dyspnea in patients with advanced cancer.

**Abstract number:** P411

**Abstract type:** Poster

**Prognostication Tools at the End of Life. Which One Helps More?**

_S. Barallat Gimeno_ E.,_2, Calal-Sotelo J._,_3, Nabal Vicuña M._,_3, Trujillano Cabello J._

_AUSS-CP HUAV-GSS, Lleida, Spain, 2AUSS-CP HUAV, Lleida, Spain, 3University of Lleida, Basic Sciences, Lleida, Spain_

**Introduction:** Survival prognostication at the end of life of oncological diseases remains a major challenge. Several tests have been developed in order to help professionals to determine survival intervals.

**Methods and population:** 246 consecutive advanced cancer patients, were recruited between June and September 2011. Data related to age, gender, diagnosis and mental status were obtained. Functional status was assessed by the use of the Barthel test (BT), Karnofsky Performance Scale (KPS) and the Palliative Performance Scale version 2 (PPSv2). Prospectively the date of death was recorded.

A 30- days survival analysis and a classification tree based on the Chi-squared Automatic Interaction Detector (CHAID) methodology were performed in order to identify which variables were associated with the 30- days survival interval.

**Results:** Male 149 (60.6%), Mean of age 65.83 (female 63.61 years), 31% lung cancer. No statistical differences were observed when comparing 30 day survival with age (p=0.713), gender (p=0.114) or diagnosis (p=0.335). Kaplan Meyer survival curve showed significative statistical differences when comparing 30- day survival with PPSv2 subgroups (p=0.000), with KPS (p=0.000) and BT (p=0.000).

The CHAID model (KPS/ BT / PPSv2 values) generates 5 decision rules with a rank of assignation of probability from 7.1 % to a maximum of 92.9 %. The Association of KPS ≤ 40 with PPSv2 ≤ 30 shows a 30-days survival of the 20.5% of the patients; However when we associate the KPS ≤ 40 with PPSv2 >30 the 30-days survival rises up to 42.9%. The association of KPS (40-70) with BT< 60 gives us a 30-days survival of 65.9% while the same KPS with higher BT (>60) shows a survival of the 89.1% of the population.

**Conclusions:** In our population the average of 30-days survival is 64.2% being the association between the different test used (KPS, BT and PPSv2)which helps us to discriminate better the 30-days survival interval.

**Abstract number:** P412

**Abstract type:** Poster

**Reporting about Palliative Systemic Treatment in Patients with Advanced Non-small Cell Lung- and Pancreatic Cancer: Descriptive Study**

_Brink M.1_, _Terpstra W.2_, _Wijnhoven M.3,4_, _Gunnink-Boonstra N.2_, _Buiting H.M.3_

1Comprehensive Cancer Center the Netherlands (IKNL), Utrecht, Netherlands, 2Onze Lieve Vrouwe Gasthuis (OLVG), Amsterdam, Netherlands, 3Comprehensive Cancer Center the Netherlands (IKNL), Rotterdam, Netherlands, 4VU University Medical Center, Amsterdam, Netherlands

**Introduction:** Secondary use of (electronic) medical files to determine the quality of care gains importance in the
**Abstracts**

field of palliative- and end-of-life care. It is unknown whether medical files provide insight in the quality of the decision-making. Doctors' reports about PST could be viewed as a description on how doctors interpret their decisions. Such information is relevant for palliative systemic treatment (PST), where clinical study-outcomes often focus on life-prolongation.

**Methods:** We examined text fragments about PST in medical files (2009-2012) from 143 deceased NSCLC and pancreatic cancer patients who did (n=62) and did not (n=81) receive PST. We focused on (1) neutral descriptions and (2) doctors' considerations.

**Results:** In total, 205 (NSCLC; 3,9 / patient) and 71 (pancreatic cancer; 1 / patient) text fragments were reported. Doctors more often reported about treatment options in patients who had received PST (53%) than in patients who had not received PST (42%); a discussion with the patient/family was more often reported in the no-PST group (52% versus 44%). Reports reflecting considerations for PST, mainly focused on patients' prognosis (44% PST; 57% no PST) and survival gain (29% PST; 33% no PST). The patients' wish concerning PST was less frequently mentioned in patients who had received PST (28% versus 45%). In patients who had not received PST, this wish mainly included a wish to preserve quality of life and/or no further outpatient-clinic visits. In their considerations about PST, doctors seldom reported about quality of life related to the toxicity/side effects of PST, comorbidity and older age.

**Conclusion:** Both neutral descriptions and doctors' considerations provide insight in how doctors interpret decisions. In patients who did not receive PST, doctors focus on the patients' wish and discussions with the patient/family. This may reflect doctors' intrinsic wish to substantiate decisions from the patient perspective when they refrain from PST.

**Abstract number:** P413

**Abstract type:** Poster

**Teenagers with a Dying Parent - A Qualitative Retrospective Study**

Melcher U.1, Henriksson A.1,2, Sandell R.3

1Ersta Sköndal University College and Ersta Hospital, Palliative Research Centre, Stockholm, Sweden, 2Capio Geriatrics, Palliative Care Unit, Stockholm, Sweden, 3Ersta Sköndal University College, Stockholm, Sweden

Teenagers with a dying Parent - Teenagers experiences

**Background:** Being a teenager living with a dying parent is well known to be distressing with a significant impact on teenagers psychological well-being. To support teenagers and prevent long-term psychological consequences we need to find out more about teenagers experiences.

**Aim:** The aim was to explore teenagers experiences from living with a severely ill dying parent.

**Method:** Repeated qualitative interviews were conducted with ten teenagers that had lost a parent within a year. The parent had received specialist palliative care by the time of death. Qualitative content analyses were used for analyses.

**Results:** Preliminary results show that teenagers carry a great responsibility in the care of the sick parent and the healthy parent, siblings and general ordinary family matters. While carrying this responsibility they experience loneliness and try to adjust to the situation in different ways by being loyal to their parents. In their process to understand that the parent is dying they prepare by observing and trying to make sense of the illness symptoms they notice. Feeling trust to and support from the parents makes them feel more involved and less lonely and responsible.

**Conclusion:** This study contributed with knowledge about great feelings of responsibility and loneliness among teenagers who has a dying parent. Healthcare professionals in palliative care could work to acknowledge and try to support the teenagers to feel involved, less lonely and less burdened by responsibility. An important aspect is also to support the healthy parent enough and thereby reduce the responsibility from the teenager.

**Abstract number:** P414

**Abstract type:** Poster

**Gentle Massage to Reduce Pain among People over the Age of 85 in Nursing Homes - A Pilot Study**


1Ersta Sköndal University College, Palliative Research Center, Stockholm, Sweden, 2Karolinska Institutet, Oncology-Pathology, Stockholm, Sweden, 3Bräcke Diakoni, Gothenburg, Sweden

**Background:** With a growing population of old people, care needs will increase as many suffer from co-morbidity and thereby various symptoms. Pain is the most common symptom yet, to a great extent unrecognised and untreated in this population. Pain is described to be overwhelming, debilitating, difficult to diagnose and affecting quality of life.

The aim is to evaluate effects of massage on pain and perceived quality of life among people ≥ 85 suffering from co-morbidity.

**Method:** A controlled multicentre study collecting both quantitative and qualitative data. The study will be performed at three large nursing homes in Sweden including 90 participants.
**Analysis:** non-parametric and parametric statistical analysis and qualitative content analysis.

**Inclusion:**

1. people ≥ 85 years,
2. ≥ 2 diagnosis,
3. experience pain,
4. providing informed consent,
5. can read and write Swedish language.

**Exclusion criteria:** cognitive dysfunction due to pharmaceutical treatment and/or palliative sedation.

- Data will be collected concerning; age, gender, diagnosis, social status, medication, various symptoms (ESAS), pain (POM), sleep (PDSS) and quality of life (AQEL-20).

**Methods:**

Intervention group will register blood pressure and heart rate before and after the massage sessions. The intervention group will receive hand or foot massage three times a week for three weeks while the control group will receive care following the principles of each nursing home. Both groups will be interviewed concerning experiences of pain and quality of life. Patients’ charts will be evaluated at baseline and after one month.

**Preliminary results:** Stimulation of CT fibres through gentle massage may normalise physiological parameters, reduce pain and increase quality of life in the intervention group compared to the control group.

**Clinical implication:** A positive result will give strength to the evidence that massage is a method helping to relieve pain and improve quality of life.

**Abstract number:** P415

**Abstract type:** Poster

**Nursing Home Staff’s Views on Residents’ Dignity: A Qualitative Interview Study**

**Oosterveld-Vlug M.G.**†, Pasman H.R.W.†, Van Gennip I.E.†, Willems D.L.‡, Onwuteaka-Philipsen B.D.†

†Department of Public and Occupational Health, EMGO Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Amsterdam, Netherlands, ‡Department of General Practice, Section of Medical Ethics, Academic Medical Center, Amsterdam, Netherlands

**Background:** Preserving dignity is an important element of nursing home care. We aimed to gain insight in the way nursing home staff perceive and preserve the personal dignity of individual residents in daily practice.

**Methods:** A qualitative descriptive interview study was designed, in which in-depth interviews were performed with 13 physicians and 15 nurses. They expressed their views on the personal dignity of 30 recently admitted residents on the general medical wards of four nursing homes in The Netherlands. Interviews were transcribed and analyzed following the principles of thematic analysis.

**Results:** According to physicians and nurses, physical impairment and being dependent on others threatened the residents’ dignity. Whether or not this led to a violation of an individual resident’s dignity, depended - in staff’s opinion - on the resident’s ability to show resilience and to keep his/her individuality. Staff mentioned treating residents with respect and taking care of their privacy as most important elements of dignity-conserving care and strived to treat the residents as they would like to be treated themselves. They could often mention aspects that were important for a particular resident, but, when asked what they could contribute to his/her dignity, frequently raised general aspects of dignity-conserving care, applicable to most nursing home residents. By attempting to give dignity-conserving care, staff often experienced conflicting values in daily care and barriers caused by the lack of resources.

**Conclusions:** Tailoring dignity-conserving care to an individual nursing home resident appears hard to bring about in daily practice. Both attention to solve contextual barriers within the nursing home as well as more awareness of staff for their own values, which they take as a reference point in treating residents, is needed to promote personal dignity in nursing homes.

**Main source of funding:** The Netherlands Organisation for Scientific Research (NWO).
Methods: Five focus groups were held with family physicians (N=39) in Belgium. Focus group discussions were transcribed verbatim and analysed using a constant comparative approach.

Results: Five key roles of family physicians in preventing and guiding hospital admissions at the end of life were identified: the family physician as an organizer of care, anticipating future scenarios; as an initiator of decisions, mostly in an advisory manner; as a provider of end-of-life care, in which competencies and attitudes are considered important; as a provider of support, particularly by being available during acute situations; and as a decision maker.

Conclusions: Family physicians face many different and complex roles and difficulties in preventing and guiding hospital admissions at the end of life. Adequate end-of-life care training and the development or expansion of initiatives to support family physicians, preferably aimed at improving their attitudes and expertise in providing such end-of-life care, could contribute to a lower proportion of inappropriate deaths in hospital.

Abstract number: P417
Abstract type: Poster

Evaluation of the Management for Hospital Patients with End Stage Liver Disease
Boland E.1, Nelson A.2, Whitford R.1, Abouda G.2

1Hull and East Yorkshire NHS Trust, Palliative Medicine, Cottingham, United Kingdom, 2Hull and East Yorkshire NHS Trust, Gastroenterology, Cottingham, United Kingdom

Introduction: Deaths from end stage liver disease are rising in the United Kingdom and over 70% of these patients die in hospital.

Aim: To determine the end of life management of hospital patients with end stage liver disease.

Method: Notes of patients with end stage liver disease who died in hospital between November 2011-December 2012 were obtained and data retrospectively collected on causes of liver failure, Childs score, re-admissions over the last year, specialist palliative care input, resuscitation decisions, discussion around preferred place of care and use of the Liverpool care pathway.

Results: 32 patients' notes were reviewed (21 males), with a mean age of 56 years (SD 14.3) at time of death. The commonest cause of liver disease was alcohol-related (88%; n=28) with 88% (n=28) of all patients having Childs C score on admission. The mean duration of hospital stay was 16 days. With regards to resuscitation decisions, 16% (n=5) had an attempted resuscitation and 56% (n=18) had a do not attempt resuscitation decision order made in the last week before dying. None of the patients received specialist palliative care involvement. Discussion around preferred place of care occurred only in 9% (n=3), 2 of which preferred to die at home. The Liverpool care pathway was started for 34% (n=11) of patients. Most (66%,n=21) patients had admissions in the year prior to death.

Conclusion: Retrospective data analysis of deceased patients showed that identifying patients with end stage liver disease is challenging and many of these patients died in hospital with no advance care planning in place. Since this after death analysis, the specialist palliative care team has been proactive in providing an in-reach service and working on providing an integrated team approach. Research is needed into assessing health-related quality of life in patients with end-stage liver disease and how they might benefit from both palliative and supportive care alongside active medical management.

Abstract number: P418
Abstract type: Poster

Physicians’ Experiences and Perspectives Regarding the Use of Continuous Sedation until Death for Cancer Patients in the Context of Psychological and Existential Suffering at the End of Life
Anquinet L.1, Rietjens J.1,2, van der Heide A.3, Bruinsma S.2, Janssens R.3, Deliens L.1,4, Addington-Hall J.3, Smithson H.5, Seymour J.7, UNBIASED

1Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium, 2Erasmus MC, Public Health, Rotterdam, Netherlands, 3VUMC, Metamedica, Amsterdam, Netherlands, 4VUMC, EMGO Institute, Amsterdam, Netherlands, 5University of Southampton, Fac of Health Sciences, Southampton, United Kingdom, 6University of Sheffield, Academic Unit of Primary Medical Care, Sheffield, United Kingdom, 7University of Nottingham, Nottingham, United Kingdom

Research aims: The use of continuous sedation until death (CSUD) for patients with unbearable and untreatable psychological and existential suffering is controversial. We aim to explore the circumstances in which physicians resort to CSUD in the case of psychological and existential suffering at the end of life.

Study population: Our study was conducted in Belgium, the Netherlands and the UK in hospitals, palliative care units, and at home. We held interviews with 35 physicians involved in the care of cancer patients who had psychological and existential suffering and had received CSUD.

Design and methods: Qualitative case study design, based on face-to-face interviews.

Methods of statistical analysis: Constant comparative analysis.
**Results:** In the studied countries, three groups of patients could be distinguished regarding the origin of their psychological and existential suffering. The first group had preexisting psychological problems before they became ill; the second developed psychological and existential suffering during their disease trajectory; and the third presented psychological symptoms that were characteristic of their disease. Before resorting to CSUD, physicians reported that they had considered an array of pharmacological and psychological interventions that were ineffective or inappropriate to relieve this suffering. Necessary conditions for using CSUD in this context were for most physicians the presence of refractory symptoms, a short life expectancy and an explicit patient request for sedation.

**Conclusions:** Physicians in our study used CSUD in the context of psychological and existential suffering after considering several pharmacological and psychological interventions. Further research and debate is needed on how and by whom this suffering at the end of life should be best treated, taking into account patients’ individual preferences.

**Funding:** ESRC (UK), VLK, BOF Ghent and FWO (BE), and NWO and ZonMw (NL).

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**Abstract number:** P419
**Abstract type:** Poster

**Introduction of Formal Advance Care Planning to a District General Hospital**

*Sethi L.1, Lawrie I.2*

1University of Manchester, Manchester Medical School, Manchester, United Kingdom, 2Pennine Acute Hospitals NHS Trust, Department of Palliative Medicine, Manchester, United Kingdom

**Background:** Poor knowledge of patients’ wishes about aspects of care when they are approaching the end of life may result in them being cared for in a way that they do not want. Feedback suggests needs must be addressed to enable informed decision-making about care before patients are too ill to do so. Advance Care Planning (ACP) is a process involving a series of discussions about patients’ preferences for care. New documentation to record ACP discussions has been introduced in England.

**Objective:** To review the amount and quality of information collected before and after introduction of formal ACP documentation in a large English District general Hospital, as well as reasons why ACP discussions may be inappropriate to initiate or complete.

**Methods:** An ACP record form was introduced to document when ACP was appropriate, wishes expressed by patients, and reasons why ACP discussions may be inappropriate. Information about patient preferences for treatment and care, and legal arrangements made prior to the introduction of the form were compared before and after its introduction. Records of all newly referred patients were reviewed (n=147). Four key areas considered essential were identified. How often and how well these areas were discussed with the patients were analysed.

**Results:** 83.7% of patients (n=123) were identified as inappropriate due to the patient being too unwell (48%) or distressed (17%), or due to minimal input from specialist services (35%). 47.5% patients referred after introduction of the new documentation had completed forms. Preferred Place of Care and family involvement were documented most frequently.

**Conclusion:** The SPC Team provides excellent support and care to patients approaching the end of life. Hospital appears not to be the best setting for ACP discussions. Formal documentation requires adaptation in the way it is used, but appears to have an overall positive impact on ACP discussions and communication between professionals.

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**Abstract number:** P420
**Abstract type:** Poster

**Renal Function in Palliative Care In-patients**

*Deskur-Smielecka E.1,2, Kotlinska-Lemieszek A.1,2, Wieczorowska-Tobis K.1*

1Poznan University of Medical Sciences, Chair and Department of Palliative Medicine, Poznan, Poland, 2University Hospital of Lord’s Transfiguration, Poznan, Poland

Multiple drugs used in palliative care, including opioids, may accumulate when kidney function deteriorates, leading to serious adverse effects. Incidence of renal impairment in cancer patients is higher than in general population. Renal function in frail palliative care in-patients has not been investigated.

**Aim:** To assess incidence and severity of renal impairment in palliative care in-patients.

**Methods:** Retrospective analysis of medical records of patients admitted to palliative care ward in 2012. Anthropometric characteristics, diagnosis, Karnofsky performance status (KPS) and laboratory findings were collected. Glomerular filtration rate (eGFR) was estimated using the abbreviated Modification of Diet in Renal Disease (aMDRD) and Cockroft-Gault (C-G) formulae.

**Results:** 331 patients were admitted to palliative care ward. Serum creatinine (SCR) concentrations were determined in 252 (76%) subjects (102 men/150 women) aged 66.3±11.5 (mean±SD). In the remaining 79 patients blood tests were not performed due to short life expectancy (hours-days). Mean body mass index (BMI) was 22.8 ±5.4 kg/m², and 44 patients (17.5%) had BMI< 18.5 kg/m². Median KPS was 40. Sixty patients (23.8%) had urogenital cancers, 191
(75.8%) had other cancers, and 2 had no malignancy. Mean SCr was 1.19±1.26 mg/dl. SCr values were elevated (>115 mg/dl) in 50 patients (19.8%). Mean eGFR estimated by aMDRD formula was 84.5±45.3 ml/min, and 70.9±40.2 ml/min by C-G equation. GFR< 60 ml/min estimated by aMDRD and C-G formulae was found in 76 (30.2%) and 114 (45.2%) subjects, respectively. Approximately 10% of patients had eGFR< 30 ml/min.

Conclusions: Renal impairment is common in palliative care in-patients, including considerable number of subjects with severely reduced kidney function. SCr fails to detect decline of renal function in many of these patients. High incidence of renal impairment implies caution while introducing and/or titration of renally excreted drugs, including opioids.

Abstract number: P421
Abstract type: Poster

Advanced Directives and Other Ethical Issues among Different Professional and Clinical Units

Gorlat-Sanchez B.1, Ojeda-Virto F.1, Martinez-Cruz E.2, Montoya-Juarez R.3, Campos-Calderon C.1, Alfaya-Gongora M.4, Hueso-Montoro C.1, Hernandez-Lopez E.2, Guardia-Mancilla P.2, Garcia-Caro M.P.5

1Servicio Andalus de Salud, Motril, Spain, 2Servicio Andaluz de Salud, Granada, Spain, 3University of Granada, Granada, Spain, 4University of Granada, Melilla, Spain

Aim: The aim of this study is to analyze professional practice related to advanced directives (AD) and other ethical issues, among different professionals and clinical units.

Methods: Observational and descriptive study. A stratified sampling was performed among physicians and nurses of different hospitals and primary care centers of Granada and Melilla. Professionals temporarily hired were excluded. A questionnaire was developed ad hoc. 55 items about end-of-life care experience, distributed in 11 main issues, were rated by professionals in a 5-point Likert scale. Results related to “Ethical Issues” are discussed in this communication. A descriptive analysis and ANOVA comparative analysis between different units was performed.

Results: 312 professionals were interviewed for this study. 62.2% of them were men. Mean age was 47 years (SD=9.28), and average professional experience was 22.5 years (SD=9.99). 40% were Physicians and 60% nurses. 99 professionals (31%) worked in Primary Care, and 69% in Hospitals (17% in surgery wards, 19% in ICUs, 18% in Internal Medicine and 5% in Oncology/Palliative Care). In general, professionals have little knowledge about AD. Internal Medicine, Intensive Care, and Surgery wards, are the units where AD are less known (p=0.00) and where AD are less discussed with patients and families (p=0.00). In the other hand, non-resuscitation orders are poor used in Primary Care units (p=0.00).

Conclusion: Access to advanced directives still is a difficult issue for professionals. Most of them do not know how to register AD and how to consult a specific register, so they feel not able to inform patients and families about this document.

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Abstract number: P422
Abstract type: Poster

Inner Curriculum in Palliative Care Professionals: Differences among Professional Roles

Sansó N.1,2, Galiana L.3, Oliver A.3, Jiménez E.4, Barbero J.3, Benito E.1

1Ibsalut, Palliative Care Program of the Balearic Islands, Palma de Mallorca, Spain, 2University of Balearic Islands, Palma de Mallorca, Spain, 3University of Valencia, Valencia, Spain, 4Institut Català de la Salut (ICS), Granollers, Spain, 5La Paz Hospital, Madrid, Spain

Aims: Professionals with different curricula and roles are involved in palliative care. The present work aims to assess how their professional roles and other socio-demographic variables influence their psychological well-being, coping with death, fatigue and satisfaction of compassion.

Method: In a cross-sectional study, 387 Spanish palliative care professionals were surveyed by an on-line platform. Of those, 43.4% were doctors, 33.3% nurses, 14.4% psychologists, 4.9% nursing assistants and 4.1% were social workers. Data from socio-demographic (gender, age, years of hospital experience and years of palliative care experience) and other variables (spiritual training, self-care, awareness, coping with death, fatigue and satisfaction of compassion, and well-being) were collected. χ², t-tests and simple and multiple analyses of variance were conducted.

Results: When differences by gender were studied, no statistical significant relations were found. In the case of age, a negative relation was found between age and compassion satisfaction (r = -.116, p = .037). Years of experience in palliative care was positively related to coping with death (r = .124, p = .036), showing greater levels of coping for those professionals with more experience. The simple and multiple analyses of variance showed statistical significant relations among the different professions and the psychological variables. For example, there were differences among professions in the dimensions of well-being (F24,1250 = 1.881, p = .006) and the dimensions of burn-out, satisfaction and compassion fatigue (F12,858 = 2.878, p = .001).
Conclusion: Palliative care professionals surveyed show appropriate levels of self-care, coping with death, awareness, well-being and quality of life, with differences on these psychological variables related to age, years of palliative care experience and profession. Implications of these results are discussed.

Funding: This research is funded by SECPAL.

Abstract number: P423
Abstract type: Poster

Advance Care Planning for Persons with Dementia in Nursing Homes: Effects of a Training In Shared Decision Making

Ampe S.1, Sevenants A.1, Cappens E.1, Spruytte N.1, Smets T.2, Declercq A.1, Van Audenhove C.1
1KU Leuven, LUCAS - Centre for Care Research and Consultancy, Leuven, Belgium, 2Vrije Universiteit Brussel, End-of-Life Care Research Group, Brussels, Belgium

Research aim: For nursing home residents with dementia and their family members it is important that (end-of-life) care choices are prepared in an earlier stage of the disease, through the process of advance care planning (ACP). For this purpose, a shared decision making (SDM) approach is presented as an ideal way to talk with residents with dementia, family caregivers and healthcare professionals. The aim of the present study is to examine the effect of a training program in which the basic principles of a model for SDM are taught and implemented in practice. This model consists of “Choice talk” (informing that there IS a choice), “Option talk” (informing on the advantages and disadvantages of every option) and “Decision talk” (making a final decision).

Design and methods: The intervention in this study consists of a training program comprising two 4h-workshops and a homework assignment. Participants were staff members (n=49) from 9 different nursing homes divided over 5 small groups. The training focused on knowledge and skills of Choice talk, Option talk and Decision talk, and 3 prototypical situations were introduced as exercises. In the time between both workshops, the participants applied the skills in their practice and reported about barriers and facilitators. The role-play exercises in both workshops were coached by the same experienced trainer and the researcher was co-trainer. The effect on the use of SDM in ACP was measured in a pretest-posttest design. The participants’ view on importance and own competence in the behavioural aspects of SDM, and the frequency of putting this behaviour into practice was assessed.

Results and conclusion: The intervention is ongoing; results are expected by the end of 2013. An increase in participants’ view on importance and competence in ACP, and on frequency of the use of these typical interventions is expected.

Abstract number: P424
Abstract type: Poster

Service Evaluation of Care Homes Inclusion in a New Web-based Electronic Service that Coordinates Key End of Life Care Services

Kwakwa J.1, Riley J.1, Joanne D.2, Shaw M.2
1The Royal Marsden NHS Foundation Trust, London, United Kingdom, 2The Institute of Cancer Research, London, United Kingdom

The ‘Co-ordinate My Care’ (CMC) service aims to improve individuals’ end of life experiences through a common electronic communication interface sharing personalised care plans of clinical details and preferences with separate services - hospitals, hospices and community services pan-London. Over 7,800 patient records have been entered by 6,116 doctors and nurses. Key information is flagged to the Ambulance Service, GP and out of hours services to coordinate support and prevent inappropriate admission.

Registered nursing care is provided to 20,756 care home residents in London, which includes a large cohort that have end of life care needs, so training care home registered nurses to use CMC has clear advantages.

Research questions: The financing, organisational culture and governance of Nursing Homes is very different to that of the National Health services and feasibility questions include; meeting information governance standards, access to computers, internet connection and staff computer and end of life care competency.

Study aim: To evaluate if the Coordinate My Care service can improve achievement of residents’ preferences at the end of life.

Method: A three month observational study of 8 pilot care homes trained to use CMC and 8 care homes prior to training.

Objectives:

1. Comparison of achievement of residents’ Preferred Place of Care (PPC) and Preferred Place of Death (PPD) between the two groups.
2. Comparison of the number who died in the home compared to acute hospital setting.
3. Identification of the number of times the Ambulance Service was called to the two groups.

The study concludes January 2014 and the process is well underway. Interim results will be available for each month of the study. The final results will be available by February 28th 2014.
Abstract number: P425
Abstract type: Poster

Decision Criteria Guiding Chemotherapies in Palliative Intention (CPI): A Prospective Study Including Patients’, Doctors’ and Nurses’ Perspectives

Ribig, K.1, Magava-Kaltermann, N.2, Mayer, A.1, Strasser, F.4

1IBCSG (Intl. Breast Cancer Study Group), Bern, Switzerland, 2Cantonal Hospital St. Gallen, Oncological Palliative Medicine, Oncology, Dept. Internal Med & Palliative Centre, St. Gallen, Switzerland, 3Cantonal Hospital St. Gallen, Palliative Center, St.Gallen, Switzerland, 4Cantonal Hospital St. Gallen, Palliative Medicine, Oncology, Dept. Internal Med & Palliative Centre, St. Gallen, Switzerland

Background: In incurable cancer patients (pts) patient-centred decision processes (DP) for CPI going beyond tumor control and toxicities are needed. Symptom control, remaining life goals, subjective treatment side-effects, information about palliative care, or logistic factors may be relevant. We systematically develop context relevant, clinical applicable decision criteria for CPI.

Methods: The project covers:

1) collection of factors (fct) relevant in the CPI-DP,
2) fct reduction including Delphi processes,
3) prospective testing of pilot decision criteria in oncology clinics.

A systematic literature review (SLR; PRISMA) investigates original papers exploring the CPI-DP. Focus groups (FG) with 3 types of participants

a) advanced, incurable cancer pts having discussed recently a CPI,
b) nurses involved in their care, and
c) oncologists together with GPs, are performed.

The interview guideline is adapted including data collected in the SLR and after each FG for the respective participant group. Ad verbatim transcripts of FG are thematically analysed (Atlas.ti-7) by 2 independent raters (psychologist, MD). Data reduction and wording of retrieved fcts involves 3 professionals until consensus, classical Delphi methodology FG participants or substitutes and int experts. Finally, independent agreement of oncologist and pt on CPI decision criteria is explored in clinical settings.

Results: SLR retrieved 44 original papers with a variety of decision fcts. Analysis of 8 FG with 15 pts, 11 nurses, and 15 physicians resulted in 95 fcts, currently undergoing primary and secondary data reduction. We expect a list of 30-50 fcts to be reduced in the Delphi to 10-20 decision criteria for pilot testing in 100 pts in 3 clinics.

Discussion: We expect that a criteria-based decision aid for CPI might promote patient-goal based care with or without effective CPI both with optimisation of QOL until death and prevent futile, expensive and burdensome chemotherapy.

Funding: This work is supported by KLS 2785-02-2011, thesis for Master of Public Health: KR, MD Dissertation: AM

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Abstract number: P426
Abstract type: Poster

Palliative Care for Patients with Terminal Heart Failure

Rhondali, W.1,2, Texier, G.3, Meunier-Lafay, E.4, Dellinger, A.5, Gérard, C.6, Morel, V.3, Filbet, M.1

1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3Centre Hospitalier de Pontchaillou, Palliative Care, Rennes, France, 4Centre Hospitalier William-Morey, Palliative Care, Chalon-sur-Saône, France, 5Centre Hospitalier William-Morey, Cardiology, Chalon-sur-Saône, France, 6Fondation Hôtel-Dieu du Creusot, Cardiology, Le Creusot, France

Purpose: Heart failure is a common disease and its progression to end-stage heart failure is responsible of high mortality. The aim of this retrospective study was to assess the access to integrated palliative care to the usual management, 6 months prior to their death, and especially during the last hospitalization.

Patients and methods: A retrospective study was performed in patients who died of heart failure in 2009 in two hospitals. The analysis was performed on 20 cases of each institution. The records of consecutive patients were included in an anti-chronological order from 31 December 2009.

Results: For their last hospitalization, 37 patients (93%) were hospitalized in emergency. Within 3 days prior to death, the most frequent symptoms were dyspnea (n=33, 82%), and pain (n=30, 75%). Therapeutic most frequently used were oxygen (n=31, 77%) and analgesics (n=30, 75%). No patient was seen by a psychologist. The decision to limit treatment for comfort care was reported for 24 patients (60%) and the median of the average time between the decision and death was 2 days (Q1-Q3, 1-5 days).

Conclusion: Patients with terminal heart failure have many symptoms often requiring multidisciplinary care. This type of study relating practices shows that there is still a lot to do to integrate palliative care in the usual management of patients with heart failure.
Consulting Palliative Care Nurses in Long-term Care Settings for People with Intellectual Disabilities, Mentally Ill and Elderly

Verschuur E.M.L.1, Nogarede R.2, Krol R.3, van der Sande R.4

1HAN University of Applied Studies, Faculty of Health and Social Studies, Nijmegen, Netherlands, 2Regional Palliative Care Network South Gelderland, Nijmegen, Netherlands, 3IKNL Comprehensive Cancer Care Centre the Netherlands, Utrecht, Netherlands, 4HAN University of Applied Sciences, Faculty of Health and Social Studies, Nijmegen, Netherlands

Background: Palliative care is not exclusively for people with non-curable cancer, but also for people with intellectual disabilities (ID), mental ill (MI), dementia and frail elderly. Healthcare workers are not trained to organize optimal palliative care for these people. Consulting palliative care nurses (CPCN), trained to support healthcare workers in delivering good palliative care, might add to the quality of palliative care in long-term care settings.

Objectives: To evaluate CPCN’s contribution to the delivery of good palliative care in long-term care settings.

Methods: Thirty-two nurses in 16 long-term care settings were trained as CPCN to identify patients with palliative care needs and supported interdisciplinary teams in offering adequate care. Questionnaires were send to 80 involved healthcare workers to collect data on their experiences with the CPCNs. In addition, the CPCNs were asked how they experienced their new role.

Results: CPNCs were consulted in 60 patients (mean age 76 yrs; 65% female). The CPCNs supported, advised and educated care teams in palliative care giving and were involved in discussing treatment policy in multidisciplinary meetings. The involved healthcare workers valued the role of CPNCs with an average of 7.8 (0-10 scale). They felt supported in assessing problems and needs (74.1%), in identifying and anticipating potential problems (76.0%), decision making in palliative care (60.6%) and promoting comfort and symptom management (78.9%). Approximately half of the CPNCs found it difficult to combine their new role with the other tasks they have. However, they feel sufficiently competent in their new role (79%). In addition, they feel they have a meaningful contribution to palliative care giving in their own long-term care setting.

Conclusions: The CPCNs contribute to structurally more focus on palliative care in long-term care settings for ID persons, MI and elderly people.

An Exploration of the Experiences of Children Affected by Life Limiting Conditions and their Families

Menezes A.

Shooting Star CHASE, Practice Education, Surrey, United Kingdom

Aims: The aim of this doctoral study was to explore the experiences of life-limited children. Participants included 11 children, their parents and siblings from 10 families (39 participants in all).

Methods: Case studies provided the overarching strategy. Methods combined participant observation, interviews and an invitation for young participants to use their own artwork and photographs to help them explain their day-to-day experiences.

Results: The study uncovered common elements (‘moments of realisation’) in the children’s life stories regardless of their diagnosis, as follows:

- Questions of inheritance
- Diagnosis and prognosis
- Acute loss of abilities
- Slow deterioration
- Life-threatening surgery
- The cycle of crisis and survival
- The child’s life and death.

The child’s condition could remain unchanged, be altered in the short term or there could be permanent deterioration. These moments stopped life for the children and families, triggering insights into immediate and future losses. The study challenges linear concepts of dying trajectory for children who continue to grow and develop.

Family awareness and communication: The children who took part were going to lead short lives. Families shut away this fact to get on with daily life with and for the child. Participants referred to the child’s life limiting illness in three ways:

1. The illness
2. Death in childhood
3. The child’s dying

Self, identity and biographical disruption: The children challenged concepts of ‘biographical disruption’ by gradually encompassing the life limiting illness into their sense of self and living life to the full.

Conclusion: Professionals should be aware that ‘moments of realisation’ in the child’s unfolding life
story highlight re-occurring times in the child’s life when pressure on family communication is heightened, challenging notions about ‘one moment’ to talk to the child about their illness.

Abstract number: P429
Abstract type: Poster

Some Issues with Cancer Patients with Dementia on the Palliative Care Unit and Special Nursing Homes for the Elderly in Japan

Kawamura M.1, Ide S.2, Kimura K.3, Takeu R.4, Nishimura K.4

1Sapporo City University, School of Nursing, Sapporo, Japan, 2Open University of Japan, Tokyo, Japan, 3Keiyukai Sapporo Hospital, Sapporo, Japan, 4Universities of Hokkaido, Tobetsu, Japan

Background: Population of elderly cancer patients with dementia is increasing in Japan; however, there is little survey about their treatment in palliative care units and special nursing homes for over 65 years old elderly who need lots of nursing care physically and mentally.

Aim: Actual situation of acceptance for dementia patients by the palliative care unit and nursing homes, and any care-related problems of dementia cancer patients were researched.

Methods: The questionnaire study was conducted onto 235 units for the palliative care and 3457 nursing homes in Japan. The study was particularly focused on the basis for the admission to the unit and nursing homes, and also on the probable difficulty for caring of the cancer patients with dementia.

Results: The recovery rate for the questionnaire was 70 units (29.8%), 343 homes (9.9%). In approx. 50% unit used the criteria of the admission of cancer patients for presence of dementia. On the other hand, in approx. 30% special nursing homes for the elderly used the criteria of the admission of elderly people for presence of cancer. 24.7% palliative units, 18.9% nursing homes rejected accepting the admission of such dementia cancer patients.

The high grade of difficulty in the care was observed in cases caused by falling down of and interrupted communication with the dementia patients, and there are no knowledge of caring for those patients.

Conclusions: It was clarified from the above study that the presence or absence of dementia in palliative care units, cancer in nursing homes seem to be an important factor for the admission. Some difficulties for caring of these cancer patients with dementia are barriers. We should research and study how to nurse and care of those patients.

Abstract number: P430
Abstract type: Poster

PALLI-study: Validity and Applicability of an Instrument for the Identification of People with Intellectual Disabilities (ID) who Are in Need for Palliative Care


1Radboud University Medical Center, Department of Primary and Community Health Care, Healthcare for People with Intellectual Disabilities, Nijmegen, Netherlands, 2Erasmus Medical Center, Department of General Practice, Intellectual Disability Medicine, Rotterdam, Netherlands, 3Radboud University Medical Center, Expertise Center Palliative Care, Nijmegen, Netherlands

Background: According to the definition of the WHO, early identification of physical, psychosocial and spiritual problems is an important aspect of palliative care. Professional caregivers in the care of people with intellectual disabilities (ID) experience many barriers in the identification of people suffering from these problems. Quality of palliative care is expected to benefit greatly with timely identification of needs.

Purpose: The purpose of the PALLI-study is to develop an instrument that will help caregivers to identify people with ID who are in need for palliative care. In the present study the validity, applicability and the ability of implementation of the instrument in the daily care of people with ID will be examined.

Study population: 100 adult patients with ID receiving care from general practitioners and 100 adult patients with ID receiving care from ID physicians will be included. Only patients who are considered to be at risk of death within one year will be included.

Study design: A prospective follow-up study.

Methods: Patients will be followed during a 10 months period. Data will be collected at 0, 5 and 10 months. Professional caregivers will complete the PALLI-instrument, the Edmonton Symptom Assessment Scale (ESAS), the Barthel-index and questions on spiritual needs. The Quality of Death and Dying (QODD) scale will be completed for the patients who die within the data collection period.

In semi-structured interviews data are collected about the applicability of the instrument and barriers and facilitators for implementation of the instrument.

Results and interpretation: The first results of the validity, applicability and the implementation possibilities will be presented at the conference.
Funding: This research has received funding from The Netherlands Organisation for Health Research and Development.

Abstract number: P431
Abstract type: Poster

The Novel Combination of Pregabalin and Oxycodone/Naloxone for Relief of Neuropathic Cancer-related Pain: A Preliminary Study

De Santis S.1, Borghesi C.1, Giovannoni D.1, Migliorino M.R.2

1San Camillo-Forlanini High Specialization Hospitals, Palliative Care and Oncological Pain Service, Roma, Italy, 2San Camillo-Forlanini High Specialization Hospitals, 1st Oncological Pulmonary Unit, Roma, Italy

The prevalence of neuropathic pain in patients with cancer has been estimated at 19-39%. The CR oxycodone plus pregabalin represent a valuable addition to the existing pharmacotherapy for cancer-related neuropathic pain (Gatti, Eur Neurol 2009; Garassino, PLoS ONE 2013). The gabapentin with alpha-lipoic acid is efficacy for the treatment of neuropathic pain (Chaparro, Cochrane Database of Systematic Reviews 2012). We set out to investigate the effectiveness and safety of Targin combined with pregabalin and alpha-lipoic acid (Tiobec, Laborest, Italy).

Method: It was conducted one observational study on lung cancer (NSCLC) patients in advanced stage, with moderate to severe neuropathic pain treated with Targin® plus pregabalin and Tiobec at dose 800 mg bid for 28 days. The initial mean daily dose of Targin was 28.04 mg, pregabalin was 96.73 mg. Daily doses were titrated at scheduled visits on days 7, 14, 21 to achieve optimal efficacy and tolerability. Concomitant fentanyl sublingual tablets was used for the management of breakthrough pain.

Results: From January 2013 to July 2013 were taken 23 pts with advanced NSCLC which showed moderate-severe neuropathic pain and BToP in 20 pts (87%). The combination therapy were effective for alleviating neuropathic pain (reduction in NRS value: 32%) for improvements from baseline in quality of life and HADS score. At the end of treatment, the majority (92.3%) of pts found that the treatment had been ‘effective’. Combination therapy also allowed neuropathic pain free in 62.5%, a reduction 60% of BTcP occurrence. Combination treatment was effective at low mean doses of Targin plus pregabalin probably due to Tiobec adjuvant therapy, and had a favorable safety profile.

Conclusion: This study find pioneering correlation between neuropathic cancer pain and emerging BTcP in a model of combination therapy that integrates Targin plus pregabalin and Tiobec into cancer pain management and allow an effective control of cancer pain and BTcP.

Abstract number: P432
Abstract type: Poster

The Growth of Palliative Care in Hungary Has Been Accompanied by a Marked Increase in Fentanyl Use: Comparison with other ECSEE Countries and the UK

Csikós A.1, Harford J.B.2

1Pecs University Medical School, Department of Hospice-Palliative Care, Institute of Family Medicine, Pecs, Hungary, 2National Cancer Institute, Center for Global Health, Bethesda, United States

From 1990 to 2010, global consumption per capita of opioids excluding methadone has increased ~7.5-fold. Over that period, significant strides have been made in enhancing palliative care in Hungary. Services have been added, and opioid consumption excluding methadone is up ~13-fold (twice the global average fold increase). To place this Hungarian progress in context, we performed a situation analysis using available data that compares Hungary to the United Kingdom (UK) as an exemplar for palliative care as well as to other countries in the United Nations’ East Central and South-East Europe (ECSEE) Division that includes Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Georgia, Greece, Hungary, Kosovo, Macedonia, Montenegro, Poland, Serbia, Slovakia, Slovenia, Turkey, and Ukraine. In 1990, the UK was consuming much more opioids per capita than Hungary (and all ECSEE countries) and was using 20-times more morphine than fentanyl (in terms of morphine equivalence). UK consumption of both morphine and fentanyl have increased since 1990 with a shift toward a higher proportional use of fentanyl resulting in a fentanyl-to-morphine ratio of ~1 for 2010. In contrast, Hungary’s comparable ratio of fentanyl-to-morphine for 2010 was ~63. This much higher fentanyl-to-morphine ratio is the result of a 25-fold increase in per capita fentanyl consumption since 1990 coupled with a decrease in morphine use per capita by a factor of 5 since 2000. Based on the most recent data available, ~92% of the opioid consumption excluding methadone in Hungary is fentanyl. While the consumption of opioids per capita excluding methadone varies by 75-fold across the ECSEE countries, analyses of their individual consumption patterns indicate that fentanyl use has risen dramatically in all ECSEE countries with three countries in the group having fentanyl-to-morphine ratios of >100. Implications of the dramatic increase in fentanyl consumption are to be addressed.

Abstract number: P433
Abstract type: Poster

The Implementation and Evaluation of a Pain Education Programme for Patients with Progressive or Recurrent Breast and Prostate Cancer
Coughlan B.1, Fox P.1, Treacy P.1, Fealy G.1, Larkin P.1, Griffin M.1, Murray M.1, Quinn M.2

1UCD, School of Nursing, Midwifery and Health Systems, Dublin, Ireland, 2St Vincent’s University Hospital, Dublin, Ireland

Research aim: Educational programmes for cancer patients may improve knowledge, promote positive attitudes about pain and can overcome barriers to pain management. A randomised controlled trial (RCT) design using the CONSORT principles was conducted to evaluate the extent to which a pain education programme (PEP) is effective in improving cancer patients’ attitudes to and knowledge of pain management.

Study design: Sixty one patients with progressive or recurrent breast and prostate cancer were randomly assigned (2cases:1case) into an intervention (n=42; 61.2 years, SD=12.5), or a control group (n=19; mean age 58.5 years, SD=12.9). The intervention consisted of two 30 mins nurse-led pain education sessions aimed at increasing the patient’s knowledge of pain management. Outcome measures; knowledge and attitude to pain, levels of depression, anxiety and self-efficacy were assessed at three time points. Results from the patients attitude to pain are presented here.

Results: A mixed between-within subjects ANOVA was conducted to assess the impact of completing PEP on participants scores on the patient’s attitude to pain across three time points (Time 1 pre-intervention, Time 2 post-intervention and at Time 3 six week follow up). There was no significant interaction between the Groups and Time, Wilk’s Lambda =0.946, F (2, 41)=1.173, p=0.32, partial Eta Squared= 0.054. There was no main effect for time, Wilk’s Lambda = 0.907, F (2,41)=02.109, p=0.134, Partial eta squared = 0.093. The main effect comparing the intervention and control groups was not significant also F(1, 42) = 0.776, p=.383, partial eta squared= 0.018, suggesting that the PEP did not improve attitude to pain for people with advanced breast or prostate cancer.

Conclusions: These preliminary findings indicate that participating in pain education programme for people with advanced breast and prostate cancer did not improve attitude to pain, these results will be discussed within the wider context of the RCT.

Abstract number: P434
Abstract type: Poster

Analgesia, Safety and Quality of Life during Treatment with Controlled-release Oxytocin in Palliative Care Cancer Patients with Neuropathic Pain: A Multicenter, Non-interventional, Observational Study, Study Code: PMS-PL-OXY-2011-02

Leppert W.1, Gaborek A.2, Stankiewicz M.2

1Poznan University of Medical Sciences, Chair and Department of Palliative Medicine, Poznan, Poland,
2Mundipharma Polska, Warszawa, Poland

Aim of the study: To assess analgesia, safety, quality of life (QOL) and compliance during treatment with controlled-release (CR) oxycodone formulation.

Patients and methods: Cancer patients with neuropathic pain diagnosed based on a clinical evaluation by treating physicians from 123 palliative care units in Poland were treated with oxycodone CR alone or in combination with adjuvants, non-opioids or other opioids for 21 days. Pain intensity and pain interference with QOL (activity, mood, relations with other people, sleep) were assessed by NRS (Numerical Rating Scale: 0 - no pain /no pain interference with QOL; 10 - the most severe pain / complete pain interference with QOL).

Results: Among 783 patients enrolled to the study of age 64 (+/- 11.1) the analysis was conducted on 272 patients with neuropathic pain. Pain intensity decreased from 6.92 (+/- 1.69) at baseline to 2.74 (+/- 1.71) [p< 0.00001] after 21 days of the treatment along with significant decrease in pain interference with all QOL items. Mean daily doses of oxycodone CR increased from 35 mg at baseline to 56 mg on day 21. Among patients studied 45% received concurrently another strong opioid, 43% non-opioids, and 30% adjuvants. The mean percentage of oxycodone CR doses omitted since the last visit was 2.0% within the first three days, 2.3% since day 4 till day 7, 1.6% since day 8 till day 14 and 1.9% since day 15 till day 21. At baseline 47% patients complained on constipation, 35% on nausea, 15% on drowsiness; during treatment these symptoms intensified or appeared for the first time in 3% of patients.

Conclusions: CR oxycodone administered alone or in combination with other analgesics in cancer patients with neuropathic pain was safe and effective opioid and significantly improved patients’ QOL.

Abstract number: P435
Abstract type: Poster

Constructing Family Identity Close to Death

Carlander I.1,2, Ternestedt B.-M.1, Sandberg J.1,2, Hellström I.1,4

1Ersta Sköndal University College and Ersta Hospital, Palliative Research Centre, Stockholm, Sweden,
2Karolinska Institutet, Department of Learning, Informatics, Management and Ethics, Stockholm, Sweden,
3Jönköping University, Department of Nursing, School of Health Science, Jönköping, Sweden,
4Linköping University, Department of Social and Welfare Studies Norrköping, Norrköping, Sweden

Both for patients and family members, daily life close to death means physical, psychological and social strain,
Aims: Risk factors for developing complicated grief are personal characteristics or responses that based on epidemiological evidence can be considered essential for being identified and prevented. The use of validated tools in accordance to strength professional decisions is known as accordance to strength professional decisions. This research aims to determine the agreement degree on assessing for CG among professionals perception and a brief grief questionnaire (BGQ).

Method: Trained psychologists assess by phone a sample of primary caregivers using a semi-structured interview based on guidelines for identifying bereavement risk in family members of people that received palliative care. Later, five structured questions of a brief survey screening for CG were responded by caregivers.

Results: Preliminary results of a growing sample show a significant degree of agreement among professional perception and results obtained by a brief questionnaire for assessing bereavement risks. 12% of the respondents screened positive for risks of complicated grief.

Conclusions: The BGQ shows validity for being a brief and useful tool that can add strength to clinical assessment. Results reinforced the need to attend to the psychological consequences of bereavement in palliative care units.

Abstract number: P436
Abstract type: Poster

Traces of Complicated Grief (CG): Searching for Clinical Assessment Endorsement
Chaurand A.1, Buscemi V.2, Lopez M.2-3, Crespo S.2
1University of Barcelona, Departamento de Personalidad Evaluacion y Tratamiento, Barcelona, Spain, 2EAPS Granollers, Creu Roja Catalunya, Granollers, Spain, 3PADES Granollers, Granollers, Spain

Aim: Risk factors for developing complicated grief are personal characteristics or responses that based on epidemiological evidence can be considered essential for being identified and prevented. The use of validated tools in accordance to strength professional decisions is known as a requirement in health issues. This research aims to determine the agreement degree on assessing for CG among professionals perception and a brief grief questionnaire (BGQ).

Method: Trained psychologists assess by phone a sample of primary caregivers using a semi-structured interview based on guidelines for identifying bereavement risk in family members of people that received palliative care. Later, five structured questions of a brief survey screening for CG were responded by caregivers.

Results: Preliminary results of a growing sample show a significant degree of agreement among professional perception and results obtained by a brief questionnaire for assessing bereavement risks. 12% of the respondents screened positive for risks of complicated grief.

Conclusions: The BGQ shows validity for being a brief and useful tool that can add strength to clinical assessment. Results reinforced the need to attend to the psychological consequences of bereavement in palliative care units.

Abstract number: P437
Abstract type: Poster

Questionnaire “Navarra Pall-Med”, a New Tool to Evaluate the Changing of Teacher’S Attitudes after a Training Course in “Teaching Palliative Medicine”
Vaquero Cruzado J.A.1, Núñez-Córdoba J.M.2, Noguera A.3, Smeding R.3, Centeno Cortés C.1,3
1Clinica Universidad de Navarra, Palliative Medicine, Pamplona, Spain, 2University of Navarra, Preventive Medicine and Public Health, Pamplona, Spain, 3Hospital Centro de Cuidados Laguna, Madrid, Spain, 4University of Liverpool, Palliative Care Institute, Liverpool, United Kingdom, 5University of Navarra, Institute of Culture and Society (ICS), Pamplona, Spain

Background: The high demand for palliative medicine training in undergraduate and postgraduate levels, justifies the need to train teachers in education. The course “training for teachers in Palliative Medicine”, developed and led by Ruthmarijke Smeding, is being provided successfully for 20 years, mainly in European countries and South America.

Methodology: A 7-point Likert scale questionnaire with 19 items was designed to assess changes in attitudes of teachers before and after the course, exploring four dimensions: personal aspects of teachers, practical aspects of teaching, student attitudes and effects in palliative care teaching. In order to refine the assessment tool and start exploring their psychometric properties, a first design was created, which has been administered in four successive editions of the course, in three countries.

Results: We collected evaluations of 93 students before and after the course (100% of participants in the 4 courses). Statistically significant differences were observed in 11 items that explored personal aspects of teachers (question 2, p=0.02), practical aspects of teaching (question 13, p<0.001; question 15-17, p<0.001; question 19, p=0.011) student attitudes (question 9, p=0.01; question 10, p=0.008) and effects in palliative care teaching (question 7, p<0.01; questions 14 and 18, p<0.001). The internal consistency of
the questionnaire was considered acceptable (Cronbach’s alpha=0.68) and its reliability improved when deleting a less discriminating item (Cronbach’s alpha=0.7).

**Discussion:** Preliminary results indicate that the questionnaire “NAVARRA PAL-MED” shows an acceptable reliability. With this questionnaire, we observed immediate changes in educational attitudes of participants in a palliative medicine-training course. Further research is required to deeper explore the questionnaire’s dimensionality.

**Funding:** ATLANTES Research Program, Institute for Culture and Society (ICS)-University of Navarra.

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**Abstract number:** P438  
**Abstract type:** Poster  
**Does the Attitude of Doctors towards Pro-active Care for Prevention of Palliative Crises Change during the Disease Trajectory of Patients with Incurable Cancer? A Prospective Study in the Emergency Department**  
de Nijs E., Wieles T., Fogteloo J., Heringhaus C., Jochems A., van der Hoeven K., Marijnen C., van der Linden Y.

**Introduction:** In patients with incurable cancer, visits to the hospital emergency department (ED) occur frequently in the last year of remaining life. A prospective study was started to identify these patients, to analyse the pro-active attitude of doctors, and to develop interventions aimed at prevention of unnecessary visits.

**Methods:** As of June 2013, electronic patient files in a large university hospital are screened daily to identify patients with an unplanned visit to the ED. Inclusion criteria are: ≥ 18 years, incurable cancer, negative response to the 1-year surprise question. Patient characteristics are collected from the patient files. For analysis, chi-square, Mann Whitney and Kaplan Meier statistics were used. Patients were divided into two groups: undergoing active anticancer treatment, or, only symptom management.

**Results:** Until Oct 15th, 84 patients were included with 105 visits. In the majority of files no specific notes were made regarding burden on informal caregivers, or presence of professional home care. Table 1 shows the important outcome so far.

<table>
<thead>
<tr>
<th></th>
<th>Anti-cancer treatment (n=51)</th>
<th>Symptom management (n=33)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (median)</td>
<td>65 yrs.</td>
<td>59 yrs.</td>
<td>0.35</td>
</tr>
<tr>
<td>WHO 3-4</td>
<td>49%</td>
<td>53%</td>
<td>0.06</td>
</tr>
<tr>
<td>On systemic therapy last 3 months</td>
<td>71%</td>
<td>28%</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>&gt; 1 ED-visit in last 6 months</td>
<td>37%</td>
<td>66%</td>
<td>0.04</td>
</tr>
<tr>
<td>Survival (median)</td>
<td>54 days</td>
<td>29 days</td>
<td>0.05</td>
</tr>
<tr>
<td>Pain recorded in patient file</td>
<td>78%</td>
<td>67%</td>
<td>0.31</td>
</tr>
<tr>
<td>Anxiety recorded in patient file</td>
<td>5.9%</td>
<td>6.3%</td>
<td>1.00</td>
</tr>
<tr>
<td>No resuscitation policy recorded in patient file</td>
<td>67%</td>
<td>44%</td>
<td>0.01</td>
</tr>
</tbody>
</table>

**Conclusion:** Preliminary outcome in patients visiting the ED in palliative crises show that a pro-active attitude in doctors is lacking despite their patients deteriorating conditions. In the patient files, no notes were found on psychosocial and/or existential issues. The future results of this on-going study lead to areas for improvement in education, involvement of palliative care teams, guidelines for discussing end of life policies.

**Source of funding:** N/A

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**Abstract number:** P439  
**Abstract type:** Poster  
**Palliative Care in a University Hospital Emergency Department (ED) - Space for Improvement**  
Iucolano N., Exadaktylos A., Eychmüller S.

1University Hospital Berne, Center for Emergency Medicine, Berne, Switzerland, 2University Hospital Berne, Center of Palliative Care, Berne, Switzerland

**Aim and objective:** Patients with far advanced disease and polymorbidity represent an increasing number of emergency visits in our department. Based on results of an US-study we examined the current concept, knowledge and patient characteristics in regard of “palliative care”.

**Study design and methods:**

1. Retrospective analysis of emergency admission lists 2002 until 2012;
2. Online survey of ED nurses and doctors in regard to training in palliative care, communication within the team, organisational issues and personal beliefs.

**Results:**

1) out of more than 200,000 datasets, 884 patients were labelled “palliative” (90% registered during last two years), 95% with oncological diagnosis. 80% of these patients were hospitalized, 15% via ICU. Advanced directives were documented in 7 patients. Guidelines for palliative care approach in the ED are missing.

2) 60 professionals (response rate 39%, 60% nurses) reported 59 different definitions of “Palliative Care”. Context of “palliative” is regarded as being far more than only oncological diagnosis including heart - and renal failure. Participants ask for more training, a 24 Palliative Care Team, as well as for better access to medical charts.

**Conclusion:** The label “palliative” has become more evident during the last years within an university ED population, but understanding, concept, approach and competencies are heterogeneous or completely missing. There is a need

   a) to define clear characteristics of these patients, and
   b) to work out a clinical approach including specialist palliative care consultation in the ED.

**Funding:** University hospital, Inselspital Bern

**Abstract number:** P440  
**Abstract type:** Poster  
**Development of a Tool to Facilitate Earlier Identification of Lung Transplant Patients Likely to Be in the Last Year of Life by a Cardiothoracic Transplant Centre**

*Everitt J., Berry L., Collis K., Fleming S., Jamal H., Carby M., Baker T., Reed A.*

Royal Brompton and Harefield NHS TRUST, Harefield Hospital, Uxbridge, United Kingdom

**Aims:** Lung transplant is an established treatment for end stage lung disease. Five year post transplant mortality rate is approximately 40%.
An audit of deaths in 2010 at a cardiothoracic transplant centre showed that many patients were lost to follow up or had late referrals to supportive and palliative care (SPC).

The respiratory and SPC teams decided to facilitate earlier identification of lung transplant patients likely to be in the last year of life.

**Methods:** A literature search was undertaken. There were no suitable lung transplant specific tools available.
Two questions in general use were combined:

1) “Would you be surprised if the patient died within the next 6 - 12 months”?
2) “Is this patient cause for concern”?

A list of relevant clinical triggers based on the evidence based gold standards framework prognostic indicator was compiled and added to the tool and evolved by analysing patient’s clinical profiles. The tool was initially trialled in the follow up clinic and then rolled out to all areas.

If question 1 triggered or question 2 and at least one clinical indicator, the case was referred for discussion at the new Transplant Enhanced Care (TEC) multidisciplinary (MDT) meeting jointly run by transplant and SPC teams.

**Results:** Lung transplant specific indicators were developed.
Consultant and registrars focused on the surprise question.
Outpatient nurses used the clinical indicators and made most referrals.
Clinicians agreed that the tool identifies patients appropriately.
At 5 months 60 patients had been identified. 15 patients early in the trial were not referred on; 32 managed by both teams; 5 for review; 6 died; 2 retransplanted.

**Conclusions:** The TEC MDT referral tool facilitates early identification of lung transplant patients in the last year of life. More patients have earlier access to interventions by the SPC team.
Future research will audit longer term outcomes; deaths and patient, family and staff experiences of care in the last year of life.

**Abstract number:** P441  
**Abstract type:** Poster  
**Polypharmacy in 2282 Advanced Cancer Patients**

*Kotlinska-Lemieszek A.1,2, Paulsen Ø.3,4, Kaasa S.4,5, Klepadl P.6,7*  

1Poznan University of Medical Sciences, Palliative Medicine Chair and Department, Poznan, Poland,  
2University Hospital of Lord’s Transfiguration, Hospice Pallium, Poznan, Poland,  
3Telemark Hospital Trust, Department of Medicine, Palliative Care Unit, Skien, Norway,  
4Norwegian University of Science and Technology (NTNU), Faculty of Medicine, Department of Cancer Research and Molecular Medicine, European Palliative Care Research Centre (PRC), Trondheim, Norway,  
5St. Olavs Hospital, Trondheim University Hospital, Department of
Aims: Patients with advanced cancer need multiple medications to control symptoms, and to treat cancer or concomitant diseases. We report the use of medications, the use of unneeded medications and the use of medications with a risk for drug-drug interactions (DDIs) in the cancer pain population.

Methods: Cancer patients using strong opioids from 17 centers in 11 countries were included. All drugs taken within 24 hours were registered. Unneeded medications and medications with a risk for DDIs were identified.

Results: 2282 patients used a mean of 7.8 drugs (range 1-20). More than one fourth used $\geq 10$ medications. The drugs most frequently co-administered with opioids were: proton pump inhibitors (62%), laxatives (52%), and corticosteroids (49%). One third of patients used paracetamol, NSAIDs, and metoclopramide. Forty-five percent of patients received unnecessary or potentially unnecessary drugs, and 7% were given duplicate or antagonizing agents. Pharmacodynamic or pharmacokinetic DDIs were frequent. Almost half of the patients received at least one drug with sedative effect in addition to a strong opioid. In 14% and 8% of patients, respectively, NSAIDs were co-administered with corticosteroids and anticoagulants. More than 50% of patients used medications with affinity for dopamine, serotonin and muscarinic receptors, which increases the risk of CNS complications. 18% of patients used drugs with a known risk of Torsades de Pointes. Many patients were exposed to DDIs involving the CYP 450 system, including almost 60% and 13%, respectively, who used opioids or benzodiazepines, metabolized by CYP3A4. About 10% used major CYP3A4 inhibitors or inducers. Multiple other potentially DDIs were also present.

Conclusion: Patients with cancer treated with a WHO step III opioid use a high number of drugs. Many of them receive unneeded drugs and are at risk of serious DDIs. These findings demonstrate that drug therapy in these patients need to be revised continuously.

Abstract number: P442
Abstract type: Poster

Suicidal Ideation, Death Ideation and Assisted Suicide in Patients with Atypical Parkinsonism

Butzhammer E., Nübling G., Lorenzl S.
University of Munich, Clinic for Palliative Care, Munich, Germany

Aims: The prevalence of suicidal ideation (SI) and Death ideation (DI) among elderly varies between 1 and 30%. The presence of a progressive disabling disease would suggest, that SI and DI are common in patients with atypical Parkinsonism. The aim of this study is to assess the prevalence of SI and DI in those patients and to identify correlates of the claim for assisted suicide (AS).

Methods: In this study, we interviewed 37 patients with either PSP (Progressive Supranuclear Palsy), MSA (Multiple System Atrophy) or CBD (Corticobasal Degeneration) visiting an outpatient department of Neurology from 04/2013 until 08/2013. We have used the following scales: Columbia suicidal severity rating scale (C-SSRS), PSP-Rating scale (PSP-RS), HADS (Hospital Anxiety and Depression Scale), Idler Index of Religiosity, PSP-quality of life and the schedule for meaning in life evaluation (SMiLE).

Furthermore, we have screened the files of a swiss right-to-die organisation for patients with Parkinson's Disease and atypical Parkinsonism from 2006-2012.

Results: In the outpatient department, 24% reported DI and another 14% SI. Only one person had a history of suicide attempt. While DI was more common in females (7 vs 2) SI was more common in male patients (4 vs 1). The prevalence of SI tended to be higher in people living in a rural area. DI and SI come along with higher scores of depression. The average PSP-RS score was 61 for DI, 50 for SI and 46 for none of both. SI is more common in early stages of the disease.

The retrospective analysis of AS files showed that 54% have been within a partnership, 44% have a Christian denomination and only 18% have been residents of nursing homes.

Conclusion: SI and DI are not more common in patients with atypical Parkinsonism than in normal population. Since most patients requesting AS lived at home or in a partnership we might hypothesize that assisted suicide is no matter of lack of social support but rather the feeling of being a burden.
Abstract number: PO1
Abstract type: Print Only


Uceda Torres M.E.¹, Ramos Villarán E.², Rodríguez Rodríguez J.N.³, Alvarado Gómez F.⁴, Muñoz Carmona D.⁵, Sánchez Ramos J.L.⁶

¹Hospital ‘Juan Ramón Jiménez’, UGC Paliativos, Huelva, Spain, ²Hospital ‘Juan Ramón Jiménez’, UGC Paciente Oncológico, Huelva, Spain, ³Hospital ‘Juan Ramón Jiménez’, UGC Hematología, Huelva, Spain, ⁴Hospital ‘Juan Ramón Jiménez’, Biblioteca, Huelva, Spain, ⁵Universidad de Huelva, Enfermería, Huelva, Spain

The oncohematologic patient is usually attended with a strong curative intention even up to the end of his life. Their informal caregivers play a crucial role as a help for the patient and the palliative team. A review of the literature referring informal caregivers of OHPP has been performed to know those aspects studied up to now to find possible field to improve.

PubMed (1966-january 2013) was the database selected to perform the search using as key words: CAREGIVER, END-OF-LIFE CARE, HEMATOLOGICAL MALIGNANCES, LEUKEMIA, LYMPHOMA, MYELOMA and MYELODYSPLASTIC SYNDROMES. Exclusion criteria were: language other than English or Spanish; articles referred to non-OHPP; and articles not referred to informal caregivers. The main topic of every selected article was pointed out.

Nineteen articles were found. Five articles were excluded: 1 written in Japanese; 3 not referred to palliative patients; and 1 not concerning informal caregivers. Fourteen articles were selected: 3 concerned general aspects of OHPP including aspects of their informal caregivers; 6 dealt with diverse ethical aspects (not exclusive of OHPP) in which the informal caregiver was involved; and 5 were qualitative studies (4 interviews and 1 clinical case) about OHPP caregivers’ impressions in different moments of the terminal phase of the patients. From these latter studies several points must be remarked: scarce or no referral of these patients to Palliative Care Units; difficulties in the communication with the palliative care team; application of high technology up to the end of life; aggravation of these problems in special situations such as intensive care units.

Literature compiled in PubMed referring informal caregivers of OHPP is very scarce. Only a few qualitative investigational articles have been found so definitive conclusions cannot be carried out. Due to its importance, a more profound investigation on OHPP caregivers should be mandatory.

Abstract number: PO2
Abstract type: Print Only

Relevance of Canadian Health Care Evaluation Project (CANHELP) Questionnaire for Patients on Homecare in Mumbai

Ghoshal A.¹, Dighe M.², Dhiliwal S.¹, Deodhar J.¹, Muckaden M.A.³

¹Tata Memorial Centre, Mumbai, India, ²Bayt Abdullah Children’s Hospice, Souk Al-Dakhili, Kuwait

Aims:
1) To study the relevance of CANHELP questionnaire
2) To identify unmet needs of care provided at end-of-life
3) Use the feedbacks as targets for improvement.

Methods: A cross-sectional IRB approved study was done for 20 Mumbai based patients and their families who were enrolled in homecare services. CANHELP questionnaire was served from September to November 2012 after taking informed consent in their preferred language. Data were collected and analyzed using SPSS.

CANHELP Questionnaire assesses importance of end of life care provision and satisfaction derived, on a scale of 1-5(ascending scale). There are 38 patient centered questions and 40 family questions/ per unit; divided into subscales by authors.

Results: IN DESCENDING ORDER OF VALUES

The mean value calculated for Importance reflects that though both the patients and families found end of life care provision to be very important, patients felt a higher need for care at the end of life.

Satisfaction reflects that both the groups were somewhat satisfied with end of life care services provided, with a higher satisfaction for the families of patients.

The families were somewhat satisfied with their own involvement in care at the end of life for their patients. They feel that they can contribute more towards it.

The patients were not very satisfied with their participation in deciding the care process at the end of life. A closer look reveals that this is particularly regarding discussions with doctor about the place of management and the use of life sustaining technologies at the end of life.
Conclusion:

1) CANHELP questionnaire is relevant to patients and their families regarding satisfaction with the end of life care services.
2) Both of them are satisfied with end of life care services provided to them.
3) There is need for further discussions with doctor about the place of care and use of life sustaining technologies in end of life care.

Abstract number: PO3
Abstract type: Print Only

How Well Are End of Life Care Pathways Completed in Long Term Care Settings


1The University of Queensland, School of Nursing and Midwifery, Brisbane, Australia, 2University of Queensland, Brisbane, Australia, 3Brisbane South Palliative Care Collaborative, Brisbane, Australia, 4WA Cancer and Palliative Care Network, Perth, Australia, 5Southern Adelaide Palliative Services, Adelaide, Australia, 6Resthaven, Adelaide, Australia

The use of end of life care pathways has demonstrated decreased transfers to hospitals for terminal care and improvements in clinical care for older people in long term care settings.

Objective: The objective of this paper is to review the use of the Residential Aged Care End of Life Care Pathway (RAC EoLCP) in long term care settings.

Method: The RAC EoLCP was implemented as part of an evidence based model of care in long term care. Chart audits for 28 residents commenced on the pathway were conducted. Data extracted included time on the pathway, reason for commencement, medical interventions, advance care planning and care management.

Results: Median number of days on the pathway was 5 (range 0-35) and all residents died at the RACF. On average, clinicians identified 6.3 (1.8) signs and symptoms from the possible 9 provided as prompts to commence the pathway. The majority of residents had medical interventions including the prescription of essential medications (92.3%), prn medications (96.2%) and the cessation of non-essential medications (80.8%) and inappropriate interventions and observations (65.4%) documented. Almost all residents had a not for resuscitation order (92.3%) and future care plans discussed (96.2%). Documentation of symptoms, comfort care and psychosocial issues was completed for 52.6% - 88.9% of residents.

Conclusion: The RAC EoLCP facilitated identification of residents requiring terminal care and documentation of key clinical processes and outcomes. The high compliance with documentation is encouraging taking into account the pathway was a newly introduced intervention in the long term care setting.

Abstract number: PO4
Abstract type: Print Only

The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Non-Malignant Conditions

Kane P.M.1, Daveson B.1, Ryan K.2, McQuillan R.3, Higginson I.4, Murtagh F.E.1, on behalf of BuildCARE

1King’s College London, Cicely Saunders Institute, Palliative Care, Policy and Rehabilitation, London, United Kingdom, 2Mater University Hospital and St. Francis Hospice, Palliative Care, Dublin, Ireland, 3Beaumont Hospital and St. Francis Hospice, Palliative Care, Dublin, Ireland

Background: Despite the long history of hospice and palliative care services in Ireland, palliative care services are predominantly accessed by those with cancer. Previous estimates of palliative care need have focussed primarily on cancer, which may not allow for adequate commissioning and service delivery to those with needs stemming from non-malignant conditions.

Aim: The aim of this study is to estimate the potential population with generalist or specialist palliative care needs in Ireland using routine mortality data inclusive of non-malignant conditions.

Methods: Irish routine mortality data (2007-2011) was analysed for malignant and non-malignant conditions recognised as potentially requiring palliative care input, using ICD-10 codes.

Results: Annually during 2007-2011, the majority of deaths were among those ≥ 65 years, this proportion (82%) remained constant during 2007-2011. 80% of deaths were from conditions recognised as having associated palliative care needs. The 2007-2011 data showed an increase in cancer deaths by 9% and a 43% increase in the number of deaths from neurodegenerative conditions. Deaths from dementia constituted the largest increase of 50%.

Conclusion: There is a disconnect between the emphasis on cancer by specialist palliative care services in Ireland and the increasing number of deaths from non-malignant conditions. Future palliative care policy decisions in Ireland must consider the rapidly ageing Irish population with the accompanying increase in chronic progressive conditions and associated palliative care need.
Associations between Opioid Use and Mortality in the Danish Population

Ekholm O.1, Kurita G.P.2,3, Højsted J.1, Juel K.1, Sjögren P.2,4
1National Institute of Public Health, University of Southern Denmark, Copenhagen, Denmark, 2National Hospital, Copenhagen University Hospital, Department of Oncology, Copenhagen, Denmark, 3National Hospital, Copenhagen University Hospital, Multidisciplinary Pain Centre, Copenhagen, Denmark, 4Faculty of Health and Medical Sciences, University of Copenhagen, Department of Clinical Medicine, Copenhagen, Denmark

Aims: This prospective study aimed to examine the associations between long-term opioid use among individuals with chronic pain and mortality and hospitalizations.

Methods: Cohort of 13,126 adults who have participated in the Danish Health Interview Surveys in 2000 or 2005. Individuals with a known cancer history at baseline were excluded. Data on prescription drug use were retrieved on an individual basis from the national prescription registry. Long-term opioid users were defined as individuals who have used at least 1 prescription/month for 6 months in the previous year (n=167). Follow-up until the end of 2011 was accomplished through linkage with population registers of causes of death and patient register. The Cox proportional hazards model was assessed to examine the associations between long-term opioid use and mortality and hospitalizations, respectively, after adjustment for potentially confounding factors (e.g. sex, age, cohabitation status, education, smoking behaviour, body mass index, alcohol intake, Charlson Comorbidity Index). The results are presented as hazard ratios (HR) with 95% confidence intervals (CI).

Results: The risk of all-cause mortality was 1.72 (95% CI: 1.23-2.41) times higher among long-term opioid users than among individuals without chronic pain. Further analyses showed that there were no associations between long-term opioid use and either cancer morbidity or cancer mortality. Interestingly, no deaths among long-term opioid users were caused by accidents or suicides. However, long-term opioid users had a substantially higher risk of accidents resulting in hospital in-patient treatment than individuals without chronic pain (HR: 2.37; 95% CI: 1.68-3.34).

Conclusion: Long-term opioid use in individuals with chronic pain was a risk factor for mortality and hospitalization due to accidents, but it was not particularly related to the occurrence of cancer disease or death by opioid accidental ingestion and suicides as generally believed.

Pharmacokinetics of Sustained Release Fine Granules of Morphine Sulfate in Patients with Cancer-related Pain

Kokubun H.1, Uezono Y.2, Matoba M.3
1Kitasato University Hospital, Department of Pharmacy, Kanagawa, Japan, 2National Cancer Center Research Institute, Division of Cancer Pathophysiology, Tokyo, Japan, 3National Cancer Center Hospital, Department of Palliative Medicine, Tokyo, Japan

Aims: Sustained-release fine granules of morphine sulfate (Morphes) is a medicine currently used only in Japan. Morphes is a sustained-release oral formulation, and its twice-a-day dosing leads to good management of cancer pain. The special feature of this product resides in its very fine particle size of 0.25 mm, in average diameter, as well as its sustained release nature. Indeed, this fine particle characteristic enables patients with dysphagia to be treated by administering Morphes with the aid of a nasogastric tube. However, there is almost no clinical pharmacokinetic data about this medicine. Thus, we analyzed the pharmacokinetics in blood of patients with cancer pain who used Morphes.

Methods: Four patients with cancer pain were enrolled in this study. We administered Morphes orally twice per day every 12 hours. Blood samples were collected 0, 1, 2, 3, 6, and 12 hours after oral administration in a steady state, using blood-collecting vessels containing a serum-separating medium. After centrifugation, the supernatant was collected and stored at -30°C until measurement. Serum morphine concentrations were measured by HPLC, and were analyzed using WinNonlin. Measurement of serum morphine concentrations was approved by the ethics committee of the Department of Medicine, Kitasato University Hospital.

Results: In three patients, the lag time-less model showed good AIC and CV%. In one patient, the lag time model showed good AIC and CV%, and the lag time was 0.799 hr. Other PK parameters were as follows: Ka=1.189±0.632 hr⁻¹ (mean±S.D.), Vd/F=1963±1057 L, Ke=0.149±0.030 hr⁻¹.

Conclusion: Morphes has almost no lag time and its absorption is prompt despite the sustained-release oral formulation.

EIR - A Computerised Communication Tool for Symptom Management

Sand K.1, Raj S.X.1,2, Kaasa S.1,3
Aim: Patients with advanced cancer frequently experience cancer related symptoms and associated concerns due to their disease and/or treatment. Inadequate assessment, lack of standardized assessment tools and insufficient implementation of evidence-based guidelines in clinical practice are barriers proposed to have an impact on undertreatment of symptoms. The aim of the software EIR is to improve and standardise symptom management, presentation of symptoms to HCPs, and evidence-based decision support.

Methods: EIR is based on patient-reported outcomes, i.e. subjective symptoms, functioning and quality of life. The content is based on symptoms in the EAPC basic dataset, diagnostic questionnaires and clinical experience. EIR is developed within a scrum framework with constant iterations between software developers, interaction designers, clinicians and researchers. Frequent testing of content, design and functionality has been conducted by clinicians and patients during the entire developmental process.

Results: EIR is an interactive communication tool for employment in general oncology and palliative care. EIR is a supplement for the traditional physician-patient interaction. The questions in EIR are dynamically constructed, i.e. a response to a particular question determines the succeeding questions. The information collected by EIR is transferred wirelessly and integrates with patients’ electronic medical record. Decision support is derived from patient-reported outcomes combined with evidence-based guidelines for treatment.

Conclusions: EIR seeks to enhance communication between clinicians and cancer patients in addition to integrate international guidelines to provide decision support for the clinician. By utilizing recent developments in information technology, EIR aims to improve the treatment of cancer related symptoms.

Funding: The project is funded by NTNU and St. Olavs Hospital, Trondheim University Hospital, Norway.

Abstract number: PO8
Abstract type: Print Only

Preparedness for Caregiving among Caregivers in Specialised Palliative Care - A Qualitative Study
Janze A., Henriksson A.
Ersta Sköndal University College and Ersta Hospital, Palliative Research Centre, Stockholm, Sweden

Background: Family members are central in providing care for patients with life-threatening illness. Studies have shown that preparedness for caregiving has a positive effect on wellbeing and rewards and less anxiety among those who are caring for a close family member during palliative care. Little is known about the experience of preparedness among those who care for their partner during ongoing palliative care.

Aim: To describe the experience of preparedness when caring for a spouse/partner during ongoing palliative care.

Method: The study design was qualitative using open in depth interviews and qualitative content analysis.

Results: The analysis resulted in three main themes: Preparedness for caregiving in awareness of death, Striving for something to relate to when preparing for the worst and Preparedness for caregiving-challenges, responsibilities and possibilities.

Discussion: The themes were interrelated and preparedness for caregiving in awareness of death was found to influence the whole situation. The event could be seen as a transition that caused a major change in the lives of the participants influencing meaning, roles and actions.

Abstract number: PO9
Abstract type: Print Only

To Bid Farewell at Home: Relatives’ Satisfaction with Palliative and End of Life Care. A Pilot Study of the FATE Guestionnaire
Hjörleifsdóttí E.1, Einarsdóttí A.1, Sigurdardóttí V.2
1University of Akureyri, School of Health Sciences, Akureyri, Iceland, 2Landspitali University Hospital, Hospice Care Unit, Reykjavík, Iceland

Background: The experience of relatives caring for dying patients in their homes has not been widely researched and is becoming a matter of urgency as the policy that has been prominent in recent years is that patients suffering from incurable diseases should receive care at home.

Purpose: The main purpose was to conduct a pilot study on the Icelandic version of the questionnaire, The Family Assessment of Treatment at the End of Life (FATE), measuring relatives’ satisfaction with the services provided at the end of life. Further the aim was to investigate relatives’ attitudes towards the care received and their experiences of it.

Method: Quantitative cross-sectional retrospective study approach was used with a . convenience sample (n=119). Data analysis was conducted with SPSS statistical package and Excel. Exploratory factor analysis and descriptive statistics were used to describe the characteristics of the data.

Results: Of the whole sample 58.8% (n=70) responded. The Icelandic FATE instrument proved reliable (Cronbach’s α = 0.9). Factor analysis discovered nine
factors. Relatives were most satisfied with information and communication (87%), but most dissatisfied with the support and information after the death of their loved one (17%). FATE overall measurement for all factors was 61%. A significant difference was found between employment status and satisfaction, those who worked full time and those who were not employed were significantly more satisfied with the services provided than those who worked part time or attended school.

**Conclusions:** The FATE instrument proved to be suitable for measuring relatives’ satisfaction with palliative and end of life care supplied at home. Increased knowledge in this area could be useful for health care professionals working in this field to improve the quality of the service. The results indicate that participants were generally satisfied with the service and treatment provided.

**Abstract number:** PO10  
**Abstract type:** Print Only  
**Where Do Terminal Patients Die Today?**  
Mencucci A., Maurizi P.

S.Donato Hospital in Arezzo, Arezzo, Italy

**Introduction:** Generally terminal patients prefer to die at home, but in contemporary society the approach to death and dying process is changed. Among the causes of an increased demand for hospitalizations, the increase of social problems second to worsening economic condition is emerging.

**Aim:** This observational study evaluates possible change of place of care at the end of life, the main motivations that led to change, the presence of a caregiver and if this one coincides or not with a family member.

**Method:** 939 patients were followed up at home by a service of palliative care between 2006 and 2012. The observation period never exceeded 3 months, because this range is considered typical care period of terminal patient. The data were obtained from medical records.

**Result:** The study showed that home and hospital are the main final destination of terminal patients but with an increase of deaths in hospital: 16.6 % in 2006, 18.3 % in 2007, 19.8 % in 2008, 22.4 % in 2009, 22.2 % in 2010, 29.1 % in 2011, 30.3 % in 2012. The primary motivations that led to hospitalization were psychomotor agitation (47.3 %) and dyspnea (52.7 %), confirming reports in the literature. In most cases the caregiver isn’t a family member and he tends to disappear, going from 63.7 % in 2006 to 45.2 % in 2012.

**Conclusion:** The explanation could be: rejection of death and dying by society, culture based on the hospital, family becoming less willing and able to assist at the end of life, family where the average age is increasingly high and with a decreasing number of its components, but also society where employment has been decreasing and where the economic crisis effects even home economy. If death in hospital seems inevitable, we should at least try to mitigate its emotional impact, without medicalizing it. All this is a field for discussion that addresses old and new difficulties that emerge in medicine, as a result of profound demographic, epidemiological, cultural but also of common ethics change.

**Abstract number:** PO11  
**Abstract type:** Print Only  
**Use of Analgesics and Hypnosedatives in the Terminal Care of Older Inpatients: Determining Factors**  
Van Den Noortgate N.J.1, Petrovic M.¹, Van Cauwenbergh E.², De Laat M.³, Piers R.¹

1Ghent University Hospital, Geriatric Medicine, Ghent, Belgium, ²Ghent University, Nursing Science, Ghent, Belgium, ³Ghent University Hospital, Palliative Care Unit, Ghent, Belgium

**Aims:** Shifts in cause of death in the old population may lead to alterations in symptoms and medical management in the last days of life. The aim of this study was to compare treatment and to detect the influencing factors in the use of analgesics and hypnosedatives on the acute geriatric (AGU) and the palliative care (PCU) unit of a tertiary hospital.

**Methods:** We performed a retrospective survey with consecutive inclusion of patients who died between 1 January 2009 and 31 December 2010 on the AGU and the PCU respectively. Hundred seventy patients aged 75 years and older were included (100 on AGU and 70 on PCU). Data on age, gender, clinical symptoms, cause of death and the use of analgesics and hypnosedatives were collected. Statistical analysis was performed using SPSS statistics version 20.0.

**Results:** The observed units differed significantly in mean age (85.2 years on AGU and 82.0 years PCU; p = .003) and cause of death (cancer in 20.0% and 81.4%, cardiovascular diseases in 56.0% and 4.3% on the AGU and the PCU respectively; p< .001). Analgesics and hypnosedatives were prescribed significantly more and in higher doses on the PCU (p< .001). Multivariate analysis showed that only the type of care unit and not the age, underlying cause of death or clinical symptoms significantly correlated with the pharmacological treatment.

**Conclusion:** Despite the difference in patient population, only the care unit seems to determine the use of analgesics and hypnosedatives in the late stage care of older inpatients. This finding raises the question whether medical and nursing staff attitudes have greater influence than clinical symptoms on the use of analgesics and hypnosedatives at the end of life.
Think Twice: A Bereaved Relatives’ Perspective on the Decision-making Process Concerning Treatment and Quality of Life in Advanced Cancer Patients

Wijnhoven M.1,2, Terpstra W.3, van Rossem R.4, Buiting H.M.5

1Comprehensive Cancer Center the Netherlands (IKNL), Utrecht, Netherlands, 2VU University Medical Center, Amsterdam, Netherlands, 3Onze Lieve Vrouwe Gasthuis (OLVG), Amsterdam, Netherlands, 4Reinier de Graaf Groep, Delft, Netherlands, 5Comprehensive Cancer Center the Netherlands (IKNL), Rotterdam, Netherlands

Abstract number: PO12
Abstract type: Print Only

Background: There has been much debate as to whether doctors provide possible invasive treatment in the last stage of a cancer patient’s life. We investigated the experiences and perceptions of bereaved relatives about the decision-making process concerning treatment and quality of life of their deceased loved ones in the palliative phase of pancreatic and non-small cell lung cancer.

Methods: Semi-structured qualitative interviews with 14 bereaved relatives. Interviews were tape-recorded, transcribed, and analyzed using qualitative content analysis.

Results: Relatives indicated that all patients were aware of the approaching last stage of life. They reported that patients’ preferences for further chemotherapy (CT) varied: some preferred CT till the very end to live a longer life whereas others only chose CT to gain some time to prepare their approaching death. In hindsight, patients in the second group more often seemed to regret the side effects of CT and/or indicated that the information provision about CT had been insufficient. In contrast, patients who primarily chose CT to live a longer life more easily accepted the side effects. All relatives reported that the short disease trajectory left little time to reflect on treatment decisions. They further agreed that information about the short prognosis was of paramount importance in preparing them to say good bye, which frequently happened implicitly. In both groups, relatives emphasized that they remembered the hospital visits as more burdensome than CT, predominantly because of their strong wish to spend their last time together.

Conclusion: Patients’ motives for potentially life-prolonging CT vary. Whereas some patients clearly state that they do not want to die, other patients only wish CT to gain some time to say good bye. Given the scarce evidence about the life-prolonging effects of CT, such a difference in patient groups is essential in making appropriate decisions about CT to ensure patient-centered care.

Abstract number: PO13
Abstract type: Print Only

An Ethnographic Interpretative Qualitative Study to Understand Better the Effects of an Art Therapy Intervention in a Hospital Palliative Care Unit

Collette N.1, Barreto P.2, Ramos A.1, Rufino M.1, Güell E.1, Fariñas O.1, Prada M.L.1, Secanella C.1, Garcia S.1, Pascual A.1

1Hospital de la Santa Creu i Sant Pau, Palliative Care Unit, Barcelona, Spain, 2Universidad de Valencia, Personality, Assessment and Psychological Treatments, Valencia, Spain

Aims: To try to get a better understanding of effects and mechanisms of an individual trans-disciplinary art therapy intervention in a Palliative Care Unit of a tertiary hospital.

Research design: Ethnographic interpretative qualitative study.

Methods: After the third art therapy session, a member of the research team made a recorded interview of each patient, caregiver and palliative care team. A second interview was carried out, according to the research team criteria, when longer therapeutic processes were involved and when the subjects wanted to contribute with new information. Artwork was systematically photographed. Informants and data triangulation strategies were performed. To codify the transcriptions the software MAXQDA 10 was used. It started as a classical codification, built from the interview guide questions, being themselves the result of a previous quantitative pilot study. Then it enhanced by an in-vivo codification.

Preliminary results: 5 patients were included in the study, without reaching yet data saturation. 23 transcriptions were obtained. Codification generated 1233 segments assigned to 81 codes and sub codes. We regrouped them into 14 families, around the most representative codes and similarity to concepts in the existing theory. These were: Process, Sensations, Symbolic contents, Interpersonal aspects, Emotions, Sources of help, Enjoyment and satisfaction, Intrapersonal aspects, Expression through colours and shapes, Creative action, Therapeutic alliance, Acceptance and healing, Integral attention, and Difficulties.

Conclusions: The results emphasize improvement in communicative aspects, the stimulation of pleasant sensations like enjoyment or calmness and the construction of meaning based on the interpretation of symbolic elements contained in the artwork. Data analysis evidences that healing connections and greater acceptance partially derive from the art therapy process.

Funding: This research is funded by Grupo Mémora.
Gratitude in Palliative Care: An Integrative Review

Aparicio M.1,2, Arantzamendi M.3,4, Centeno C.2,4
1Hospital da Luz, Lisbon, Portugal, 2University of Navarra, Institute for Culture and Society (ICS), ATLANTES Research Program, Navarra, Spain, 3University of Navarra, School of Nursing, University Campus, Navarra, Spain, 4Clinica Universidad de Navarra, Palliative Medicine and Symptom Control Department, Navarra, Spain

Introduction: Palliative care improves the quality of life of patients who face life-threatening illness and their families (1). The professionals, who provide care for these patients and their families, should be attentive to their needs, offering a holistic care. Gratitude is defined as the recognition for a good that is received (2). We found gratitude emerged at end of life.

Objective: To characterise the scientific literature production related to gratitude in palliative care.

Methodology: We performed an integrative review (3,4), with the descriptors: gratitude, palliative care, end of life, grief, bereav*, mourning, death, letter, in various international databases.

Results: From 169 articles, 42 went in for analysis. 22 integrated reviewing, 91% are written in English and 91% are written after the year 2000. 55% are qualitative. Gratitude manifests itself as a need for communication, patients feel the need to say thank you to those who stand by them and say thank you to life. For the families it is also a need for communicating with their loved ones (7,10). They also manifest gratitude to the professionals who care for them, and it is because of this that they agree to participate in studies (10–14). Those who live their last days claim that the revision of their narrative of life in a positive and grateful way helps lessen the death anxiety and increases the feeling of wellness (5–7). The same happens with healthy people (21–24). Families are also grateful for the care given to their relatives (25-26) and after the death of the patient they want to say it to the professional team (14–20).

Conclusions: The gratitude emerges as a spiritual dimension in patients at end of life and their families, in different situations. Health professionals should be aware of these needs of gratitude, and how this can have a positive effect on patients, so to increase the feeling of well being and quality of life, a fundamental goal of providing palliative care.

Research aims: The aim of this research project is focused on discovering a conceptual model which would allow identifying the relevant dimensions in advanced care planning (ACP) at the End of Life (EoL). It also pursues to provide guidance for conducting interventions on decision making process (DMP) in advanced disease (AD).

Study design and methods: Exploratory clinical study from a randomized pilot trial with preference for usual care (UC) or ACP intervention together with UC. The study was conducted in a palliative care (PC) Hospital and in Home care resource from Sept. 2011 to Oct. 2013. The research design consists of 4 phases: exploration of the study field, targeting of critical cases, pilot test and development of the controlled randomized clinical trial. The sample population includes a total of 197 observations/interventions which 128 were held during exploration, 13 in targeting critical case, 16 in the pilot study and 40 in the clinical trial. The methodology of analysis used is the Grounded Theory (GT), based on the systematic use of Constant Comparative Method, Theoretical Sampling and Theoretical Saturation.

Results and interpretation: The emerging core category is: “Recognizing the EoL: being aware of the position of AD. This category identifies the awareness in the experience of AD. The identified basic social process is “Resignifying the EoL experience” as a way of giving meaning of EoL. The variables that modulate the process are: disease-path; interaction between P/F/IT: Presence “quality of being present”; experience of meaning at EoL (self-recognizing in the experience of EoL from the sense of “being”). The application of these results to clinical practice enables to generate ACP intervention tools in PC: A Pattern-Intervention Instrument designed to help identifying dimensions in ACP. A Questionnaire to assess the impact of the management of critical cases, as a training system for discussing the ACP experience in IT.
Abstract number: PO18
Abstract type: Print Only
Active Palliative Rehabilitation in Lung Cancer (APRIL)
Payne C.1, Larkin P.J.2,3, McIlfatrick S.1, Dunwoody L.4, Gracey J.H.1

1Institute of Nursing and Health Research, University of Ulster, Jordanstown, United Kingdom, 2University College Dublin, School of Nursing, Midwifery and Health Systems, Dublin, Ireland, 3Our Lady’s Hospice and Care Services, Dublin, Ireland, 4Psychology Research Institute, University of Ulster, Coleraine, United Kingdom

Background: Interest is growing regarding the potential benefits of providing rehabilitation as a key component of palliative care. Nutritional support and physical activity interventions have been specifically advised as part

Calvo C.1, Galañena B.1, Ruiz de Gaona E.2

1San Juan de Dios Hospital, Palliative Care, Pamplona, Spain, 2Fundacion Hospital Calahorra, Hematology and Hemotherapy, Calahorra, Spain

Aims: Analyze the survival of inpatients debuting with symptoms of, and compare between developing delirium or not.

Methods: Inclusion: all patients admitted to our Palliative Care Unit during the follow-up. Excluded: treated with curative intent. Variables: age, gender, functional status at admission through the Eastern Cooperative Oncology Group (ECOG), previous cognitive impairment, survival from admission and primary location of neoplasm. The DSM-IV delirium diagnostic criteria were used. We excluded vague terms in the records, as well as delirium 24h before death. In the group of delirium, we registered “presence of delirium at admission” and “debut of delirium during hospitalization”. In these, survival from diagnosis of delirium; reversibility; subtype of delirium, and contributors-precipitating factors. Kaplan-Meier functions were used, as well as Mantel-Haenszel test.

Results: 200 patients were admitted, with 192 included (8 excluded), with a man of 70 years old with gastrointestinal tract location as most common. The mean ECOG = 3-4, and previous cognitive failure of 24%. The prevalence was 50% (25% during income and 26% at admission); was reversible in 16%, being the hyperactive and mixed the most common. The overall survival was 60 days (median=14). Survival presented a median of 22 days in patients without delirium, against 5 days in those at admission. From diagnosis of delirium was 8 days (16 from admission). There were statistically significant differences between survival of the patients with delirium at admission compared to those without it (log Rank p=0,000), as well as comparing patients with delirium at any point of income versus those without it (log Rank p=0,005). No significant differences were observed between those that debuted during the hospitalization and those without it (log Rank p=0,35).

Conclusions: We believe that our data show that delirium is a weight factor prognosis, but specially in patients with improved survival expectancy.
of the multidisciplinary supportive care for people with non small cell lung cancer (NSCLC) receiving palliative chemotherapy; optimal timing and composition of such interventions remains unclear.

**Aim:** The aim of this study was to develop an active palliative rehabilitation intervention targeting nutrition and physical activity and the related concepts of quality of life and wellbeing using all available evidence and consensus expert opinion.

**Methods:** The development phase of the Medical Research Council framework for developing and evaluating complex interventions was employed to guide the process of the research. A substantive literature review was undertaken and in addition, a focused systematic review specifically considered evidence pertaining to the effectiveness of nutrition and physical activity interventions for advanced lung cancer. The resultant Active Palliative Rehabilitation in Lung Cancer (APRIL) programme and intervention protocol were further developed and endorsed by a multidisciplinary advisory group panel consisting of palliative and oncology clinical and research experts and lay advisors.

**Results:** APRIL is a 6 week individualised programme of moderate intensity cardiovascular and resistance exercise and nutritional guidance to maintain and strengthen lean mass and promote function and quality of life. Participants complete an activity diary and record daily pedometer step count. Individual goals are reassessed weekly dependent on current need.

**Conclusion:** The APRIL programme is currently undergoing feasibility and acceptability testing within a clinical cancer setting.

**Funding:** Doctorate funded by the All-Ireland Institute of Hospice and Palliative Care and the HSC R&D Division, Public Health Agency, Northern Ireland.

**Abstract number:** PO19
**Abstract type:** Print Only

**Are Feasible the Survival Scales in Clinical Practice? One Strategy to Reduce Suffering**

*Gamboa Antíñolo F.M.*, *Martínez-Moro B.*, *Beltrán-Martínez A.*, *Ortega-Hidalgo E.M.*, *Dela Calle Velez M.*

1Hospital Universitario Valme, Internal Medicine, Sevilla, Spain, 2Hospital de Valme, Sevilla, Spain

An adequate clinical decision making is not only about suitable diagnosis and treatment, is also about prognosis. In Patients with advanced chronic medical conditions it is difficult to properly identify end-of-life trajectory. This study hopes to optimise the appropriate integral support strategies and avoid suffering, through the application of the PROFUND and PALIAR scales in a hospitalised cohort of polypathological patients in their final stages of life.

**General purpose:** Evaluate the suitability of recently published scales for non-oncological medical disease criteria in advanced or terminal stages. Analyse the feasibility of the application of these scales as a prognostic element in clinical decisions.

**Methodology:** Patients admitted for advanced or terminal diseases, underwent an evaluation with the PROFUND and PALIAR scales.

This study is a cross-sectional, observational study about usual practice.

**Results:** In the firsts weeks had included 55 patients. The average age is 84 years. The average PROFUND scale is 13. Average PALIAR scale is 8. The realization of both scales requires an average time of 10 minutes with the learning curve.

The main problem identified is the lack of data on malnutrition. To circumvent this problem we make nutritional scales that provide insight into the state of malnutrition without biochemical data.

In more than half of the patients the prognostic information provided is relevant to modify the therapeutic attitude.

**Discussion:** It seems feasible to apply both scales in clinical practice. The data provided by this prognostic assessment may change clinical decision making and help reduce the suffering associated with healthcare.

**Conclusion:** Reliable tools for prognostic decision making are necessary for polypathological terminal patients. The implementation of these scales seems feasible and the results may change clinical practice.

**Abstract number:** PO20
**Abstract type:** Print Only

**The Development and Initial Validation of a Questionnaire to Measure the Key Attributes of the Clinical Nurse Specialist in Palliative Care that Contribute to Quality, Patient-centred Care, from the Patient Viewpoint**

*Johnston B.M.*, *Cameron D.*

1University of Nottingham, Sue Ryder Care Centre Research Group, Nottingham, United Kingdom, 2NHS Tayside, Palliative Care, Perth, United Kingdom

**Background:** The Scottish Government recognises the importance of quality, person-centred healthcare, and current worldwide events have forced an examination of the nursing contribution to this agenda. This increasing requirement to demonstrate quality, person-centred care has resulted in the use of patient reported outcome measurement (PROMs) becoming essential, especially in palliative care.

**Aim:** The aim of this study was to develop a questionnaire (PROM), the Palliative Nursing Quality Measure (PNQM), and undertake initial validation. The PNQM aims to measure the quality of care provided by palliative
care Clinical Nurse Specialists (CNSs), from the patient’s perspective.

**Method:** Humanistic Nursing Theory provided a theoretical foundation to this study. In addition, Johnston’s Expert Palliative Nurse Model provided an evidence-based framework on which to develop the questionnaire. The process of questionnaire development had six phases; including systematic literature review, questionnaire formation, advisory group of patients, expert panel review and initial testing with patients; which contributed to the questionnaire’s face and content validity.

**Results:** The development phases identified that input from CNSs contributes significantly to the quality of care given to palliative patients. Patients benefit from the personal and professional interaction with the CNS. This includes the provision of emotional support, the CNSs expert knowledge, practical help and advice, together with on-going review of their condition and symptom management. The personal qualities of the CNS, their ability to communicate effectively and spend time with patients were deemed most important and valuable to patients.

**Conclusion:** The PNQM will be presented with recommendations for further testing to establish reliability and concurrent validity. In addition, recommendations for use of this questionnaire are proposed.

**Abstract number:** PO21

**Abstract type:** Print Only

**Difficulties Faced by and the Learning Needs of Nurses in Japan Involved in Providing Palliative Care to Patients with Chronic Heart Failure and Respiratory Failure**

*Yoshida M., Morita M., Higuchi Y.*

Japanese Red Cross College of Nursing, Tokyo, Japan

**Objective:** In Japan, palliative care for illnesses other than cancer is still underdeveloped in terms of medical policy, the country’s insurance system, use of pharmaceuticals, and the training of medical caregivers. The present study was conducted to clarify the difficulties being experienced by and the learning needs of the nurses who are the primary providers of palliative care, and to identify what specific training is required for implementing palliative care for illnesses other than cancer.

**Research methods:** The research participants comprised 10 nurses in caregiving for patients with chronic heart failure and chronic respiratory failure. The method used for the study was a qualitative descriptive design that employed semi-structured interviews. The interview data was classified by theme using qualitative methods.

**Results:** Nurses face difficulties in the following areas partially because of the difficulty of knowing when to prepare for or provide deathbed care: Emotional support for the family of the patient that is wavering between hope for recovery and acceptance of the end; Respect for the patient’s decisions; Interaction from the perspective of deathbed care; Resistance in the patient and family toward the use of opioids; Balance between aggressive treatment, pain palliation and regard for quality of life; Selection of the place of care and identification of the timing, and providing support for such; and Balance between aggressive treatment, elderly care and palliative care. Difficulties were related to the underdeveloped sociocultural situation of palliative care for non-cancer patients.

**Conclusion:** From these results, the learning needs of nurses who are involved in palliative care for patients with chronic heart failure and chronic respiratory failure are suggested.

**Abstract number:** PO22

**Abstract type:** Print Only

**Occupational Engagement at the End-of-Life: Occupational Therapists’ Perceptions**

*Faddy K.A., Bye R.A., Cook C.*

University of Western Sydney, School of Science and Health, Occupational Therapy, Penrith, Australia

**Introduction:** Each year in Australia, over 70,000 people require services and support due to terminal illness. Occupational therapists have provided unique care to meet the diverse needs of people with life-limiting illnesses since the palliative care movement began. However there is limited research to guide practice in this clinical area and to support how occupational therapists enable clients after they receive a life-limiting diagnosis.

**Aim:** This study aimed to identify occupational therapists’ perceptions of what occupations their clients wished to engage in after receiving a life-limiting diagnosis.

**Methods:** A national survey of Australian occupational therapists working with people with a life-limiting illness was completed. Recruitment occurred over a one month period in April 2012 using a purposive, snowball sampling technique, leading to 171 survey responses. Qualitative analysis of survey responses was completed using grounded theory methods.

**Results:** Two overarching categories and four sub-categories were identified during analysis. The first category, focusing on life has two sub-categories: prioritised engagement and altered engagement. Focusing on life centres on therapists’ perceptions of how clients continue to focus on living post diagnosis by remaining engaged in their chosen occupations. The second category, preparing for death has two sub-categories: practical preparation for death and “facilitating closure”. The category of preparing for death focuses on therapists’ perceptions of what clients do to practically prepare for death and how they find closure as their illness progresses. Both categories were found to be inter-related, with clients’ priorities perceived to change from focusing on life,
to preparing for death, as their occupational performance level decreased over time.

**Conclusion:** Therapists perceive clients want to continue focusing on life whilst preparing for death when they are diagnosed with a life-limiting illness.

**Abstract number:** PO23

**Abstract type:** Print Only

**Less than 24 Hours: Too Short a Stay in Palliative Care Units?**

Zulian G.B., Butel J.

Geneva University Hospitals, Palliative Medicine, Collonge-Bellerive, Switzerland

**Research aims:** The added value of concomitant care by a trained palliative specialized team concomitant with medical oncology specialists has been well demonstrated. Such active cooperation should allow death to occur as expected in a calm atmosphere at home or in selected appropriate places. In the present study, we explore the reasons why patients (pts) are still transferred moribund to a specialized palliative care (PC) station.

**Study design and methods:** Retrospective study of the characteristics of pts hospitalized in 2 PC units with 32 beds for less than 24 hours in an area of about half a million population during the year 2012. Length of stay was determined using the computerized medical notes system from the exact time of admission up until official registered time of death. Pts’ characteristics such as age, gender, origin, diagnosis, reason for admission were collected using the same tool.

**Results and interpretation:** 385 pts were admitted in 2012, mean length of stay was 16 days with a death rate of 80%. Twenty one pts (5.45% of admissions, 6.8% of stays) died within 24 hours, 3 between 6 and 12h, 8 between 12 and 18h. Shortest length of stay was 2h. 57% were male, general characteristics didn’t differ from other pts. 12 pts were admitted from home either directly by their treating physician or via the emergency service, 6 came from other hospital units and 3 from nursing homes. Main reasons for admission were so-called difficult or uncontrolled symptoms together with management problems, specifically at home. In conclusion, despite much effort to meet the needs of vulnerable populations, including second-line mobile PC teams, admissions to PC units still occur under questionable conditions unable to ensure appropriate quality of care.

**Abstract number:** PO24

**Abstract type:** Print Only

**Pact of Silence among Terminally Ill Patients Attended by a Hospital-based Palliative Care Unit from Southern Spain**


Hospital Universitario Virgen del Rocio, Internal Medicine, Seville, Spain

**Background:** A pact of silence (POS) may have a deeply negative impact on quality of care, decision-making and emotional support offered to terminally ill patients.

**Objectives:** To determine the variables associated to POS among terminally ill cancer (CP) and non-cancer patients (NCP).

**Methods:** Cross-sectional study. Patients were recruited from those attended by a palliative care unit (PCU) in a Southern Spain university hospital from January 2011 to March 2012. Analysed variables were age, gender, presence of POS, acknowledge of the disease, submitting specialty, main disease’s profile, carer features, complexity degree, number of visits/patient, Barthel index, Karnofsky index, days of follow-up during the stay and if received potent opioids. Univariate and multivariate logistic regression analyses.

**Results:** 569 patients were included for analysis (NCP/CP 179/390). A POS was diagnosed by a physician of the PCU in a 26.9% (36.7%/5.6% for CP/NCP; OR=9.842 (95%CI 5.035-19.238) P=.000), which largely differed depending on the PCST physician (7.5%-55%; P=.000) and between CP/NCP (36.7%/5.6%; OR=9.842; P=.000). Among NCP, the only variable independently associated to a POS was an age > 80 years old (aOR=.161; P=.023). For CP, the variables independently associated to POS, were: number of visits > 7 (aOR=.347; 95%CI .206-.586; P=.000), PPS< 40 (aOR=2.213; P=.002) and if the carer was the partner vs other (aOR=.7; P=.034).

**Conclusions:** The existence of a pact of silence may vary considerably among the physician’s perception or features of the patients. Cancer patients were more prone to suffer a pact of silence, as mostly are knowing their diagnosis and/or prognosis more frequently than NCP, who would be mostly elderly disabled, who indeed would have an impaired ability to understand. Younger age, among NCP, and number of visits, better performance status and when ther carer is other than the wife or husband, among CP, associated with POS.

**Abstract number:** PO25

**Abstract type:** Print Only

**Evaluation Tool for Identifying Complex Palliative Care Situations**

Vayne-Bosser P., Déramé L., Schneider M., Pautex S.

University Hospital of Geneva, Readaptation and Palliative Medicine, Collonge-Bellerive, Switzerland
**Introduction:** Many patients need palliative care (PC) the last months of their lives; some of them even in a specialized palliative care unit (SPCU). These units are staffed with trained health care professionals and have sufficient resources to treat complex and unstable PC situations. Many scores/indexes have been developed in order to detect patients who will need general PC. However, none of them consider patients needing specialized PC. We therefore developed such a tool. The aim of this study is to determine if our tool is helpful in identifying complex PC situations.

**Methods:** Our PC consulting service regularly evaluates PC situations in order to determine the relevancy of a transfer to a SPCU. During such a consultation our evaluation tool is applied. Retrospectively, all files from 2011 and 2012 were analyzed. We measured if there was an association between the total score, certain items and the admission to a SPCU. Associations were determined with the $\chi^2$ test; for survival analysis, the Cox model was used.

**Results:** A total of 149 files were analyzed. 77 women, average age 79.5 years (standard deviation 10.7), 72% had advanced cancer, 12% cardiac, respiratory or renal disease, 11% neurological disease, 5% miscellaneous. 74 patients were hospitalized in a SPCU. During such a consultation our tool is helpful in identifying complex PC situations.

**Conclusion:** Our tool is useful to determine complex PC situations, which may need an intervention from a specialized PC team. Single items cannot be used as separate indicators, but the sum indicates complexity. Survival is not associated with the need of specialized PC which well reflects reality where acute aggravation of symptoms can occur anywhere in the course of the last couple of months of life.

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**Abstract number:** PO26  
**Abstract type:** Print Only

**Depression and Advanced Cancer: Agreement between Different Screening Strategies**

Rhondali W.1,2, Chirac A.1, Celles L.1, Filbet M.1

1 Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2 MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3 Centre Hospitalier d’Orange, Palliative Care, Orange, France

**Background:** Depression is a frequent problem in advanced cancer patients. However, many cancer patients with depression are not treated because of the lack of systematic screening. The main objective of this study was to assess the level of agreement between self-reported depression by the patient and the physician and nurse assessment using the same tools.

**Methods:** We used two scales for depression screening: the Brief Edinburg Depression Scale (BEDS) and the depression item of the Edmonton Symptom Assessment System (ESAS). One of the secondary objectives was to estimate the possibility of a systematic and repeated (at one month) assessment.

**Results:** Twenty-nine patients were included and 8 of them (28%) had a BEDS score >6 and benefited from the initiation or modification of their antidepressant treatment. At visit 2, 15 patients were seen again and BEDS score was found ≤6 for all of them. A moderate concordance was found between the self-assessment by the patient using the BEDS and the physician’s evaluation using the same tool. A significant association was found in the visit 1 between the BEDS score >6 and ESAS items depression (p=0.006), anxiety (p=0.007), well-being (p=0.053) and nausea (p=0.075).

**Conclusion:** We found limited agreement between patient self-reported depression and physicians and nurses assessment. Researches with larger cohorts are now needed to confirm the benefits of depression’s screening in this frail population and also to explore available strategies involving all partners in care.

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**Abstract number:** PO27  
**Abstract type:** Print Only

**Preliminary Validation of the Brazilian Version of the Palliative Care Outcome Scale (POS-Br)**

De Carlo M.M.R.P.1, Correia F.R.2, Laboratory for Research on the Human Activity

1 Ribeirão Preto Medical School, University of São Paulo, Department of Neuroscience and Behavioral Sciences, Division of Occupational Therapy, Ribeirão Preto, Brazil, 2 Clinic Hospital of School of Medicine of Ribeirão Preto - University of São Paulo, Palliative Care Group, Ribeirão Preto, Brazil

**Introduction:** Objective measures of Quality of Life are required in order to advance palliative care practice and research.

**Objective:** To present the process of translation, cultural adaptation and preliminary validation of Palliative care Outcome Scale in Brazil (POS-Br).

**Methods:** For translation and cultural adaptation of POS, followed the following steps:

a) translation and back translation of POS version self (for the patient);  
b) Evaluation of the versions produced by a committee of experts and approval of the pre-final version of scale;
c) Pre-test approved version with 36 patients diagnosed with advanced cancer;

d) submission and final approval of the POS-Br by the author of the instrument.

A pilot test was carried out with 50 patients with advanced cancer. This step also applied the instrument European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire-Core -30 (EORTC QLQ C-30).

Results: The results showed a Cronbach’s alpha of 0.535 for the total scale. In respect to test-retest reliability, Kappa values ranged between 0.07 and 0.052. Satisfactory convergent validity data was found in the correlation analyses between the items of the POS-Br and the dimensions of the EORTC QLQ C-30.

Discussion: Although some results may not be desirable under the parameters, this fact can be related to the small sample size, the small amount of scale items and the low educational level of the population, requiring adjustment of the issues that were not well understood, a larger sample and check other psychometric properties.

Conclusion: Considering the complexity of the underlying clinical phenomenon of the population studied, we conclude that the POS-Br is a valid and reliable scale for clinical intervention and research in Palliative Care in Brazil. With the POS in Brazil, will be available a tool for identifying needs and implementation of care best suited to the real needs of patients.

Abstract number: PO28
Abstract type: Print Only

Bereavement and Health

Lacasta- Reverte M.A.1, Vilches Y.2, Alonso A.3, Diez L.3, Manrique T.3, Felitius M.3

1Hospital Universitario La Paz, Cuidados Paliativos, Madrid, Spain, 2Unidad de Cuidados Paliativos, Hospital Universitario La Paz, Madrid, Spain

Background: Bereavement may represent a serious problem for Healthcare system as it has implications for health through possible associations with morbidity and mortality. Research projects show that there is a significant increase in doctor visits and prescriptions number.

Objective: To evaluate the self-reported perceived physical-mental health changes in widowers’ after a psychological treatment and in the doctor visits frequency.

Method: Quasi-experimental design with 2 groups (experimental and control) and 2 pre-post-treatment evaluations. Percentages in self-reported changes in physical and mental health and doctor visits frequency were compared between control and experimental group. Data were analysed using SPSS 9.

Results: In total, 187 caregivers of cancer patients attended because of complicated grief, were included in the research. The average age (SD) was 59 years (15). 81 families belong to control group (16 male) and 106 to experimental group (19 male). No pre-treatment differences were detected between both groups (p=0,162). Unable to perform any statistical test in the variable perceived physical-mental health by the distribution of the data, however at the descriptive level there is a significant difference between groups. After the treatment, the experimental group consider that its physical and mental health improved (68 %) with a significant difference from the control group (20 %). According to doctor visits frequency, caregivers from experimental group visit hospital less often than control group after treatment (51% vs 9%) (p< 0,01).

Conclusion: A decrease in the rate of visits to the doctor and better self-reported physical and mental health was detected in the experimental group demonstrating the usefulness of the program for complicated grief. This is consistent with the results of this research in other objective variables. We believe that these variables could be considered as health indicators in grief.

Abstract number: PO29
Abstract type: Print Only

Development of Educational Program for Training of End-of-Life Care Facilitator in Community Care

Nagae H., Ikemoto N.

Chiba University, Graduate School of Nursing, End of Life Care in Nursing, Chiba, Japan

Aims: The aim of this study is to develop an educational program of end-of-life care that can be utilized by professionals in charge of the care management in communities, such as public health nurses, hospital nurses and social workers, in their practical activities.

Methods: “End-of-life Care Training Course” is held for social health nurses, hospital nurses and social workers working at the Community Comprehensive Support Center in A district. The training course organized this time was held three times every other month, and a combination of lecture and group work practice was exercised in three hours. During the one-month period between the training courses, every participant set themselves challenges to practice what they learned in the training in order to introduce a study method of utilizing the simulation of the group work practice in practical activities. The contents of the education were “Dying with Dignity” for the first course; “Advance Care Planning in Japan” for the second course and “Support for Decision-making as a process of care” for the third course.

Results: The 14 participants are 7 public health nurses, 2 hospital nurses, 3 care workers and 2 social workers; ave-
In literature there are no epidemiologic data regarding Vascular or Subcutaneous Access Device (VSAD) selection in palliative care can be troublesome because many aspects must be taken into consideration. In literature there are no epidemiologic data regarding vascular and subcutaneous access devices specifically in palliative care.

**Aim:** The main purpose is to describe prevalence and incidence of VSADs in general and specifically for device typology in terminally ill cancer patients. A further aim is the evaluation of the pertinence of access device according to international guidelines.

**Method:** The research is an observational retrospective chart review referred to patients admitted in an Italian Palliative Care Unit (PCU) whose death occurred in a six-month’s period.

**Results:** The study refers to 461 patients. A VSAD had already been positioned in 43.9% of the patients before being admitted in the PCU. Among the 56.1% of the patients who were admitted without a VSAD, the 11.7% never received one. The prevalence of VSADs was 88% while the incidence was 44%. The typology of VSAD inserted during the period of assistance was distributed as follows: 86.4% subcutaneous cannula; 12.8% intravenous peripheral cannula; 0.6% medium or long lasting access devices.

**Conclusions:** The presence of a medium or long lasting vascular access device in a patient coming to a palliative care program satisfies all therapeutic needs. The main aim is the correct management in order to avoid other VSADs insertion during the assistance. The prevalence of VSADs calculated throughout our study leads us to think the parenteral route is often essential in palliative care. The results also suggest that VSAD selection is often appropriate in relation to the international guidelines.

**Abstract number:** PO30  
**Abstract type:** Print Only

**Vascular and Subcutaneous Access Devices in Palliative Care**

Maynani C.1, De Marinis M.G.2, Bartolozzi F.2, Bacelli A.3, Guidotti C.3, Valerio M.3, Espino M.4, Giunta D.4, Ruggeri P.4, Casale G.4, Mastroianni C.4

1Antea, Rome, Italy, 2University Campus Bio-Medico, Rome, Italy, 3University La Sapienza, Rome, Italy, 4Antea, Palliative Care Unit, Rome, Italy

**Background:** Vascular or Subcutaneous Access Device (VSAD) selection in palliative care can be troublesome because many aspects must be taken into consideration. In literature there are no epidemiologic data regarding vascular and subcutaneous access devices specifically in palliative care.

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**Abstract number:** PO31  
**Abstract type:** Print Only

**Intensity of Physical Symptoms and Unbearability Studied Longitudinally in End-of-Life Cancer Patients in Primary Care**

Ruijs C.1, Kerkhof A.2, van der Wal G.1, Onwuteaka-Philippsen B.1

1VU University Medical Center, EMGO Institute for Health and Care Research, Public and Occupational Health, Amsterdam, Netherlands, 2VU University Medical Center, EMGO Institute for Health and Care Research, Clinical Psychology, Amsterdam, Netherlands

**Aim:** To longitudinally study the relationship between physical symptom intensity and unbearable suffering.

**Methods:** 44 general practitioners during 3 years recruited cancer patients with estimated life expectancy shorter than 6 months. Intensity and related unbearable suffering were assessed bimonthly with the State-of-Suffering V, a quantitative instrument addressing 69 symptoms with a 5-point rating scale (1-5). Presentation of most frequent physical symptoms.

**Results:** 76 out of 148 requested patients (51%) participated. In 33 patients 2 successive interviews were administered. Median time to death was 4 weeks for the final interview and 18 weeks for the prefinal interview. Statistical analysis was not performed due to patient numbers.

**Conclusion:** Largest increase over time of patients with high symptom intensity occurred for shortness of breath, general discomfort and weakness. Largest increase in unbearable occurred for not sleeping well and weakness. Pain remained stable. Also low intensity frequently resulted in unbearable suffering. Assessment of unbearable next to symptom intensity may indicate choice for symptom control interventions and/or psycho-oncologic interventions.

**Funding:** Netherlands Organization Scientific Research
Background: A Danish study has shown that burnout due to long term exhaustion among general practitioners (GPs) is a problem affecting approx. 25% of GPs. The degree of burnout may affect the work performance of the GP, especially the tasks requiring time, empathy and personal involvement. It has not previously been investigated if the degree of burnout among GPs is associated with the delivery of end-of-life care.

Aim: To investigate associations between burnout among GPs and end-of-life care services provided by the GPs.

Method: A register-based cohort study among solo GPs in the Central Denmark Region who had participated in prior surveys in 2004 or 2012, respectively. Burn-out was measured by the Maslach Burnout Inventory (MBI).

This instrument includes three dimensions of burnout: exhaustion, cynicism, and inefficacy. All solo GPs who answered (92 in 2004 and 85 in 2012) are included (duplicates will be removed in the final cohort using the most recent answer). Data from Danish health care registers on the GP’s deceased patients during either 2005 or 2013 (the year after answering the questionnaire) will be retrieved.

Main outcome measures: Place of death for deceased patients, use of GP services during daytime and out-of-hours, time spent at home, use of contacts and number of hospital admissions during the three months before death. The causes of death for deceased patients will be registered and adjusted for in the analysis.

The association between the GP’s burnout status (not burned out, burned out and very burned out) and the different outcome measures will be analysed using multivariate models. The work is in progress and results will be presented at the conference.

Perspective: If the degree of burnout affects the palliative care performed by the GP, this has to be taken into account when working with quality assurance and education in palliative care in the primary sector.

Funding: “Trygfonden” and “The Danish Cancer Society”.

### Table. Intensity and unbearability; 33 patients.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Prefinal interview %*</th>
<th>Final interview %*</th>
<th>Prefinal interview %**</th>
<th>Final interview %**</th>
<th>Prefinal interview %*</th>
<th>Final interview %*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weakness</td>
<td>79</td>
<td>94</td>
<td>36</td>
<td>55</td>
<td>75</td>
<td>83</td>
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<tr>
<td>Tiredness</td>
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<td>88</td>
<td>39</td>
<td>55</td>
<td>85</td>
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</tr>
<tr>
<td>Changed appearance</td>
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<td>30</td>
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<tr>
<td>General discomfort</td>
<td>79</td>
<td>79</td>
<td>9</td>
<td>27</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>Pain</td>
<td>70</td>
<td>67</td>
<td>24</td>
<td>21</td>
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<td>Shortness of breath</td>
<td>61</td>
<td>61</td>
<td>6</td>
<td>21</td>
<td>50</td>
<td>71</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>61</td>
<td>61</td>
<td>27</td>
<td>18</td>
<td>56</td>
<td>83</td>
</tr>
<tr>
<td>Not sleeping well</td>
<td>36</td>
<td>42</td>
<td>12</td>
<td>6</td>
<td>75</td>
<td>100</td>
</tr>
</tbody>
</table>

0-2 missing scores per aspect.

Score: 1-not at all; 5-hardly can be worse.

High intensity: intensity score 4 or 5.

Unbearable: unbearability score 4 or 5.

*: % of patients.

**: % of high intensity symptoms.

1University of Aarhus, Department of Oncology, Aarhus, Denmark, 2Aarhus University Hospital, Palliative Team, Department of Oncology, Aarhus, Denmark, 3Aarhus University Hospital, Department of Oncology, Aarhus, Denmark, 4University of Aarhus, Research Unit for General Practitioners, Aarhus, Denmark, 5University of Aarhus, Research Unit for General Practice, Aarhus, Denmark.
Abstract number: PO33
Abstract type: Print Only

A New Methodology with GIS Capable of Analyzing Equity and Accessibility in the Planning and Development of Palliative Care Resources

Herrera E.1, Librada S.1, Nabal M.2, Jaraiz F.J.3, Gutierrez J.A.4

1NewHealth Foundation, Sevilla, Spain, 2Hospital Arnau de Villanueva, Palliative Care, Lleida, Spain, 3University of Extremadura, Department of Territorial Sciences, Cáceres, Spain, 4University of Extremadura, Department of Territorial Sciences, Cáceres, Spain

Until now, the development of palliative care (PC) was only described by the total number of resources, type and location.

The services provided, team members, distance to the population and geographical distribution of PC resources are essential to analyze two fundamental aspects to strategic and operational planning: accessibility and inequity.

Geographic Information Systems (GIS) provide a real insight into the distribution of resources and decision-making for population location in the provision and use of these services.

Aim: To design and test a methodology with GIS capable of analyzing Equity and Accessibility in the planning and development of PC resources.

Methodology:

- PC resources characterization: Spanish directory of PC (2009).
- GIS: population intelligent maps, towns, roads, impedance, distance from teams and municipalities (ArcGIS tool).
- Indicators: Accessibility geographical and access times to the nearest resource.
- Measurement / Comparison of resource coverage.
- Equity indicators: Lorenz curves, Gini indexes, access times, resource allocation, optimal rate.

Results: Population, distance, location by type, professionals, territorial differentiation, access time of the municipality to the team and coverage maps. We have obtained tens of coverage results for PC team. Example: The average time of access to a hospital is less than 30 minutes. The distribution of hospital care is more unequal than at home. 97.20% of the population with less than optimal coverage results for PC team. We have obtained tens of coverage results for PC team. Example: The average time of access to a hospital is less than 30 minutes. The distribution of hospital care is more unequal than at home. 97.20% of the population with less than optimal coverage ratio of doctors (1.66 per 100,000 inhabitants). (In Congress).

Results contributed to the evaluation of the National Strategy of PC conducted by the National Ministry of Healthcare, and was accepted by National Committee of PC as a valid tool conveniently replicable.

Conclusions: The new method evaluates accessibility, coverage and equity of PC resources to the population, and improve previous outdated descriptive methods to analyze and planning the development of PC resources.

Abstract number: PO34
Abstract type: Print Only

Prevalence and Clinical Characteristics of a Population-based Cohort of Patients with Advanced Chronic Disease and Palliative Needs

Blay C.1,2, Barcena A.3, Vila L.1, Costa X.1, Arjona M.3, Vilaplana E.1, Epelde A.1

1University of Vic, Chair of Palliative Care, Vic, Spain, 2Departament of Health Generalitat de Catalunya, Chronicity Program, Barcelona, Spain, 3Institut Català de la Salut (ICS), SAP Osona, Vic, Spain

Introduction: Caring persons with advanced chronic diseases and palliative needs (ACDPN), is a nuclear policy of the Catalonian Health Plan.

The description of prevalence and clinical characteristics of these persons are first steps to develop new care models.

Objectives:

1. To describe the prevalence and the basic demographic and clinical characteristics of a community cohort of ACDPN patients.
2. To compare and validate results with similar studies.

Method: Cross-sectional study, using NECPAL-CCOMS-ICO®, a validated tool to detect palliative needs, by a transversal population-based approach applied to three rural and semiurban primary care teams after a 4 hour teaching intervention.

Results: 250 ACDPN patients identified. Community prevalence = 1.1% (75% of the expected prevalence). 56% were women and the average age was 90.

Main causes of ACDPN were dementia 27.3%, frailty 22.1%, tumors 13.7%, heart failure 13.3%, neurological diseases 9.6%, COPD 8%, chronic kidney disease 3.2%, liver failure 1.2%, other conditions 1.6%. The ratio between advanced disease/frailty-dementia = 1:1. The ratio cancer/non-cancer was 1:6.

194% live in nursing homes with a ratio disease/frailty-dementia = 1:4.

Discussion: Minimal teaching interventions allow the identification of the majority of community ACDPN patients. A significant part is living in nursing homes.

The cohort is comparable to expected standards with respect to age, gender, distribution of diseases/conditions and characteristics of the nursing home population.

In the short term, data will be available to substantiate the apparent presence of two different clusters. First cluster, almost ubiquitous in nursing homes, are female
patients, older than 80, with dementia or frailty. The second includes younger males with cancer or organ failure.

The data allow a better target for care modeling and emphasize the need for new community-based palliative approaches.

**Abstract number:** PO35  
**Abstract type:** Print Only  
**Ethical Dilemmas Related to End-of-Life that Might Affect Professionals among Different Clinical Units**  
Montoya-Juarez R.1, Alfaya-Gongora M.M.2, Hueso-Montoro C.2, Campos-Calderon C.1, Hernandez-Lopez E.1, Martinez-Cruz E.2, Gorlat-Sanchez B.2, Guardia-Mancilla P.1, Ojeda-Virto F.1, Garcia-Caro M.P.1  
1University of Granada, Nursing, Granada, Spain, 2University of Granada, Melilla, Spain, 3University of Granada, Granada, Spain, 4Servicio Andaluz de Salud, Granada, Spain, 5Servicio Andaluze de Salud, Motril, Spain  

**Aim:** The aim of this study is to determine the most frequent ethical dilemmas related to end of life, among different professionals and clinical units.  
**Methods:** Observational and descriptive study. A stratified sampling was performed among physicians and nurses of different hospitals and primary care centers of Granada and Melilla. Professionals temporarily hired were excluded. A questionnaire was developed ad hoc. 55 items about end-of-life care experience, distributed in 11 main issues, were rated by professionals in a 5-point Lickert scale. Results related to the frequency of 10 “Ethical Dilemmas” are discussed in this communication. A descriptive analysis and ANOVA comparative analysis between different units was performed.  
**Results:** 312 professionals were interviewed for this study. 62.2% of them were men. Mean age was 47 years (SD=9.28), and average professional experience was 22.5 years (SD=9.99). 40% were Physicians and 60% nurses. 99 professionals (31%) worked in Primary Care, and 69% in Hospitals (17% in surgery wards, 19% in ICUs, 18% in Internal Medicine and 5% in Oncology/Palliative Care). The most frequent dilemma in all units is “Disagree in clinical aims between patients and families”. Oncology and Palliative Care are the units where most frequently have to perform. A comparative analysis between different units was discussed in this communication. A descriptive analysis and ANOVA comparative analysis between different units was performed.  

**Conclusion:** The frequency of ethical dilemmas showed in this research supports a clinical scenario of a low participation of patients and families. In some clinical units such as Internal Medicine and Intensive Care, dilemmas related to therapeutic efforts are the most problematic.

**Abstract number:** PO36  
**Abstract type:** Print Only  
**A Spiral of Precariousness: A Qualitative Study on Relationship Dynamics between Adult Children with Cancer and their Older Parents**  
Van Humbeeck L.1, Dillen L.2,3, Piers R.1, Verhaeghe S.4, Grypdonck M.4, Van Den Noortgate N.1  
1Ghent University Hospital, Department of Geriatrics, Ghent, Belgium, 2Ghent University Hospital, Oncology Centre, Ghent, Belgium, 3Federation of Palliative Care Flanders, Vilvoorde, Belgium, 4Ghent University, Department of Social Health and Nursing Sciences, Ghent, Belgium  

**Background:** Research consistently indicates that family members tend to avoid open communication when someone close is diagnosed with cancer. Yet, these findings almost exclusively stem from parent-young child dyads and patient-spouse dyads. Insight in communication patterns between adult cancer patients and their older parents is virtually nonexistent. We aimed at gaining insight in these dynamics by analytically confronting the story of the children with that of the parents.  

**Methods:** Interview data of 10 patients with cancer and 22 parents (≥70 yrs) were analyzed with support of NVivo 10 based on the principles of Grounded Theory.  

**Results:** The interaction between adult cancer patients and their parents is marked by two entangled helices. The outer, visible helix is constituted by a cascade of withholding and withdrawal. Both actors tend to contain the impact of the diagnosis and their concerns for each other. The adult children talked at length of shutting down emotionally and withdrawing into themselves or from others, while the older parents experienced this as a sudden change in their interrelatedness, enforcing them to redefine their role in the process. This outer helix is maintained by the inner helix typified by a mechanism of under-burdening, in which both actors strive not to unduly burden the other. Driven by a belief that open communication will over-burden the other, both actors attempt to display an upbeat attitude, leading up to unintended pain and distancing. The perpetual interplay of these spirals can be altered, stopped or intensified by the (dis)congruence in matching coping styles of both actors.  

**Conclusion:** Communication is generally seen as pivotal in dealing as a family with illness. The current findings give insight in how interaction may unfold between a cancer patient and his older parents, what the seed-bed is for some processes, and how (dis)congruence in coping styles may influence the balancing act between distance and closeness.
Abstract number: PO37
Abstract type: Print Only

Improving Palliative Care for Older People through European Collaborations
Froggatt K.1, Albers G.2, Van den Noortgate N.3, Pautex S.4, Van den Block L.5, Gambassi G.6

1Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom, 2Vrije Universiteit Brussel, Brussels, Belgium, 3Universiteit Ziekenhuis Gent, Gent, Belgium, 4Hôpitaux Universitaires de Genève, Geneva, Switzerland, 5Vrije Universiteit Brussel/End-of-Life Care Research Group, Brussels, Belgium, 6Università Cattolica del Sacro Cuore, Rome, Italy

Background: A manifesto: “Palliative Care for Older People in the European Union” was launched at the European Parliament, by the Maruzza Foundation, EAPC, and the EUGMS, in September 2013. This sought to assist policy makers and national organisations to improve palliative care for older people in Europe. A working group has been established to take this work forward. The group is firstly undertaking a consultation exercise with EAPC and EUGMS members about palliative care for older people.

Aims:
- To identify areas of collaboration between palliative care and geriatric care
- To identify barriers and facilitators to on-going collaboration

Methods: Two discussion groups with EUGMS members were held in October 2013. Two further discussion groups with EAPC members are planned for June 2014. A template analysis of the accounts was undertaken.

Findings: Fifteen participants (8 women and 7 men), from nine European countries, participated in the two discussion groups. All participants held medical posts either in acute care, community settings and/or palliative care units. Examples of collaboration were identified with respect to clinical care, education, policy, research and leadership and organisational structures. Clinical collaboration often relied on the individual clinician as the driving force for the service. The geriatrician as a bridge between specialists in general medicine and palliative care was highlighted. Barriers and facilitators identified concerned: funding models in different healthcare systems; availability of either geriatric and/or palliative care specialists in all care settings; location of geriatricians outside of palliative care teams; and a lack of clarity re the term palliative care and its remit.

Conclusions: Examples of innovative collaborations drawing upon personal and service expertise exist across Europe. Building upon these examples, recommendations for policy makers and service providers will be made.

Abstract number: PO38
Abstract type: Print Only

Long-term Opioids and Naloxone Administration in a District General Hospital
Facey C.L.1, Brooks D.2

1Chesterfield Royal Hospital, Chesterfield, United Kingdom, 2Chesterfield Royal Hospital, Palliative Medicine, Chesterfield, United Kingdom

Background: Respiratory depression is a known side effect of opioid medications. Naloxone is an opioid antagonist used in the reversal of opioid overdose. The use of naloxone in patients on long-term opioids can lead to refractory pain and opioid withdrawal.

Objectives: To determine the number of patients on long term opioids, admitted either electively or as an emergency, given naloxone in a district general hospital. To determine if naloxone use is in line with local guidance, which recommends naloxone should only be administered to patients with respiratory depression, evidenced by a respiratory rate less than 8 and oxygen saturations less than 85%.

Method: A retrospective audit for all patients administered naloxone over a 12 month period (January - December 2012) at Chesterfield Royal Hospital.

Results: A total of 21 patients on long-term opioids were administered naloxone. Of the 21 patients in whom naloxone was administered, 2 patients had had an opioid dose increase during the hospital stay and 4 patients had been given additional opioid. Of the 21 patients, 1 patient given naloxone had documented evidence of respiratory depression. 7 of patients given naloxone had no documentation to support respiratory depression while 13 of the patients given naloxone had documentation that supported no respiratory depression.

Conclusion: Current practice compared to the local guideline is not satisfactory. Patients on long-term opioids, without respiratory depression, are being given naloxone, which could lead to refractory pain. The main areas identified for improvement are staff education and changes to the electronic prescribing system. This would include an opioid reversal bundle with recommended guidance for evidence of respiratory depression.

Abstract number: PO39
Abstract type: Print Only

Pilot Study of Delirium in Two Inpatients Palliative Care Units
Zuriarrain Reyna Y.1, Bravo Perez M.C.2, Gonzalez Garza M.3, Alonso Babarro A.4

1Hospital Centro de Cuidados Laguna, Palliative Care Unit, Madrid, Spain, 2Hospital Centro de Cuidados
Delirium is a complex syndrome and has a difficult diagnosis in early stages.

**Aims:** To determine the frequency of Delirium in palliative patients admitted to two hospital units, a short stay (SS) and a medium-large stay (MLS), describe the characteristics of patients and delirium, and the utility of the Memorial Delirium Assessment Scale (MDAS).

**Methods:** Prospective longitudinal study of patients with advanced disease hospitalized for a period of 1 month. We use MDAS as clinically screening and follow up in the 1st, 3rd and 7th day. We excluded patients with language barriers or low consciousness, severe cognitive impairment or major psychiatric illness.

**Results:** N: 55 patients: 32 (SS) and 23 (MLS), 25% were lost by lack of monitoring. The median age was (67:75), mean of Palliative Perform Status (PPS) (60:40). The mean drugs during hospitalization (15:8). The most common psychoactive drugs: corticosteroids opioids and benzodiazepines. Delirium prevalence: 20 (49%), being more frequent in the SS: 45%, reversibility was (50%:20%), median severity at diagnosis was low-moderate in both units. The most frequent type and cause was hypoactive and infectious (53%). Died after the diagnosis (62%:80%) with lower survival in MLS. Psychoactive drugs were slightly modified after diagnosis. All patients started neuroleptic or increase doses after diagnosis (54%). The MDAS tool was useful for the diagnosis and evaluation. We found difficulties in the assess of the global cognitive: disorientation, short-term memory impairment, impaired digit span, and disorganized thinking in patients with excessive sleepiness or fatigue.

**Conclusions:** The prevalence and the type of delirium were similar to other studies. UCE seems to have higher prevalence and reversibility and patients were exposed to more number of drugs. Infectious cause was high. We found difficulties in the application of MDAS in patients with low PPS. The results are not definitive because of a preliminary sample.

**Abstract number:** PO40
**Abstract type:** Print Only

**A Qualitative Evaluation of the Intervention Project „Hospice and Palliative Care in Nursing Homes“ in Eight Nursing Homes, a Two Year Process**

**Rauscher O,1, Beyer S,2, Pissarek A.H.,1, Pelttari L.2**

1Vienna University of Economics and Business, NPO-Competence Center, Vienna, Austria, 2Dachverband Hospiz Österreich, Vienna, Austria

**Background:** From 2009 to 2012 Hospice Austria carried out the intervention project “Culture of Hospice and Palliative Care in Nursing Homes” (a 2-year organizational development process including advanced training in palliative geriatrics, in which 80% of all employees participated.) The NPO-Competence Center of the Vienna University of Economics and Business was commissioned with the implementation of an evaluation.

**Aims and questions:** The evaluation surveyed the effects of the intervention project and analyzed it against the background of the goals stipulated.

**Main scientific question:** What effects does the intervention project have on the most significant target groups?

**Methods:** A multiple case study design was chosen in which two respectively three pilot nursing homes were selected as subjects for a single case study. Upon completion of the intervention a pre-post design was used to determine the changes in comparison to the initial state. In addition, surveys were taken during the project which enabled feedback on the results.

**Results:** Hospice culture and palliative care have been anchored to a higher degree in everyday life in the homes. An active debate about the topic took place amongst employees. Palliative groups and palliative care representatives in the homes have become an integral part of everyday life. Interdisciplinary cooperation has been improved. Personal wishes of tenants during the end stage of dying are being better met, complementary therapies have increased and pain therapy was improved. Relatives and other loved ones are better informed about the topic and more strongly integrated. It became apparent that medical care and palliative medical care are insufficient and recurring personnel shortages occur.

**Conclusion:** Due to the project, overall improvements regarding quality on the various levels could be achieved, for tenants as well as for caregivers and relatives.

**Abstract number:** PO41
**Abstract type:** Print Only

**Preliminary Validation of the Spanish Version of the Frommelt Attitudes toward Care of the Dying Scale (FATCOD)**

**Aradilla-Herrero A,1, Edo-Gual M,1, Monforte-Royo C,2,3, Tomás-Sábad J,1**

1Gimbernat School of Nursing, Autonomous University of Barcelona, Nursing, Sant Cugat del Vallès, Spain, 2International University of Catalonia, Nursing, Sant Cugat del Vallès, Spain, 3WeCare Chair, End-of-life Care, Faculty of Medicine and Health Sciences, International University of Catalonia, Sant Cugat del Vallès, Spain

**Aims:** The attitudes that student nurses may hold towards end-of-life care is a key aspect to consider during their
training. Using a sample of nursing students the aim of this validation study was to analyse the psychometric properties of the Spanish version of the Frommelt Attitudes Toward Care of the Dying Scale (FATCOD) and to examine its relationship with other variables. **Method:** Subjects. Participants were 423 nursing students (79 males and 344 females) with a mean age of 22.43 years (SD= 5.34, range 18-47). Instruments. Participants responded to a questionnaire that contained the Spanish versions of the following instruments: a) Frommelt Attitudes Toward Care of the Dying Scale (FATCOD); b) Trait Meta-Mood Scale (TMMS-24); and c) Collett-Lester Fear of Death Scale (CLFDS). Procedure. After obtaining permission from the scale’s author a Spanish version of the FATCOD was produced by means of a back-translation procedure involving four bilingual professionals. The nursing students responded individually and voluntarily to the questionnaire (three scales) in a usual classroom setting. Anonymity and confidentiality were ensured throughout the process. **Results:** Analysis of the internal consistency of the Spanish version of the FATCOD yielded an alpha value of 0.78. This was followed a principal components analysis with varimax rotation. Although the scree plot shows the existence of two significant factors, the factor loadings’ distribution suggests that it should be used as a unidimensional scale. Finally, the correlation coefficients showed that the FATCOD was positively and significantly correlated with the TMMS, and negatively and significantly correlated with the CLFDS. **Discussion:** The results indicate that the Spanish version of the FATCOD has similar psychometric properties to those of the original scale. Therefore, it can be regarded as a valid instrument for assessing the attitudes of Spanish-speaking nurses towards end-of-life care. **Abstract number:** PO43 **Abstract type:** Print Only **Online Learning: A Scoping of the Literature for a Study in Integrated Palliative Care** Hughes S., Preston N., Payne S. Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom **Background:** A study of patient-centered integrated palliative care pathways in advanced cancer and chronic disease, InSup-C (EC FP7 funded) plans to develop online learning modules to disseminate and promote best practice in this field across Europe. **Aims:** To identify the key components of effective online learning models in higher and professional development education with particular reference to palliative and end of life care contexts. **Methods:** A search was conducted for papers that reported peer reviewed studies using MEDLINE, ERIC, CINAHL, AMED, PsycINFO and Academic Search Complete databases. The main subject term: online learning, was used in combination with evaluat*, research, palliative, and end of life as free text terms. This yielded 1441 results. Further filtering and removing duplicates reduced this to 1084 of which 26 papers were selected for narrative review. Of
these, four studies evaluated purely online (un-moderated, asynchronous) learning inputs, 10 were reviews or meta-analyses, and 12 considered online components of blended learning courses.

**Findings:** Evidence for the effectiveness of un-moderated learning was equivocal and where part of a blended approach, confounded by other factors such as tutor input or peer interaction. Reported positive effects included improved access for remote learners and those with resource constraints, and increased flexibility for those studying alongside work commitments.

**Conclusions:** Published results of evaluative research into purely un-moderated, online educative tools were relatively few. There is a need for better research into the efficacy of these approaches given that there is evidence of their increasing use in palliative and end of life care education. In designing new material for its project, InSup-C will incorporate robust evaluative techniques at the module design stage.

**Abstract number:** PO44
**Abstract type:** Print Only

**Terminal Stage of Illness from the Perspective of Czech Palliative Patients**

**Dubovska E.**

**Tavel P.**

**Polackova Solcova I.**

**Kračmárová L.**

1Palacky University Olomouc, Olomouc University Social Health Institute, Olomouc, Czech Republic,

2Academy of Sciences of the Czech Republic, Institute of Psychology, Prague, Czech Republic

**Objectives:** The objective of our study was to find out more about the quality of health care and the quality of life of Czech palliative patients. Main questions were focused on satisfaction with palliative health care with emphasis on the communication between medical staff and patients.

**Design:** Qualitative design with in-depth semi-structured interviews.

**Setting:** Participants were palliative patients with terminal diagnoses (mostly cancer), recruited directly or through a co-operation with medical staff. The study was approved by ethics committee at Palacky University in Olomouc.

**Participants:** Participants (N=30) were selected from the relevant institutions in the Czech Republic.

**Method:** The study was a part of Palliative care module of Czech DIPEX study, based on methodology of DIPEX International. The interviews were realized by a team of four independent researchers. Interviews were audio / video taped, transcribed verbatim and coded by two researchers. Inductive thematic analysis was performed using QSR NVivo 10.

**Results:** Main drawbacks include the lack of time and empathy of medical staff, informing patients insufficiently or solely in medical terms and also medical staff talking behind the back of the patient about “bad” prognoses. On the other hand, our participants declared that they received a satisfactory pain treatment. However the institutional support for the caring family members was viewed as poor. Emotions connected to the terminal stage of illness were possible thanks to these facts feelings of hopelessness or guilt (responsibility of own infirmity), fear of being a burden to the family, fear of being useless, but also feelings of gratitude toward the family and medical staff. In many cases we found a strong need to talk to someone, which is very often not fulfilled.

**Funding:** This study was supported by the ECOP project Social determinants of health among social and health disadvantaged groups of population (reg. No. CZ.1.07/2.3.00/20.0063).

**Introduction:** Information on the use of health resources by patients with advanced chronic disease and palliative needs (ACDPN) is limited and it could be a key element to improve health outcomes, patient experience and efficiency.

**Method:** Cross-sectional study, using NECPAL-COMS-ICO®, a validated tool to detect palliative needs by a transversal population-based approach applied to three rural and semiurban primary care teams sharing both general and intermediate care hospitals.

**Objectives:**

1. To describe number and location of ACDPN patients’ contacts with health system the year prior to their identification.

2. To define their profile in resource utilization depending on patients’ clinical characteristics.

**Results:** 250 ACDPN patients were identified. Community prevalence = 1.1%

The main average rates per patient and year are: 0.7 admissions in general hospital (55.7 % with no admissions), 1.14 contacts to emergency rooms (39.8 % with no contacts), 18.4 on site visits to the primary care center
(52% to nurses, 48% to doctors). 11.1 and 4.2 were, respectively, home or virtual contacts.

Less than 1% of primary care visits were done by specialized palliative care teams.

23.6% of patients were admitted in intermediate care settings.

The type of contacts strongly depends on the clinical cluster the patient belongs.

Discussion: The year before ACDPN is identified patients mainly use primary and intermediate care settings, where nurses lead at least half of contacts. Care is usually provided by non-specialized teams with a possible underuse of virtual contacts. Older-than-80 females with dementia or frailty consume community and nursing home resources. Younger-male-patients with cancer or organ failure cluster have more need of specialized services in acute general hospitals.

ACDPN patients are cared in all settings but the model of proactive caring probably depends on clinical profile. Health authorities should adapt their planning to this fact.

Abstract number: PO46
Abstract type: Print Only

What Strategies Are Helpful when Dealing with Severe Illness in a Partnership? A Quantitative Questionnaire Study
Jansky M.1, Eggebrecht D.2, Stahl J.3, Friedemann N.1, Kröner-Herwig B.3

1University Medical Center Göttingen, Palliative Medicine, Göttingen, Germany, 2Red Cross Hospital, Kassel, Germany, 3University of Göttingen, Psychology, Göttingen, Germany

Introduction: In a severe illness like cancer, patient’s partners can use different strategies for social support. They can actively engage (AE) patients to cope with the illness, shield them as protective buffers (PB), or overprotect them (OP). AE seems a beneficial strategy; while PB and OP seem dysfunctional. This might be influenced by patient’s physical functioning (PF).

Aim: We analyzed to what extent these strategies influence the well-being of patients and their partners in a palliative care setting (PC).

Method: Outcome variables (depression, anxiety, self-efficacy (SE), life satisfaction (LS), tranquility, positive mood), AE, PB, OP and PF were assessed using reliable scales for 39 cancer patients (15 male, 24 female; mean age 58.6) and their partners at PC units. Correlations were analyzed using Spearman’s rho; PF was used as a moderator variable in multiple regression.

Results: Patients showed above-average scores for depression. Their partners experienced even higher depression and anxiety than the patients. AE and PB were more often reported than OP. AE was positively correlated with LS ($r_s = .44$). While no significant correlation was found between OP and the outcome variables, PB was associated with LS ($r_s = -.32$) and anxiety ($r_s = .34$). PF did not influence the relation between AE, PB and the outcome variables. PF moderated the influence of OP on tranquility ($R^2_m = 0.215, R^2_{lin} = 0.027, t_{(36)} = 2.63$) as well as SE ($R^2_m = 0.113, R^2_{lin} = 0.002, t_{(36)} = 2.00$). OP was positively correlated to SE and tranquility when PF was low, and negatively when it was high.

Conclusion: Partners’ support strategies do not have a stable influence over the course of illness, but rather change over time. Patients with a good general condition may feel restricted when overprotected, those with poor health may instead feel sheltered. AE has a smaller effect on well-being. Longitudinal studies are necessary to assess change and redefine concepts of support strategies.

Abstract number: PO47
Abstract type: Print Only

Distortions and Dissatisfaction with the Body Image in Cancer Patients
Albuquerque K.A.1,2, Pimenta C.A.M.1

1University Federal of Pernambuco, Departament of Nursing, Recife, Brazil, 2University of São Paulo, School of Nursing, São Paulo, Brazil

Distortions between the real body and the image that one has in itself can result in illness and intervene with eating and personal satisfaction. The aim was to analyze the accuracy of self-assessment of body image in cancer patients and satisfaction with their body size. 136 patients with gastrointestinal tumors, aged between 18 and 65 years old, at least education of 6 years and KPS $\geq 60$ % were evaluated in 2013. The actual BMI was calculated and patients rated their previous, current, ideal and ideal population BMI for Scale of Stunkard silhouettes. We obtained the domain distortion (current BMI - actual BMI) and dissatisfaction (current IMC - ideal BMI) with body size. Statistical analysis was performed using ANOVA, Kruskal-Wallis and Post hoc Tukey. Most patients were male (59.6%), average age of 53.1y (SD = 8.0, CI = 51.5-54.7). Tumors prevalent were rectal (28.9%), stomach (21.5%) and colon (17.0%); without metastasis (69.1%), with an average diagnosis 19 months (SD = 1.32) and any current treatment (65.9%). Most had KPS $\geq 80$ (88.2%). The actual BMI was 24.1 (SD = 0.4, CI = 23.1-25). The majority (71.2%) showed distortion of body size: 47.0% underestimated and 24.2% overestimated their body size. As to dissatisfaction, more than half (55.9%) showed desire to increase their body size. The distortion was associated ($p<0.05$) to weight loss, race, religion, KPS, be in current treatment, paleness, intensity and impact of fatigue. Dissatisfaction
was associated ($p<0.05$) weight loss, KPS, tumor location, be in current treatment, time since diagnosis, paleness, have dry skin, pain, fatigue and anxiety. Patients showed distortions about their body size and desire to be fatter, especially those with greater weight loss. Inaccurate self-assessments can be a source of stress and decreased quality of life of these patients. Knowing the factors that associate can assist in planning care.

**Abstract number:** PO48  
**Abstract type:** Print Only

### Advanced Directives: Nurses’ and Physicians’ Perceptions in 2012

Ledoux M.1, Rhondali W.1,2, Monnin L.3, Thollet C.3, Gabon P.3, Filbet M.4

1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France. 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States. 3Hôpitaux du Pays-du-Mont-Blanc, Sallanches, France

**Background:** In cancer patients, decision-making process is crucial and patient’s involvement is described as a central component. In 2005, a new tool appears to convey patient’s opinion even if he is not able to communicate anymore: advanced directives (AD). Unfortunately, their documentation is marginal. The objective of this study was to investigate nurses’ and physicians’ perceptions towards AD.

**Methods:** A questionnaire had been sent to hospitals, public health facilities and liberal practitioners during February 2012.

**Results:** We collected responses from 42/251 physicians (17 %) and 80/198 nurses (40 %). Sixty percent of participants reported that they were not familiar with the legislative framework for AD. For physicians, main barriers were patient cognitive impairment ($P = 0.004$) and lack of information on the clinical situation ($P = 0.004$). For nurses, difficulties were toward end of life and prognosis discussion ($P = 0.002$), clinical situation evolution since AD documentation ($P = 0.008$), time frame for AD application ($P< 0.001$) and the fact that final decision is made by physician alone ($P = 0.015$).

**Conclusion:** AD should be part of a good medical practice and literature has highlighted the benefit of AD on patient’s quality of life. End of life discussion therefore requires dedicated time and specific training for physicians and nurses to improve the rate of patients with AD.

**Abstract number:** PO49  
**Abstract type:** Print Only

### Assess Prevalence of the Positive-NECPAL Patients and the Main Characteristics in a Chronic Patient Day Care Hospital (DCH)

Camell H.1, Blanch J.1, Claver G.1,2, Görbig N.1, Picon M.1, Gil M.3, Garcia J.1

1Consortori Sanitari del Garraf, Internal Medicine, Sant Pere de Ribes, Spain, 2Consortori Sanitari del Garraf, Sant Pere de Ribes, Spain, 3Institut Catala Salut, Atencio Primaria, Vilanova i la Geltrú, Spain

**Methods:** We conducted an observational review of all patients who were attended between 18th March 2013 and 18th June 2013. A univariated and bivariate analysis has been conducted, in which qualitative variables were analyzed using the chi-square test (Fisher test), with application of Student t-test for quantitative variables. NECPAL CCOMS-ICO test is used to identify chronic and advanced illness patients who needed supportive / palliative care. Emergency room visits and hospitalizations of the last 6 months before the admission in the DCH were recorded.

**Results:** 25% of the 91 patients included in the study resulted to be NECPAL positive. The main characteristics of these patients are: average age 76 years old and 70% men. The main pathologies were referred to the DCH were COPD/ashma (26%), cardiac failure (39%), hepatic cirrhosis (18%) and anaemia (17%). All of them (100%) had 2 or more chronic pathologies, such as diabetes (61%), hypertension (83%) chronic renal failure (57%) or dementia (9%). Comparing positive-NECPAL patients with non-positive ones, we found: >3 points in the Charlson comorbidity index: 74% versus 49% ($p = 0.034$), < 60 in the Barthel index: 61% versus 16% ($p = 0.000$), more than one hospitalization during the study: 74% versus 44% ($p = 0.016$), more than one re-hospitalization during the study: 26% versus 10% ($p = 0.061$). No significant differences found in the number of visits to the Emergency Room.

**Conclusions:** There is a high prevalence of positive NECPAL patients in our DayCare Hospital. 2. The most frequent pathologies are COPD and cardiac failure in 65%. Comorbidity is considerably prevalent, and implies severe dependence in more than a half of the patients. There is a higher prevalence of diabetes, hypertension and chronic renal failure. There is a higher percentage of hospitalizations and re-hospitalizations of positive-NECPAL patients. Therefore, identification and inclusion to a DCH may imply a diminution of hospitalizations.

**Abstract number:** PO50  
**Abstract type:** Print Only

### Effect of Systematic Palliative Care on Quality of Life of Patients with Advanced Cancer of the Upper Gastrointestinal Tract: A Randomized Controlled Trial

Vanbutsele G.1, Pardon K.1, Geboes K.2, De Laat M.3, Van Belle S.1,2, Deliens L.1,4
Background: Studies suggest that introducing palliative care (PC) early in the course of a disease may improve quality of life (QoL) in the final phase. PC is typically provided late in the course of the disease, when death is imminent, at the request of the patient or physician and not as a planned and comprehensive intervention. The present study is based on the results of a recently performed randomized controlled trial (RCT), measuring the effect of introducing early PC to metastatic lung cancer patients. The aim of our study is to examine if systematic PC provided earlier in the disease course affects QoL both in patients with advanced cancer of the upper gastro-intestinal tract and their family carers.

Method: This RCT compares early systematic PC combined with standard oncology care to standard oncology care alone. This design, stratification and committed sample size (n=160) allow for reliable measurement. Patients are recruited from the oncology day care ward in Ghent University Hospital in Belgium. Assessment of QoL, mood, illness understanding and satisfaction with care are performed at baseline, 12 weeks and every six weeks thereafter.

Results: In a first phase of the study, 12 patients and 11 family carers have been recruited. Three patients refused to enter the trial (participation rate of 80%). Seven patients (and their family carers) have been allocated to the intervention arm, six (80%) patients met with the palliative care team at least once a month. From four patients who were hospitalized, three had a minimum of one consultation during their stay. During a 5-month period, 87% of the participants completed the questionnaires at the scheduled time.

Discussion: The preliminary data support the feasibility of recruiting patients for a systematic PC intervention. Monthly consultations prove to be feasible for the support team. The goal is to recruit 160 patients during 30 months’ time. Results of the analyses of the QoL data can be expected in May 2016.

Abstract number: PO51
Abstract type: Print Only

Opioid Rotation and Route Switch in Cancer Patients
Lester L.1, 2, Walsh D.3, 4, Dhuibhir P.2, Balding L.2, 5, Higgins S.6, 7, O’Leary N.2, 8

Background: Opioid choice is influenced by availability, economic factors, education and marketing. Opioid Rotation is the substitution of one strong opioid for another to improve the balance between pain relief and adverse effects. Route Switch describes a change in route of administration. The scientific basis for these common practices is unclear.

Aims:
1. Investigate period prevalence of Opioid Rotation and Route Switch
2. Examine choice of opioid for Rotation and Route Switch

Methods: Retrospective period prevalence chart review from admission day to study day. Medical notes and opioid prescriptions of consecutive Specialist Palliative Medicine Unit cancer patients evaluated. Data entered in Microsoft Excel.

Results:
Opioid rotation: Median length of stay (admission - study day) = 19 days (range 1-68). 22/26 (85%) had cancer. 14/22 (64%) on Around The Clock Opioid (ATCO) on study day.

6/14 (43%) had rotated ATCO post-admission:
1. Oral Hydromorphone (H) → Oral Tapentadol (T) → Subcutaneous Infusion Alfentanil (A)
2. Oral Oxycodeone (O) → Oral H → Transdermal Fentanyl (F)
3. Oral O → to oral H
4. Subcutaneous Infusion H → Subcutaneous Infusion A
5. Oral O → Transdermal F
6. Subcutaneous Infusion O → Transdermal F

These six had 8 Opioid Rotation episodes in total: four had 1 rotation; two had 2. Median 12.5 days (range 3-23) between rotations.

8/22 (36%) not prescribed Around The Clock Opioid on study day: 4/8 never on ATCO; other 4/8 ATCO discontinued.

Route switch:
7/14 (50%) had an ATCO Route Switch.
12 Route Switch episodes in total: Oral to subcutaneous infusion = 7; oral to transdermal = 1; subcutaneous infusion to transdermal = 3; subcutaneous infusion to oral = 1.
4 episodes of simultaneous Opioid Rotation and Route Switch.

Conclusion:

1. Period prevalence: Route Switch > than Opioid Rotation
2. Most frequent Route Switch → Subcutaneous Infusion
3. Most frequent Opioid Rotation → Transdermal Fentanyl
4. Most prescribed opioid: Hydromorphone

Abstract number: PO52
Abstract type: Print Only

Approach and Monitoring at Home on Patients with Untreated Pain and Intratecal Pump Implantations in Palliative Cares

Aguilera González C., Calle Cruz L.F., Fernández Lopez A., Sobra Calderon S., Garrido Nieto J., Romero Mena Bernal J., Galindo Ocaña J.

Hospital Universitario Virgen del Rocío, Sevilla, Spain

The intrathec al analgesy emerges as a therapeutical option when other treatments have failed, and in cases with high opium doses presenting unacceptable secondary effects.

Objectives: To analyze the viability of the home handling of patients with intratecales pumps by a team of palliative cares supported at home.

Material and methodology: Retrospective descriptive analysis of terminal patients with intratecales pumps implanted to control the pain. Variables analyzed: age, sex, pathology type, functional capacity, survival from the pump implantation, average stay, medication received, recharged number, secondary effects, necessary doses, adjuvant treatment, hospital transfers avoided and place of death.

Results: 15 patients with advanced oncology illness is analyzed. Average age 60 (40-75). Males-60%. Colon neoplasia: 40%, Lumb:26.6%. Others: 33.4%. Average Barthel index 38 (10-65). Medium survival since the pump implantation to the death. 137.46 days (10-425). Medium stay at hospital 26.6 days (4-78). 60% required a progressive increase of opioids as the illness progressed.

Conclusions: The intratecales pumps management can be performed at home safely by advanced Palliative Cares Units avoiding transfers to the hospital in 48 occasions to recharge the pump. No problems were found in the recharges at home.

Abstract number: PO53
Abstract type: Print Only

Prevalence of Vitamin D Deficiency in Oncology Palliative Care Patients and its Association with Cancer-related Fatigue and Quality of Life. Pilot Study

Martinez- Alonso M.1, Palomar C.2, Ariza i Carrió G.3, Dusso A.4, Nabal M.4

1Institut de Reserca Biometrica de Lleida, Unitat de Bioestadistica i Suport Metodològic, Lleida, Spain
2Hospital Universitario Arnau de Vilanova, Palliative Care Suportive Team, Lleida, Spain
3Hospital Universitario Arnau de Vilanova, Rehabilitation, Lleida, Spain
4Institut de Reserca Biometrica de Lleida, Experimental Nefrology, Lleida, Spain

Aim: To assess the prevalence of vitamin D deficiency in advanced cancer patients and its association with physical functioning, fatigue and quality of life.

Method: Pilot cross-sectional study with patients aged older than18 undergoing palliative care for advanced solid cancer. Exclusion criteria: Karnofsky Index < 30; severe liver failure; renal dysfunction (GRF< 60); cognitive impairment (Pfeiffer test > 5); pain, dyspnea, nausea or vomits >6 in Numerical Rating Scale 0-10; chemo or radiation therapy within the last 3 weeks. Measurements included: socio-demographics; anthropometrics; tumor stage; treatments; chemistries; functional capacity (Barthel scale, Karnofsky index, Palliative Performance scale (PPS)); cancer-related fatigue (FACT-F); and quality of life (EORTC QLQ-C15-PAL, with physical functioning (PF) subscale). Vitamin D deficiency was defined as 25-hydroxyvitamin D levels below 20 ng/ml.

Binomial distribution was used to estimate a 95% confidence interval (CI) for the prevalence of vitamin D deficiency. Spearman correlation coefficients (s) were used to assess the association between serum Vitamin D levels and the rest of quantitative measurements. Significance level fixed to 0.05.

Results: (Preliminary):N= 9; Mean (standard deviation) were age 64.2(11.2), fatigue 25.8(12.8), PPS 60.1(12.7) and PF 46.7(29.8). Prevalence of Vitamin D deficiency was 78%, 95%CI [40%, 97%]. There was a significant inverse correlation between vitamin D levels and microalbuminuria (s=-0.79). Serum vitamin D levels were

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significantly correlated with the FACT-F, PPS, and PF scores ($r=0.66$). A high correlation was also found with overall quality of life ($r=0.54$), although it did not reach statistical significance.

**Conclusion:** Vitamin D deficiency is of high occurrence in oncology palliative care patients. Its correction may improve microalbuminuria, fatigue, palliative performance and physical functioning.

**Abstract number:** PO54  
**Abstract type:** Print Only  
**Discussing Incurability and Palliative Care with Advanced Cancer Patients: An Interview Study in Flanders and Brussels, Belgium**  
Hoirila M., Champaere K., Pardon K., Van Belle S., Deliens L.  
1Vrije Universiteit Brussel, End-Of-Life Care Research Group, 2Vrije Universiteit Brussel & Ghent University, Brussel, Belgium, 3Hasselt University, Department of Behavior, Communication and Linguistics, Hasselt, Belgium, 4Ghent University, Department of Medical Oncology, UZ Gent, Gent, Belgium, 5VU University Medical Center, EMGO Institute for Health and Care Research, Expertisecentrum Palliatieve Zorg, Amsterdam, Netherlands

**Background:** Discussing incurable cancer, treatment options and prognosis is for most oncologists a very difficult issue in clinical practice and is often avoided, leading to delays in transition to adequate palliative care. As first phase in the development of a clinical guidance tool for such discussions, an interview study was designed with oncologists, advanced cancer patients and family members to identify key factors in conducting discussions of incurability and palliative care.

**Method:** Several methodological requirements guided the drafting of the protocol. A qualitative approach was the most appropriate to gain insight in preferences, opinions and experiences. Special attention was paid to the recruitment of oncologists, and of patients and family members given their vulnerability and the sensitivity of the topic. Another challenge was to motivate and persuade oncologists to participate.

**Results:** Semi-structured in-depth interviews were used to gather data. A purposive sample of 10 to 15 participants was selected for each interview group: oncologists, patients and family members. Recruitment of all participants was done from 33 Belgian Medical Oncology Departments. Oncologists received monetary compensation for interviews which were scheduled according to their timetable and lasted at most 1 hour. They were also asked to identify and approach advanced cancer patients under their care with whom they had communicated incurability and palliative care options. Patients who agreed to participate identified the most relevant family member. Interviews were conducted in an environment where patients felt comfortable, mostly in their own home, and overly burdening and confronting questions were avoided.

**Discussion:** Ample measures were taken to counter oncologists’ lack of time to participate in studies, and to minimise emotional burden for patients. This study will provide a strong basis for creating a clinical guidance tool and communication training for physicians.

**Abstract number:** PO55  
**Abstract type:** Print Only  
**Is the Bode Index Useful to Stablish the Need of Palliative Care (PC) in COPD Patients?**  
Canal J., Michans B., Palomar C., Aguilà M., Barallat E., Nabal M.  
1Hospital Santa Maria GSS, Palliative Care Supportive Team, Lleida, Spain, 2Hospital Universitario Arnaud de Vilanova, Pneumology Deptartment, Lleida, Spain, 3Hospital Universitario Arnaud de Vilanova, Palliative Care Supportive Team, Lleida, Spain

**Aim:** To establish the utility of the BODE scale to detect COPD patients needing early palliative care intervention.

**Methods:** This is part of a larger study between the Respiratory Department and the Palliative Care Department to provide earlier PC interventions. Patients attending the COPD outpatient clinic were able to be enrolled after informed consent. Two independent blind assessment were done by pulmonologist and PC physicians. At the COPD clinic, apart for the routine, global functional respiratory assessment was done including: Spirometry, 6 minute Walking test, Modified MRC Dyspnea Scale and Body Mass Index to perform the BODE index. At the PC outpatients clinic every patients was asked to completed the Edmonton Symptom Assessment System, Edmonton Classification System for Cancer Pain, Charlson Comorbidity Index, Palliative Performance Status (PPS) and FAGESTROM test added to usual PC psychosocial assessment and global physical examination. Statistics: Descriptive analysis with frequencies and central tendency measures. Comparative analysis by t Student and Chi square test ($\alpha$ of 5%, a level 95 % and $p < 0.05$). Statistical analysis was performed using SPSS (v.17).

**Preliminary results:** During the study unfinished period 53 patients were assessed as a first visit at the PC clinic. 38 of them were COPD patients. 47.3% were men. Mean age was 71.2 SD 8.7; mean number of symptoms detected were 5 (1-11): Dyspnea average was 3 (SD=2.7; min=0 max=9) other highest symptoms were Asthenia 2.8 SD 3; Dry mouth 2.4 SD 3.6 and Global wellbeing: 2.6 SD 1.1. BODE average was 3.1; Charlson Index was 5.3 (2.4-
12.6). PPS average was 66.1. Only 11 (28 %) patients were considered for PC further interventions. No significant relationship was found between BODE Index and the need of further PC interventions. More results will be provided as soon as the study finish. **Conclusion:** Other factors apart from BODE Index are needed to identify COPD patients needing early PC intervention.

**Abstract number:** PO56
**Abstract type:** Print Only

**Conceptual and Methodological Issues with Medical End-of-Life Practices’ Studies: From National Feasibility to International Comparability**

Marcoux I.1,2,3, Boivin A.3,4, Graham I.D.1,5, Campbell J.1,2, Hébert P.1,6

1University of Ottawa, Faculty of Health Sciences, Ottawa, ON, Canada, 2Centre for Research and Intervention on Suicide and Euthanasia, Montreal, QC, Canada, 3Centre de Recherche - Hôpital Charles- Le Moyne, Longueuil, QC, Canada, 4University of Sherbrooke, Longueuil, QC, Canada, 5Ottawa Hospital Research Institute, Ottawa, ON, Canada, 6Centre Hospitalier de l’Université de Montréal (CHUM), Montreal, QC, Canada

Studies on medical end-of-life practices are important for an informed debate on end-of-life public policies. They document what types of decisions and actions are taken before death, monitor evolution of practices over time, and should preferably take place beforehand in a context of a possible legal change on medical practices. Actual debates in Canada stimulate the necessity to conduct such a study, and European experiences (e.g.: the Netherlands, Belgium, UK and France) are undoubtedly of great relevance. In addition to comparison of incidence, baseline data from different countries allow contrasting medical practices at the end-of-life from distinct jurisdictions. However, methods’ replication brings important challenges for adapting to a specific national context. For example, until now, studies mainly proceeded by death certificate sampling in order to better determine their incidence. This procedure is however difficult to implement in some countries like Canada where death certificate declaration is of provincial authority (more than 10 different instances). Also, apart from the well-known issue of definition’s comparability, the classification of medical practices (treatment withholding and withdrawal, intensification of pain symptom management, palliative sedation, euthanasia, physician-assisted suicide) may engender under or overestimations because of questions’ formulation or different interpretation of subjective concepts like “physician’s intention”. In fact, intention is difficult to circumscribe and may also not be entirely meaningful in considering legislative principles in some countries. This paper will discuss methodological and conceptual challenges we are facing in piloting the feasibility of such study in Canada, taking into account international comparability issues, but also proposed solutions we developed as a research team in consultation with an interdisciplinary advisory committee.

**Abstract number:** PO57
**Abstract type:** Print Only

**Case Finding for Chronic Advanced Patients in Need of Palliative Measures at Risk of Death: Development of Algorithm to Identify High Risk Patients**

Martínez-Muñoz M1, Martori J.C.2, Oller R.3, Blay C.3, Amblàs J.1, Vila L.3, Costa X.1, Espinosa J.1, Villanueva A.1, Espaulella J.5, Gómez-Batiste X1

1Catalan Institute of Oncology, University of Vic, The “QUALY” Observatory, WHO Collaborating Centre for Public Health Palliative Care Programmes, Chair of Palliative Care, L’Hospitalet de Llobregat, Spain, 2University of Vic, Department of Economics and Business, Vic, Barcelona, Spain, 3Government of Catalonia, Department of Health. Programme for the Prevention and Care of Patients with Chronic Conditions, Barcelona, Spain, 4Hospital de la Santa Creu and Hospital General de Vic, Vic, Barcelona, Spain, 5Institut Català de la Salut, SAP Osona, Vic, Barcelona, Spain, 6EAP Vic-Sud, Vic, Barcelona, Spain

**Research aims:** To develop a method of identifying chronic advanced patients in need of palliative measures at high risk of death in the next 12 months for practical use by health and social care services.

**Study population:** Patients with chronic advanced conditions and life limited prognosis in need of palliative measures as assessed using the NECPAL CCOMS-ICO tool by healthcare professionals.

**Study design and methods:** Observational, analytic, prospective cohort study of 922 NECPAL+ patients from tertiary hospitals, socio-health centres, nursing homes and primary care centres. Selected variables are NECPAL CCOMS-ICO tool indicators and data on demographics, conditions and settings of care.

**Method of statistical analysis:** A series of logistic regressions have been performed to identify which NECPAL CCOMS-ICO tool indicators are helpful in predicting death in the next 12 months. The key factors -included in the model to produce the algorithm- are: consideration by healthcare professionals that patient requires palliative care, request from main carer for palliative care or limitations to the use of major therapeutic interventions, functional decline, functional dependency, nutritional decline, admissions in previous year and multimorbidity.
Results (preliminary): The algorithm produces a risk score (from 0 to 1) for each NECPAL+ patient. At a risk score threshold of 0.5, the algorithm identified 38.1% (sensitivity) of NECPAL+ patients who would die in the next 12 months and 92.3% (specificity) who would not die. More analyses are needed to combine NECPAL CCOMS-ICO tool indicators with the rest of selected variables. Final results will be available in June 2014.

Conclusion: A method of predicting individual patients at highest risk of death in the next 12 months has been developed, which has a reasonable level of sensitivity and high specificity.


Abstract number: PO58
Abstract type: Print Only

Patients Living Cervical Cancer

Mindiera C.C., Hamling K., Educational Research
NdiMoyo Palliative Care, Clinical, Salima, Malawi

Introduction: Cervical cancer is the second common cancer in women worldwide, and a number one cancer amongst women in Malawi. However, many women in Malawi seek treatment when the disease has reached inoperable stage; the majority are told to wait at home while a few access palliative care service.

Objectives: The study aimed at exploring some of the experience of patients living with cervical cancer at NdiMoyo Palliative Care Salima Malawi.

Study design and methods: The study was an exploratory study and utilized qualitative data collection and analysis method. An in-depth interview was conducted using a semi-structured interview guide on purposive sample of 6 women registered with NdiMoyo Palliative Care Centre. Thematic content analysis was used to analyze the qualitative data.

Findings: The following themes were developed from the narrations of the women regarding their experiences of living with cervical cancer: health seeking behaviour, physical impact of diagnosis, psychosocial/sexual impact of the disease, spiritual impact of the illness and positive impact of palliative care treatment.

Recommendations: There is need to create community awareness on the symptoms of cervical cancer of both individuals and health professionals to allow treatment to be initiated. Awareness of the benefits of palliative care for those with advanced disease needs greater acceptance also.

Keywords: Cervical cancer, experience, Palliative care.

Abstract number: PO59
Abstract type: Print Only

EORTC Spiritual Wellbeing Module - Preliminary Results from Singapore

Yang G.1, Young T.2, Vivat B.1, EORTC Quality of Life Group
1National Cancer Centre, Palliative Medicine, Singapore, Singapore, 2Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, United Kingdom, 3Brunel University, School of Health Sciences and Social Care, Uxbridge, United Kingdom

Aims: The EORTC QLQ-SWB36 is a 36-item module assessing spiritual wellbeing in patients that was tested in Singapore.

Methods: Participants (P) completed the EORTC QLQ-C15-PAL and EORTC QLQ-SWB36 and took part in a short debriefing interview.

Results: 15 participants were recruited - 9 completed all items, 6 completed at least 80%.

The items were taken literally, leading to challenges in interpretation. In response to ‘I have felt able to deal with problems’, P13 said, “I don’t have any problems. Problems with who?” 3 participants also could not understand the statement ‘I live one day at a time.’ P1 thought it was “very pessimistic” and P14 said “How can anyone live one day at a time? I don’t understand what it means”.

In the Asian culture of pragmatism, life is just lived rather than spent reflecting on how to make sense of it. Hence, items such as ‘there is more to life than we can perceive directly’ were difficult. When asked if this statement was helpful or not, 4 participants could not answer. Those who answered seemed to miss the point: P8 said, “After my illness, I feel we just have to go ahead and do what we want to do, cannot wait.” P2 said, “Yes, we take everyday for granted, there are more things that can be done.”

There were also difficulties in articulating themselves as English is a ‘working language’ rather than a ‘heart language’ for many. P12 said, “I also don’t know how to answer you. You ask all these questions, actually they are very simple but I don’t know what to say.”

When asked what spiritual wellbeing meant to them, the range of responses was wide and covered the multidimensional aspects of the EAPC spiritual care taskforce definition, supporting the idea that spirituality is universal, even if there may be differences in cultural emphases.

Conclusion: The EORTC QLQ-SWB36 can be feasible, applicable and relevant in Singapore, although cultural aspects should be considered when interpreting results.

Abstract number: PO60
Abstract type: Print Only

Offering Professional Support for Children and Young Adults Living in Families with One Member Suffering from Cancer. Analysis of Needs and Interventions during the First Year of a Pilot Project at the Kliniken Essen-Mitte

Kloke M., Defren B., Becker K.
Kliniken Essen-Mitte, Department for Palliative Care, Essen, Germany

**Background:** Living in a family with one member suffering from cancer means a challenge for children and young adults. Parents, relatives and professionals often experience insecurity how to deal with this situation, they are in need of advice and support as well as the children and young adults themselves. In order to counsel and to assist them a project was started at an academic teaching hospital.

**Aims:**
- to offer professional support by two remedial teachers to the parents and the children.
- to evaluate the needs and demands of parents, professionals and children according the course of disease.
- to define aims of priority in relation to the stage of disease.

**Methods:** Analysis of counseling records and activities during the first year of the project.

**Results:** Professional support is strongly needed because parents, physicians and nurses feel quite uncertain about the needs and coping capabilities of children in this situation.

- Needs and demands of families vary during the course of disease as well as the pattern of supporting. We identified 4 clusters being correlated to the aim of therapy: curative with risk of relapse, palliative but with good prognosis concerning survival time, rapid progression with high frequency of different interventions and terminal phase.
- The goal of children’s and parent’s support is the prevention of mental disorders in the youngest family members.

**Conclusion:** The children of cancer patients are exposed emotional pressure; this should be recognized and professional support should be offered by cancer centers in accordance to the actual situation and the individual needs.

**Funding:** This project is sponsored by Menschenmögliches e. V.

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**Abstract number:** PO61

**Abstract type:** Print Only

**Prevalence of Mechanism-based Subgroups in Cancer Pain: A Cross-sectional Survey for Preliminary Validation of Mechanism-based Classification**

Kumar S.P.1, Shenoy K.2, Prasad K.3, Kumar V.4

1Srinivas College of Physiotherapy and Research Centre, Physiotherapy, Mangalore, India, 2A J Hospital and Research Centre, Radiation Oncology, Mangalore, India, 3Kasturba Medical College (Manipal University), Medicine (Medical Oncology), Mangalore, India, 4Kasturba Medical College (Manipal University), Physiotherapy, Mangalore, India

**Aim:** To evaluate the validity of mechanism-based classification (MBC) of cancer pain by examining cancer survivors for prevalence of mechanism-based subgroups based upon their clinical presentation.

**Methods:** A cross-sectional survey of 142 cancer survivors (46 female, 96 male) was performed in an in-patient oncology ward. The people had primary complaints of pain due to multiple etiologies (28 breast cancer, 24 prostate cancer, 46 bone cancer, 17 blood cancer, 17 soft tissue cancer). The tester classified cancer pain into either of five mechanisms based upon their presenting symptoms and signs according to MBC. The five mechanisms in MBC were cognitive-affective (CA), central sensitization (CS), sympathetically mediated (SM), peripheral sensitization (PS) and nociceptive (N). The subgroups were also evaluated for their scores on Brief-pain inventory-cancer pain (BPI-CP) and European organization for research and treatment of cancer-quality of life questionnaire 30-item version (EORTC-QLQ-C30) and between-group scores were then compared.

**Data analysis:** Prevalence was reported in descriptive analysis (percentiles) and subgroups were compared using one-way analysis of variance at 95% confidence interval using SPSS version 16 for Windows (SPSS Inc, Chicago, IL).

**Results:** There were prevalence of all five subgroups, with presence of more than one mechanism per patient. There was greater prevalence of CS (63%), CA (43%), PS (28%), SM (19%) and N (15%). CS group had significantly (p<.05) higher pain severity (28.8±3.42), pain interference (44.6±12.8), higher scores on symptoms sub-scale with lesser scores on functioning and global health status sub-scales of EORTC-QLQ-C30 than the other groups. The other between-group differences were not statistically significant.

**Conclusion:** The study findings provide preliminary validation for MBC in cancer pain and there was a greater prevalence of CS mechanism in cancer pain which was demonstrated by BPI-CP and EORTC-QLQ-C-30 scores.

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**Abstract number:** PO62

**Abstract type:** Print Only

**Challenges in Recruitment of Palliative Patients for a Cluster Randomized Controlled Trial in Home Care**

Vermandere M., Warmenhoven F., Van Severen E., De Lepeleire J., Aertgeerts B., RITUALL (Research In The Ultimate Aspects of Life, Leuven)

KU Leuven, Department of General Practice, Leuven, Belgium
**Background:** Randomized controlled trials (RCTs) in palliative home care remain uncommon despite recent evidence favouring end-of-life care in this setting. Recruitment of eligible patients is often a major challenge.

**Purpose:** The purpose of this article is to describe difficulties in recruitment of patients with an incurable, life-threatening disease for a RCT in home care to inform future research.

**Methods:** In a first phase, recruitment of health care providers (HCPs) for a cluster RCT is described. HCPs’ identification and recruitment of eligible patients is described in a second phase. Difficulties experienced during both phases are identified.

**Results:** Recruitment of family physicians was difficult due to lack of time, interest, or remuneration. Identification of patients in an early stage of the palliative care process, inviting palliative patients to participate in research and patient-provider communication about the end of life were significant hurdles in recruiting patients.*

**Conclusion:** Early identification of palliative care patients and patient-provider communication about end-of-life issues were major difficulties in the recruitment of patients for a RCT in home care. The use of identification tools and clinical decision support systems integrated in the electronic health record, as well as substituting the term palliative care resource utilisation.

**Abstract number:** PO63

**Abstract type:** Print Only

**Anticipation and Participation in Cancer Care - The SENS System**

Eychmüller S.1, Büche D.2, Mettler M.2, Schuler S.2, Grossenbacher-Gschwend B.3, Forster M.2, Domeisen Benedetti F.2, Fliedner M.1

1University Hospital Berne, Center of Palliative Care, Berne, Switzerland, 2Cantonal Hospital, Centre of Palliative Care, St.Gallen, Switzerland

**Aim and objective:** To structure documentation and care plans, to assess core topics, all based on patients’ and families’ needs, and to test its implementation into clinical practice.

**Study design and methods:** During implementation of a hospital wide palliative care (PC) program in a big Swiss teaching hospital between 2007 and 2011, specialist PC consultation records have been reviewed and thematically restructured based on feedback from patients and professionals. The resulting system has then been tested prospectively for clinical use over 4 years.

**Conclusion:** SENS seems to capture most of patients’ and family needs, and turned out to be a widely accepted practical system to structure complexity, and to improve profile and acceptance of PC. The system will now be tested within a RCT on early palliative care for testing its ability to improve quality of life and even redirect health care resource utilisation.

**Funding:** Cantonal hospital St.Gallen, Switzerland

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**Results:** Four distinct areas essential for counselling have been retrieved from 500 consultation records over a period of one year (2008): Symptom management issues including self-help; End of life decision making including patient preferences; Network organisational issues including anticipation of emergency situations; Support of distressed family members. The resulting SENS-structure has then been established to guide patients’ expectations and planning (patient prompt sheet) as well as defining care priorities, specialist PC recommendations, required competencies (individualized interprofessional PC-Team), and finally integration of PC complexity within medical diagnosis lists for financial reimbursement. SENS has also been welcomed to structure case discussions, to prepare and record family meetings, and to create balanced educational curricula in PC. This system has been adopted by various PC settings in Switzerland.

**Conclusion:** SENS seems to capture most of patients’ and family needs, and turned out to be a widely accepted practical system to structure complexity, and to improve profile and acceptance of PC. The system will now be tested within a RCT on early palliative care for testing its ability to improve quality of life and even redirect health care resource utilisation.

**Funding:** Cantonal hospital St.Gallen, Switzerland

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**Abstract number:** PO64

**Abstract type:** Print Only

**Pharmacological Interventions for Pain for Life-limiting Conditions in Children and Adolescents: Cochrane Systematic Review of Trials**

Beecham E.1,2, Howard R.3, McCulloch R.4, Candy B.1, Laddie J.3, Rees H.2, Vickerstaff V.1, Bluebond-Langner M.2,6, Jones L.4

1University College London, Marie Curie Palliative Care Research Unit, Mental Health Sciences Unit, London, United Kingdom, 2University College London, Institute of Child Health, Louis Dundas Centre for Children’s Palliative Care, London, United Kingdom, 3Great Ormond Street Hospital, Department of Anaesthesia, London, United Kingdom, 4Great Ormond Street Hospital, Louis Dundas Centre for Children’s Palliative Care, Palliative Care Team, London, United Kingdom, 5Evelina London Children’s Hospital, Department of Paediatric Palliative Medicine, London, United Kingdom, 6Rutgers University, Department of Sociology, Anthropology and Criminal Justice, Camden, NJ, United States

**Aims:** Pain is one of the most common symptoms in children and young people (CYP) with life-limiting conditions (LLCs) which include a wide range of non-cancer diagnoses as well as cancer. The current literature indicates that pain is not well managed however the evidence base to
Palliative Care

Assessment of Pain in Children and Adolescents in Palliative Care

Rossato L.M.1, Silva E.M.R.1, Bousso R.S.1, Dias C.G.2, Borghi C.A.2, Santos M.R.1, Sposito N.P.B.1

1University of São Paulo, São Paulo, Brazil,
2Universidade Federal de São Paulo, São Paulo, Brazil

Pain is a constant and meaningful event for children and adolescents with chronic disease and in palliative care. In this context, the experience of children and adolescents with pain should be considered to assess and intervene in their relief. This study aimed to assess pain in children and adolescents by their descriptions of the intensity, quality and location of pain. The Theory of Cognitive Development Piaget was used as theoretical framework and the Oral History used as the methodological one. Results. There were done six interviews semi structured with children and adolescents from 6 to 17 years. Ethic aspects were respected according the preconized rules. The results unveiled the theme The analysis of the narratives by Theory of Cognitive Development Piaget showed the following aspects: describing the pain; Looking For a life closer to normality, despite the pain and disease; Using various alternatives for pain management and Living with self image impaired. Reports of children and adolescents revealed that pain assessment may be adversely affected by barriers of communication. The cards pain descriptors can help nurses access to these children and adolescents and intervene to relieve pain. Another aspect highlighted by children and adolescents with regard to pain management, which should cover techniques besides pharmacological, nonpharmacological measures. This study showed that the assessment of pain when used effectively by nurses, can be seen as a key component in the care of children and adolescents in palliative care and pain situation.

Abstract number: PO65
Abstract type: Print Only

Aim: Aim of the study was to state the effectiveness of BFT in BTcP on the titrated baseline opioid therapy or ATC (around the clock analgesia) with stable titrated TDS (Transdermal Systems or Fentanyl patches) 100 mcg/h. ATC pain analgesia in medium ranged from 1-2 in the numeric scale (NS) out of 10.

Study design: 20 cancer patients (pts) in advanced stage of disease had 184 BTcP episodes, ranging from 6-7 by numeric scale (NS). BFT dosage for BTcP was titrated as soon as ATC was adjusted. BTcP episodes ranged from 2 to 5 per day.

Results: All pts on stable ATC with BTcP received the initial dose of BFT 100 µg.
7 (35%) pts remaining on ATC 100 mcg/h continued to receive BFT 100 µg per dose in 58 (32%) BTcP episodes, but in 126 (68%) BTcP episodes the BFT dosage was raised up to 200 µg. Significant BTcP relief was observed in 5-10 minutes when pain reduced from 6-7 to 2-3 by NS. Slight nausea and dizziness were observed in 4 BTcP episodes (2.1%) from BFT.

Conclusion:

1) ATC and BFT should be always titrated in chronic cancer pain.
2) BFT should be used in a very early phase of BTcP.
3) Mouth rinse is advised before use of BFT if dry mouth symptom is present.
4) BFT dose has no correlation with ATC.
5) BFT has rapid onset.
6) BFT is easy and safe to use for pts.
7) Rare (2.1%) and slight side effects were observed.

**Abstract number:** PO67
**Abstract type:** Print Only

**Testing a Web-based Tool for Registration of Quality Indicators in Palliative Care Services - A Qualitative Analysis**

*Sommerbakk R., Kaasa S., Haugen D.F., Hjermstad M.J.*
Norwegian University of Science and Technology, Department of Cancer Research and Molecular Medicine, Trondheim, Norway

**Background:** There is increased focus on the quality of care in palliative care (PC) patients. Quality indicators (QIs) may indicate the need for improvement and be used to guide and measure improvement of care; the focus of the EU-funded IMPACT project. A tool for registration and evaluation of QIs in a service may improve a systematic use of QIs. As part of the IMPACT project a registration tool was developed, containing 23 QIs.

**Aim:** Evaluate the perceived usefulness and potential difficulties when using the tool for registration of QIs in diverse PC settings.

**Methods:** The 23 process and structure indicators were identified through a Delphi process. The QIs were then operationalized into questions that were completed online by each PC service. After the registration, an interview was conducted asking about challenges encountered when completing the tool.

**Results:** 40 home care services, nursing homes, hospices and hospitals in 5 countries (England, Germany, Italy, Norway and the Netherlands) participated. The challenges were grouped into the following 6 categories (with examples):

1. Technical difficulties: deletion of data;
2. Content of questionnaires: unclear wording;
3. Difficulties finding information: no access to medical records;
4. Individual professional: lack of knowledge;
5. Organizational context: time constraints; and
6. Political context: national reorganization.

Regardless of these challenges, all services completed the questionnaires, although better instructions regarding completion are necessary.

**Conclusion:** The results showed that better instructions are needed to facilitate the registration process and will be used to develop a DVD and a user manual to guide PC services in quality improvements by using QIs.

**Abstract number:** PO68
**Abstract type:** Print Only

**Plan EARLY: Is There Evidence we Ought to?**

*Sands M.B.1,2, Forero R.3, Caplan G.4*

1The Prince of Wales Hospital, Palliative Medicine, Sydney, Australia, 2University of New South Wales, Bondi Beach, Australia, 3Simpson Centre for Health Services Research, SWS Clinical School, Sydney, Australia, 4University of New South Wales, Sydney, Australia

**Background:** When well people are surveyed, the preference to die at home is widely reported. For example while 86% of Australians state a preference to die peacefully at home, in fact only around 20% die at home. What is the evidence that supports our approach to Advance Care Planning? Which patients should be approached to make plans for the future? What are the best ways of communicating plans across primary and tertiary care settings? What are the important outcomes? What are the critical factors that support concordance between plans and patient outcomes? Is there a role for the Emergency Department in planning for future care?

**Aim:** To review the evidence that supports a co-ordinated approach to ACP.

**Methods:** This presentation is a systematic review of the evidence that looks at the who, when and where of advance care planning.

**Results:** We will present the evidence in terms of patient identification, patient intervention and systems interventions across acute and primary care settings. In addition, we will seek to identify patient characteristics that may be used to further define the kinds of interventions appropriate at different time periods, across the continuum of life threatening, chronic illness.

**Discussion:** 96% of decedents present to an Emergency Department (ED) in the last year of life. The trajectory of chronic illness and co-morbidity determine that ED presentations provide the opportunity to identify patients who might benefit from ACP. The ED, however is the antithesis of settings desirable in effective communication; how then, can we proceed?

**Conclusion:** Advance Care Planning has been associated with improved patient outcomes. The suggested approach supports the aspiration to Plan EARLY, and identifies appropriate target populations and outcome measures for testing this model that combines individualised advanced care planning and systems interventions to support its success.

**Abstract number:** PO69
**Abstract type:** Print Only

**Reflection and Learning in a Palliative Care Unit**
Statement of aims: Caring for patients in the palliative care unit is stressful for professionals. The continued contact with death, pain, anxiety and ethical dilemmas increase this risk. In the Intermediate Care Hospital, we dedicate a monthly meeting to support the multidisciplinary team of palliative care unit, chaired by a trained psychologist, who drives reflection and experience-based learning and improvement. The aim of the study was to explore attitudes, thoughts, feelings, experiences, and knowledge of professionals participating in this forum, after one year of experience.

Method: Participants: physician, nursing staff, psychologist, physical therapist and social worker in a 14 beds unit.

Procedure: Qualitative study using semi-structured interviews and focus group. The focus groups took place in the hospital’s meeting room during the participants’ working hours. A semi structured topic guide ensured the development of focus group. The interviews lasted 90 minutes, it was tape recorded and later transcribed contributions.

Results: According to participants, an organizational time for reflection and learning has afforded an opportunity to meet away from the clinical environment, and to work together, finding fresh insights to inform practice. This time has helped reviewing clinical cases, manage emotions, explore one’s beliefs and feelings about death and grief, and generate personal resources for coping with stress. However, most participants considered that once a month is not enough to address the complexity of the work to be done in the palliative care unit.

Conclusion: The results indicate that professionals of palliative care unit may need emotional support in addition to practical aspects of care. Time for reflection and learning in hospitals is well received by professionals to coping with stress.

Abstract number: PO70
Abstract type: Print Only

Decision Making at the End of Life - Cancer Patients’ and Relatives’ Views on Artificial Nutrition and Hydration

Bükki J.1,2, Unterpaul T.1, Nübling G.1,3, Jox R.J.1,4, Lorenzl S.1,2

1Ludwig Maximilians Universität, University Hospital, Campus Grosshadern, Department of Palliative Medicine, München, Germany, 2Hospice DaSein, Mobile Palliative Care Team, München, Germany, 3Ludwig Maximilians Universität, University Hospital, Campus Grosshadern, Department of Neurology, München, Germany, 4University of Munich, Institute of Ethics, History and Theory of Medicine, München, Germany

Background: Deciding on artificial nutrition and hydration (ANH) at the end of life (EoL) may cause concerns in patients and their caregivers but there is scarce evidence regarding their needs and preferences. Therefore, the aim of this study was to assess the impact of factors associated with ANH decision making.

Methods: Prospective, cross-sectional survey on adult cancer patients admitted for symptoms of advanced disease in a 10 months’ period and their family caregivers using a self-administered 12 item questionnaire that had been adapted from an earlier intensive care research version.

Results: Thirty-nine out of 65 patients (60%) and 30 out of 72 relatives (42%) responded. Forgoing ANH (defined as stopping or not initiating ANH) was preferred by 39% of patients and 24% of relatives while 36% and 52%, respectively, would continue artificial hydration only. Age was correlated with foregoing ANH in patients (Kruskal Wallis test, p = 0.001) while religiosity, amount of information, and previous caregiver exposure to ANH decisions were not. Patients felt more confident about decisions regarding artificial nutrition (T test, p < 0.05) and less concerned about physical symptoms than caregivers (χ²-Test, p < 0.05). Satisfaction with communication correlated with confidence in patients (Spearman’s ρ 0.582, p = 0.008). Being informed by the physician was the favoured source of support while relatives’ involvement and advance care planning were preferred at the point of decision making.

Conclusion: Of this German cancer patient cohort, 75% wished no ANH or artificial hydration only at the EoL. Caregivers rather opt for giving hydration than for forgoing ANH altogether. While patients seem to be confident with decision making, caregivers may particularly benefit from discussions that address their concerns.

Abstract number: PO71
Abstract type: Print Only

Structure, Content and Interaction in the Advance Care Planning-discussion, and the Experiences of Patients and Relatives

Andreasen P., Neergaard M.A., Brogaard T., Jensen A.B.

Aarhus University Hospital, Department of Oncology, Aarhus C, Denmark

Studies have shown that use of a formalized discussion called Advance Care Planning (ACP) can help facilitate the difficult decisions that patients, relatives and health care professionals have to make in connection with end-of-life care. During the ACP-discussion a health professional discusses worries and wishes for end-of-life care and death with the seriously ill patient, preferably with one or more relatives present.
The purpose of this study is to illuminate what actually happens during the ACP-discussion, and how the difficult topics of death and end-of-life care are approached. This issue has so far been left virtually unexplored. Furthermore, this study seeks to shed light on patients’ and relatives’ experiences of the ACP-concept immediately after the discussion.

Methods used were participant observation and in-depth interviews carried out by a trained anthropologist. Participant observation was carried out in connection with ACP-discussions, and subsequently the participating patients and relatives were interviewed about their experiences with the ACP-concept.

Preliminary results show that during the ACP-discussions many different issues were touched on, including issues that were not directly related to end-of-life care and death. This suggests that patients and relatives saw the discussion as an opportunity to voice their general and current concerns. Most patients and relatives were initially sceptical about participating in the ACP-discussion, because they felt uncomfortable talking about issues that had to do with end-of-life care and death. However, after participation they felt an increased sense of security because they had made up their minds about difficult decisions. They also felt a sense of relief that these difficult issues had been openly addressed.

Funding: The project is funded by TrygFonden and The Danish Cancer Society.

Abstract number: PO72
Abstract type: Print Only
Preventive Medication: A Patient Burden at the End of Life?
Arevalo J.J.1, Geijteman E.C.T.3, Dees M.K.1, Huisman B.1, van der Heide A.2, van Zuylen L.4, Dekkers W.1, Zuurmond W.W.A.1, Perez R.S.G.M.1
1VU University Medical Center, Anesthesiology, Amsterdam, Netherlands, 2Erasmus MC, Public Health, Rotterdam, Netherlands, 3Erasmus MC, Public Health, Rotterdam, Netherlands, 4Radboud University Medical Center, Scientific Institute for Quality of Healthcare, Nijmegen, Netherlands

Context: Patients in the palliative phase of a chronic disease use many medications for the treatment of co-morbid conditions, symptom control or prevention. With a limited life expectancy, use of preventive medication may become useless, burdensome and costly.

Aim: To describe the use of preventive medications and to study the reasons for continuation or stopping of these medications in the last 3 months of life.

Methods: A retrospective review of palliative care patient records was performed in different settings in the Netherlands. Records were selected from patients dying at home (n=61), in high care hospices (n=60) and in hospitals (n=59). We collected data about types of medication used, doses, period of use and aspects related to decision-making.

Results: In 59 (32.7%) patients, a total of 83 prescriptions of preventive medications were identified that included 30 (16.7%) lipid modifying agents, 19 (10.5%) vitamins, 18 antiemetic preparations (10%) and 16 mineral supplements (8.9%). These were more frequently prescribed to patients dying at home (49.2%, p< 0.001) and in hospitals (42.4%, p< 0.001) as compared to those dying in a hospice (6.7%). In addition, 45 (54.2%) of these medications were continued up to 3 days before death. Reasons for stopping these medications included rejection by the patient, difficulty with swallowing, obstipation and imminent death. Medications were frequently continued because they had been chronically used by the patient.

Conclusion: Preventive medications were frequently continued during the last phase of life of palliative care patients. Patients dying at home and in hospitals may have a larger probability of being prescribed preventive medications as compared to patients dying in hospices.

Abstract number: PO73
Abstract type: Print Only
Validation of Quality of Death and Dying (QoDD) Assessment with Bereaved Family Members in Romanian and German Language
Curca R.O.1, Rosiu A.1, Rus R.1, Magaya-Kalbermatten N.2, Achimas-Cadariu P.1, Mosoiu D.4, Grigorescu A.1, Poroch V.1, Strasser F.7, Swiss-Romanian Partnership (SNF-IZERZO_142226 / 1)
1Spitalul Judetean de Urgenta, Alba Iulia, Romania, 2Cantonal Hospital St. Gallen, Oncological Palliative Medicine, Oncology, Dept. Internal Med & Palliative Centre, St. Gallen, Switzerland, 3The Oncology Institute ‘Prof. Dr. I Chiricuta’, Cluj-Napoca, Romania, 4Hospice Casa Sperantei, Braso, Romania, 5Institute of Oncology, Bucharest, Romania, 6Regional Oncologic Institute, Iasi, Romania, 7Cantonal Hospital St. Gallen, Oncology, Dept. Internal Med & Palliative Centre, St. Gallen, Switzerland

Aim: Structured post-death interviews with bereaved family members (BFM) are important to estimate quality of death and dying of patients. Review of validated and easy to apply tools retrieved the QoDD. To validate translate and validate the QoDD in Romanian and German language.

Methods: The approach of the Manual for cross-cultural adaptation and psychometric validation of the POS (http://pos-pal.org) was applied.

Results: The conceptual definition or equivalence by the IZERZO and local groups (Alba [AI], St.Gallen [SG])
revealed no substantial differences of the concepts compared to the English version but RO cultural concerns to expose BFM to end-of-life discussions. Formal forward and backward translations and expert review revealed no relevant differences. For cognitive debriefing in AI of 78 BFM, 30 could be called, 17 reached, and 9 were interviewed individually, in SG: 14/16 reached, 11 agreed, 5 interviewed in 1 focus group. Comprehension (Co), Relevance (Re) and Acceptance (Ac) of the introduction of QoDD was good. Co of response options, Question (Q) 2 (.control of what was going around him?), Q12 (financial aspects) and Q16 (hastening death) was insufficient without, for Q16a with explanation (AI & SG). Minor wording changes for several Q were proposed. Re was high for all Q, Ac for all Q except Q16 (AI), which was then revised. The tool as a whole was considered appropriate, but only with interaction of a known, psychologically trained health-care professional. Remembering the dying experience guided by the QoDD was perceived by BFM positive (emotional but no burden), suggesting a therapeutic value. The option to identically interact by phone was supported. Presentation of the results (same groups) and discussions revealed: the challenge when being both researcher and clinician, the value of QoDD as bereavement care tool, and the insight that in the RO culture QoDD is feasible and desirable.

**Conclusion:** The revised QoDD is available in RO & German.

**Abstract number:** PO74

**Abstract type:** Print Only

**Is SWOT Analysis a Useful Tool at Regional Levels? A Look at the Development of Palliative Care in Latin America (LA)**

**Pastrana T.**, **De Lima L.**

1University Hospital RWTH Aachen, Department of Palliative Medicine, Aachen, Germany, 2International Association for Hospice and Palliative Care (IAHPC), Houston, TX, United States

**Background:** All countries in Latin America (LA) register Palliative Care (PC) in different development stages. A structured method used to evaluate the Strengths, Weaknesses, Opportunities, and Threats (SWOT) involves identifying internal (S and W) and external (O and T) factors, favourable and unfavourable to achieve a desired goal. SWOT analyses have been applied to palliative care programs at national levels. The authors were unable to identify SWOT analyses carried out at regional level in PC.

**Aim:** To implement SWOT analysis in palliative care development in LA.

**Method:** A survey was undertaken among 59 PC workers in 19 LA countries from January to April 2010 requesting them to list the SWOT in the development of PC in their own country. A content analysis was also performed, identifying 7 categories: Policies, Opioids, Service Provision, Civil Society, Education, Community, and Other. A ranking of the frequency of terms identified the most used.

**Results:** Total number of favourable factors (Strengths - Opportunities) was 259 (166 and 93 respectively). Total number of unfavourable factors (Weaknesses - Threats) was 297 (197 and 100 respectively). Categories with the highest scores were Civil Society (70) and Policies (69) for favourable factors and Policies (86) and Education (52) for unfavourable factors. The number of internal factors listed were 363, almost double the number of external ones (193).

The most frequent terms used were health, lack and opioids (98, 75, 57 times each). Of these, health was listed 52 times in favourable comments.

**Conclusions:** The stage of PC development among countries in LA is very varied. SWOT may be a useful tool in the analysis of the development of palliative care at the national level. However, its usefulness may be limited in large contexts such as regional analyses, especially when there is high variability in the stages of development among the countries included in the study.

**Abstract number:** PO75

**Abstract type:** Print Only

**Interventions for Sexual Dysfunction Following Treatments for Cancer: Cochrane Systematic Review**

**Candy B.**, **Jones L.**, **Dowswell G.**, **Tookman A.**, **King M.**

1UCL, UCL Mental Health Sciences Unit, London, United Kingdom, 2UCL, London, United Kingdom, 3University of Birmingham, Birmingham, United Kingdom, 4Marie Curie Cancer Care, London, United Kingdom

**Background:** Increasing numbers of people are living with cancer and more are cancer survivors. For both men and women a common problem following treatments for cancer is sexual dysfunction (SD). It has negative impact on quality of life and implications for psychological well-being. The types of treatments for SD are wide ranging, including

- complementary medicine (e.g. yohimbine)
- psychological (e.g. psychotherapy)
- pharmacological (e.g. vaginal creams)
- exercise (e.g. kegel)
- mechanical (e.g. for men vacuum devices).

In 2007 we undertook a Cochrane review to assess the benefits and risks of interventions for sexual dysfunction following treatments for cancer (Miles 2007). We found
10 trials for SD in men following treatments for non-metastatic prostate cancer. Pooling the trials we found PDE5 inhibitors drugs (e.g. sildenafil) are an effective treatment for SD secondary to treatments for prostate cancer. We found one trial for SD in women following radiotherapy for cervical cancer. Our review was limited as the trials reported were not representative of the range of treatments available for men and women. PDE5 inhibitors may not be suitable for all men following treatments for prostate cancer (Candy 2008). We are aware of new evaluations and new treatments, particularly for SD in women.

**Aims:** To update a Cochrane systematic review to determine the effectiveness of interventions for SD following treatments for cancer.

**Method:** Eight citation databases, including MEDLINE, and EMBASE were searched. Only randomised controlled trials (RCTs) were eligible. Two reviewers extracted the data and assessed trial quality. Meta-analysis was considered for trials with comparable characteristics including type of intervention.

**Findings and interpretation:** We are currently running our search. In early 2014 we will have updated our 2007 findings with any new trials available. This will provide up-to-date evidence on the benefits and harms of these interventions.

**Abstract number:** PO76
**Abstract type:** Print Only

**The Choice Campaign**

Whitfield A.M., Tymon L., Quinn D.

1Blackpool Teaching Hospitals NHS Foundation Trust, Palliative Medicine, Blackpool, United Kingdom, 2Blackpool Teaching Hospitals NHS Foundation Trust, End of Life Team, Blackpool, United Kingdom, 3Blackpool Teaching Hospitals NHS Foundation Trust, Communications, Blackpool, United Kingdom

**Introduction:** Offering patients and their carers opportunities to have conversations about preferences for care is key to enabling realistic decisions and choices. Feedback from acute trust clinicians shows that holding these conversations can be difficult, resulting in lack of patient and carer involvement, increased bed days at end of life and carer distress in bereavement.

**Aims:** Raise awareness that choice in place of care at end of life is possible.

Encourage patients, carers and staff to initiate conversations about end of life care (EoLC) and advance care planning (ACP).

Empower staff to have effective and sensitive discussions with patients and carers

Provide readily available information to support decision making.

**Method:** As part of the Choice Campaign we designed a poster fronted by a young cancer patient. Pilots were held on 2 wards with training for staff and support provided to patients and relatives at visiting times. Following a launch involving local media, posters were placed next to all clinical areas accompanied by information about ACP and contact details for the EoLC Coordinator with an Out of Hours answer phone for messages.

**Results:** Feedback has been positive although some clinicians were initially concerned that the poster would cause distress and raise unrealistic expectations. Since launching the campaign the EoLC Coordinator has reported increasing contacts via the telephone helpline for further information. Patients are exercising choice with an increase in the use of the rapid discharge at end of life pathway. Staff are demonstrating an awareness of the value of advance care planning. An evaluation will be included in the presentation.

**Conclusion:** This is the first step in enabling choice in end of life care within the Trust. We plan to consolidate this through an intensive ward based programme of EoLC training with outcomes monitored at Clinical Commissioning Group and Acute Trust Board.

**Abstract number:** PO77
**Abstract type:** Print Only

**Pain Treatment with Tapentadol in Departments of Radiation Oncology**

Muñoz Carmona D.-M., López Ramírez E., Contreras Martínez J.

1Hospital Juan Ramón Jiménez, Department of Radiation Oncology, Huelva, Spain, 2Hospital Inmaculada Concepcion, Oncosur Granada, Department of Radiation Oncology, Granada, Spain, 3Hospital Universitario Carlos Haya, Department of Radiation Oncology, Málaga, Spain

**Introduction:** Tapentadol is a centrally acting analgesic with a dual mechanism of action (µ receptor agonism and inhibiting the reuptake of norepinephrine).

**Objective:** To evaluate the efficacy of Tapentadol in cancer patients with chronic and/or acute pain.

**Patients and methods:** Between October 2011-September 2012, 28 patients were treated with Tapentadol in 3 Departments. Retrospective descriptive analysis of treatment with Tapentadol (SPSS 20.0).

**Results:** Patients were 10 women (35.7%) and 18 men (64.3%). Age range 28-85 years (mean = 60.8). The 17.8% of patients stopped treatment because of death, 7.1% because of improvement and 3.6% because of pruritus The 71.4% continued treatment. The 14.3% increased dose to achieve analgesia.a) Primary tumor type: The most common cancer were 21.4% lungs, 21.4% head and neck, 17.8% breast. b) Pain was due to: 32.1% tumour, 28.6% bone metastases,
14.3% benign problems, 10.7% induced by RT, 7.1% visceral metastases and 7.1% neuropathic pain, e) VAS before and after treatment: the mean VAS pretreatment = 7.2 and posttreatment = 3 (4.2 points difference). The 71.4% of patients progressed to mild pain (VAS <= 4), d) Tapentadol mean dose = 114.3 mg. The dose most used was 50 mg (42.9%); e) Other medications associated: none (17.8%), rapid onset fentanyl (60.7%), antiepileptics (28.6%), steroids (28.6%) NSAIDs (21.4%), morphine (7.1%), anxiolytics (7.1%), antidepressants (3.6%), 5% lidocaine (3.6%) and acupuncture (3.6%) f) Analgesic efficacy: 100% of cases. Mean analgesic = 41.7 % and maximum = 87.5 %; g) Side effects: Well tolerated with mild effects (pruritus, constipation) in 3 cases (10.7%).

Conclusion:

1. Our data support the use of Tapentadol pain in cancer patients with moderate to severe chronic or acute pain (VAS= 5).
2. Tapentadol is an effective pain reliever with few side effects.

Abstract number: PO78
Abstract type: Print Only

A Resources and Palliative Care Services Questionnaire Validation through a Qualitative Methodology

Izquierdo-Botica F.1, Ruiz-López D.2, Guerra-Rodríguez M.1, García-Baquero Merino M.T.3, Blasco-Amaro J.A.1

1Agencia Laín Entralgo. Consejería de Sanidad, Comunidad de Madrid, Unidad de Evaluación de Tecnologías Sanitarias (UETS), Madrid, Spain,
2Dirección Asistencial Noroeste de Atención Primaria, ESAPD Legazpi, Madrid, Spain, 3Consejería de Sanidad, Comunidad de Madrid, Coordinación Regional de Cuidados Paliativos, Madrid, Spain

Objective: To establish the composition, content and criteria validity of a questionnaire of resources for services provision in Palliative Care (PC) through a qualitative methodology using focus groups with PC professionals. This is a part of a validation and evaluation research project for the provision of services (CP) in the Community of Madrid (CM).

Methods: We performed a qualitative approach to the resource questionnaire validation. It was selected the focus group technique based on the personal experience of the professionals involved in PC. The groups were made up of physicians, nurses, psychologists, social workers and pastoral agent.

Results: Discussion items in the groups were: human resources, geographical dispersion, work and personal motivation, “psycho-emotional” help for professionals, comprehensive and holistic patient approach, equipment equity, social budget, caregiver support, support between teams, overburden and human relationship with CEOs, future of teams: “be burned”, teamwork, teaching in PC, PC nursing work, PC welcome protocol and terminological and conceptual clarifications.

Conclusions: This study tries to be the starting point for the development and validation of the PC provision of services questionnaire. It will be useful to assess the human and technical resources of our palliative health care network.

Abstract number: PO79
Abstract type: Print Only

Seeking New Methods for Palliative Care Research: Generating Conceptual Models from Grounded Theory Methodology

Carrero Planes V.1, Navarro Sanz R.2, Serrano Font M.1, Camacho López H.1, Castellano Vela E.2, Vaquer Chiva A.3, Rochina Puchades A.3

1Universitat Jaume I, Departamento de Psicología Evolutiva, Educativa, Social y Metodología, Castellón de la Plana, Spain, 2Hospital Pare Jofré, Área Médica Integral, Valencia, Spain, 3IES Vicente Sos Baynat, Departamento de Orientación, Castellón de la Plana, Spain

Research aims: Recent contributions on palliative care (PC) research have emphasized the relevance of seeking new methodologies and types of research designs. The study of advanced disease and End of Life (EoL) experience faces the researcher with many ethical and practical challenges. Most of these challenges deal with sample recruitment (highly vulnerable samples); relevance in the choice of methods and analysis techniques (inclusion of different perspectives: family, patient and interdisciplinary team); complexity and multidimensionality of the processes studied (disease paths) and bioethical considerations (dignity, be competent to). The aim of this paper is to emphasize the basic principles of Grounded Theory (GT) as a new methodological approach to evaluate interventions on making decisions process (MDP) of the EoL care using a pilot randomized controlled trial.

Study design and methods: The study was conducted in a PC hospital and home care resource. The research design consists of three phases: exploration, targeting critical cases and pilot testing. The sample population includes a total of 157 observations/interventions which 128 were held during exploration, 13 in the targeting phase and 16 in the pilot study. The application of GT generates a research design open and flexible enough to incorporate the findings that were significantly affecting the MDP in advanced disease cases, without decreasing the scientific rigor and the reliability of the results obtained.

Results and interpretation: The results show the impact that GT has on the research design. Theoretical sampling
and Constant Comparative Method generate conceptual propositions (formal theory), which are independent of the context, thus overcoming cross level fallacies. The proposed methodology guarantees the possibility of understanding and transferring the emerging processes to different health care contexts, reaching high levels of analytical generalization.

Abstract number: PO80
Abstract type: Print Only

C - Reactive Protein and Prognosis in Solid Tumors: A Systematic Review

Shrotriya S., Walsh D., Thomas S., Bennani-Baiti N.
Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Harry R. Horvitz Center for Palliative Medicine and Supportive Oncology, Cleveland, OH, United States

Aims: Serum C-reactive protein (CRP) is an acute phase reactant and a stable downstream marker of inflammation. We conducted a systematic literature review to examine the relationship between elevated CRP and prognosis in solid tumors. The role of CRP in prediction of treatment response and tumor recurrence was also determined.

Methods: Related MeSH (Medical Subject Heading) terms were used to search electronic databases (PubMed, EMBASE, Web of Science, SCOPUS, EBM-Cochrane). Inclusion/Exclusion criteria were developed. Two reviewers independently reviewed selected research papers. A quality Assessment (QA) score was devised and utilized. Studies with QA scores < 50% were deemed inadequate and excluded.

Results: 271 articles were selected for final review. 45% were prospective studies; 52% retrospective. Seven had an adequate QA score (80% - 100%); 264 intermediate QA score (≥50% but < 80%). Elevated CRP predicted prognosis in 90% (245/271) of studies; in 80% of the 245 studies by multivariate analysis; 20% by univariate analysis. High CRP level was not prognostic in 10% (26/271). Over half (52%) of all studies were either in gastrointestinal malignancies (GI) or renal cell carcinoma (RCC). High CRP predicted prognosis in 90% (127 of 141) of the studies in these two specific tumor groups. Most reports in other solid tumors also supported its prognostic role (High CRP = worst prognosis).

Conclusions:

1. An elevated CRP was prognostic in 90% of studies in solid tumors.
2. Most studies were in GI malignancies and RCC; a high CRP level predicted prognosis in 90%
3. High CRP predicted prognosis in other solid tumors (lung, pancreas, hepatocellular cancer, and bladder) as well.
4. CRP may help determine treatment response and tumor recurrence.

Abstract number: PO81
Abstract type: Print Only

Relative’s Perception of the Quality of Death of their Family Member in a Regional Teaching Hospital in NSW, Australia

Clark K.1, Byfieldt N.2
1Calvary Mater Newcastle, Palliative Care, Waratah, Australia, 2Calvary Mater Newcastle, Palliative Care, Newcastle, Australia

Background: People dying in hospitals may not receive care to address issues important to them or their relatives. People nearing death have articulated that excellent symptom control, clear communication with health professionals and maintenance of autonomy as important. Family members have identified comfort of their relative as paramount. As part of a quality project to improve care of the dying in an Australian context, families were surveyed, exploring their perceptions of their relative’s care. This study reports these interviews.

Methods: The realtives of people who died in a NSW hospital were approached 6-8 weeks after the death. The 31-item Quality of Death and Dying (QODD) questionnaire was administered and people were encouraged to elaborate as they wished. A mixed qualitative and quantitative was used to analyse the results.

Results: Ten interviews were conducted with the interviewees being predominantly women (n=9). The questions most answered were those that focused on the physical comfort of the dying person with these highlighting concerns that the person died in pain (n=7) and with breathing difficulties (n=6). Other issues such as place of death were not answered. At the end of each interview people were asked if they had anything they would like to add which universally prompted comment. Five themes emerged including the perception of poor communication, a lack of communication that the person was dying, a perceived need for their care around their relative’s death, the concern that their relatives did not receive good symptom control and a sense of a lack of practical support offered to them.

Interpretation: This survey suggests optimising symptom control is important to the family of people dying in hospital. The information provided by this survey provides a valuable baseline from which to gauge the success of a quality project from the point of view of the relatives of dying people.
Background: Palliative care (PC) program structure is diverse and evolving. This MASCC survey queried palliative care leaders internationally regarding program structure, service research and education.

Methods: A survey adapted from Hui et al was used. Palliative care leaders were contacted through MASCC, ESMO and EAPC to complete this survey on the MASCC website.

Results: 62 program leaders completed the survey. Overwhelmingly, most services included outpatient clinics (82%) inpatient consultation services (80%) and dedicated inpatient palliative beds (62%). Most programs were small, with 2 physician FTEs. Leaders were commonly from Med Oncol, Int. Med, Anesthesics and family medicine. All services incorporated inpatient and outpatient nursing services. Paramedical staffing was less consistent: dieticians 66%, pharmacist 46%, psychologists 88%, social workers 84%. 75% of services indicated that most referrals were > 4 weeks before death, 25% reported referrals less than a month prior to death. Symptoms were by far the most common reason for referral to inpatient PC, other reasons included terminal care, psychosocial issues and respite. Average LOS 10 days and mortality 40%. Half of programs had weekly grand rounds; half required rotations for medical oncology-hematology fellows.

Discussion: Most PC programs incorporate inpatient consultation services, outpatient clinic services and inpatient acute palliative care beds. A substantial minority do not have dedicated acute palliative inpatient services. Staffing levels are often low with small and constricted teams carrying very large clinical loads. Protected time for research and teaching is limited.

Conclusion: Defining characteristics and scope of services anticipated from a palliative care service is still developing. Program development is hampered by inadequate allocation of resources to effectively staff interdisciplinary academic and clinical services.

Abstract number: PO82
Abstract type: Print Only

MASCC Palliative Care (PC) Survey: Integration into Cancer Care
Davis M.1, Strasser F.2, Cherny N.3

1The Harry R. Horvitz Center for Palliative Medicine, Department of Solid Tumor Oncology, Taussig Cancer Center, The Cleveland Clinic, Cleveland, OH, United States, 2Kantonsspital, St Gallen, Switzerland, 3Shaare Zedek Medical Center, Jerusalem, Israel

Introduction: The degree of competence and the attitude of the professionals before the end of the life are essential for the patients treatments and in major cases it conditions their actions before the illness and the death proximity. It is important to know their necessities in order to promote activities which can help to face them in a satisfactorily making possible the correct professional development. In this research, different attitudinal profiles presented in primary and hospital attention are described and analyzed.

Objectives: To study the profiles of facing and fear of death on health professionals.

Methodology: Quantitative study. Survey conducted in 116 health professionals from different levels of care, applying Bugen scale for coping and Collet-Lester scale about the attitude or fear to death. Statistical analysis using SPSS 20 for Windows.

Results: After standardizing the total scores on both scales, an analysis of k-means cluster was performed, obtaining a good fit with a division of the sample into two groups consisting of 40-60% of the subjects. These groups are characterized by the combination of two levels of coping and fear to death: Level 1 - low coping and high scaled score of fear to death; Level 2 - High level and low coping scale score fear to death.

Conclusions: Two different profiles emerged on coping and attitude to death of health professionals: one being characterized by a high competence and the other of low one. We must deepen in this approach to study the existence of other groups and their relationship with other variables.

Abstract number: PO84
Abstract type: Print Only

Expressions of a Teenager under Palliative Care on Facebook
Bousso R.S., Santos M.R., Borghi C.A., Frizzo H.C.F.
University of São Paulo, São Paulo, Brazil

Pediatric palliative care is an approach for end of life situations, but is not limited to it. Children with long-term chronic disease need broad type of support and can be favored by palliative care. An increasing number of health related communities on the Internet show that people use
virtual socialization also looking for support. The aim of this study was to explore the use of the social network Facebook by an adolescent with a genetic disease requiring palliative care and analyze the behavior of other users as well as the sharing contents. This is a qualitative, case study research and used the virtual Ethnography and content analysis as method. Fifty four comments posted including photos and messages were analyzed in a 13 years old female adolescent’s profile. The participant is osteogenesis imperfecta carrier. It is a genetic and inherited disorder characterized by fragile bones, causing multiple fractures and pain without a specific cause. This profile was observed during 222 days when all posts, comments and photos were decoded for content analysis. It was possible to identify themes that include: feelings and emotions, coping with stigma and prejudice and religious beliefs. These themes captured the manifestation of feelings usually retraced and the interaction of social issues, which are hardly treated openly, and are essential in a palliative approach, especially with school age child and adolescents. Virtual social networks have an important role for expressing and communicating stories, thoughts and feelings. This teenager shared her suffering, coping abilities, beliefs and daily tasks with friends. Considering that palliative care can enhance quality of life, and may also positively influence the course of illness, by providing relief from pain and other distressing symptoms; virtual social networks can be an important tool for health professional to get closer to children, adolescents and families.

Abstract number: PO85
Abstract type: Print Only

Bevacizumab in Patients with Brain Radionecrosis
Cumplido D.1, Arroyo A.1, Toral J.C.1, Palomares E.2, García P.2, del Pozo N.2
1Torrevieja Hospital, Torrevieja, Spain, 2Vinalopo Hospital, Elche, Spain

Introduction: Bevacizumab is a monoclonal antibody which inhibits VEGF, normalizes vascular permeability and improve edema. Currently is indicated for the treatment of many solid tumors. In recent years it has been used for the treatment of brain radionecrosis. The high-grade gliomas express high levels of VEGF and after use of bevacizumab have been observed rapid effect on the improvement of neurological functions, allowing lower doses of corticosteroids.

Patients and methods: We used bevacizumab in a patient under compassionate use in our center for the treatment of brain radionecrosis.

Results: 53 year old woman with no relevant medical history was diagnosed of grade II astrocytoma three years ago. The patient underwent partial resection of the lesion, subsequently receiving radiotherapy dose 50.8 Gy. After such treatment continues follow up. In November 2010 he entered the area of internal medicine secondary to worsening neurological functions. Radiological study was performed showing an extensive radionecrosis after radiotherapy with associated edema. Despite the use of high-dose corticosteroids she was admitted again two months later. We offer treatment for radionecrosis to the patient with bevacizumab under compassionate use procedure. The response of the patient after the first administration is excellent with improvement of neurological functions and without use of corticosteroids. She had four sessions, ending in April 2011. Later she carried on periodic reviews and in April 2012, presents a new radiological worsening. We decides to begin a new treatment with bevacizumab. Again the patient showed clinical response with improvement of neurological functions and currently continues periodic revisions without tumor progression and with a good quality of life.

Conclusions: Bevacizumab can be considered as palliative therapy for the treatment of cerebral radionecrosis as it improves the symptoms of patients and allows reduced use of corticosteroids.

Abstract number: PO86
Abstract type: Print Only

Implementation of the Care Pathway for Primary Palliative Care
Leysen B., Wens J., Van den Eynden B.
University of Antwerp, Wilrijk, Belgium

Aim: Primary palliative care is an emerging field. The Care Pathway for Primary Palliative Care (CPPPC), developed at the University of Antwerp, helps primary health care workers to provide high quality palliative care. Starting from early identification of palliative patients by general practitioners (GPs), patient- and family-centered care is believed to be delivered towards the end of life. The care pathway has been tested in a small-scale pilot-study, and will now be implemented and evaluated in 5 Belgian regions: 2 Dutch-speaking regions, 2 French-speaking regions and the bilingual region of Brussels.

Methods: A stepped wedge cluster design is set up with the 5 regions being 5 clusters. GPs who volunteer to be involved will recruit people with reduced life expectancy and their informal care giver. Quality of care will be measured by 1) web-based questionnaires filled by GPs and patients in a secured way, and 2) health care consumption data in the last year of life. A prospective cohort as well as a case control design is developed within and between the 5 clusters.

The primary outcome of this quantitative part is hospital admission rate in the last year of life. Secondary out-
comes are death at home, health care consumption, and quality of care as perceived by the web-questionnaires. A multiple case study design will be used to evaluate the implementation in a more qualitative way. Focus groups will reveal which best practices of strategies every region uses in improving the local palliative care organization. Semi-structured interviews will find how GPs implement the CPPPC and how patients and/or informal carers experience receiving the CPPPC.

Discussion: Now, there is a trend to use mixed methods to evaluate palliative care interventions. A stepped wedge cluster design has logistical and ethical, but also statistical advantages. A multiple case study design can give answers to ‘how’ and ‘why’ the CPPPC is used per region and across the regions.

Abstract number: PO87
Abstract type: Print Only

A Qualitative Longitudinal Study on Elderly Patients with Advanced Heart Failure in Germany:
A Critical Reflection on Methods and Study Design
Klindtworth K.1, Hager K.2, Oster P.3, Schneider N.4
1Hannover Medical School, Institute for General Practice, Palliative Care Research Group, Hannover, Germany, 2Diakoniekrankenhaus Henriettenstiftung, Centre for Geriatrics, Hannover, Germany, 3AGAPLESION Bethanien Hospital, Geriatric Centre at the University, Heidelberg, Germany, 4Hannover Medical School, Institute for General Practice, Hannover, Germany

Background: Heart failure is major cause of death worldwide. Studies have shown that patients with advanced heart failure can have a high symptom burden but so far little is known about the patients’ needs and the health care they receive and any changes over time when the illness progresses. Therefore, for the first time in Germany we carried out a qualitative longitudinal study with interviews quarterly for an eighteen-month period to prospectively explore the experiences and needs of elderly patients with heart failure. Here, we critically discuss the study design and research method.

Method: Reflection and discussion of the study design and methods in the interdisciplinary research team including experts from public health, geriatrics, general practice and palliative medicine.

Results: The longitudinal design enabled us to accompany patients over a period of time with growing confidence between the patients and the interviewer. The patients were multimorbid with various other diagnoses in addition to heart failure (NYHA III/IV), and they had different initial points of suffering from heart failure (e.g., heart attack). As a consequence, there was no common illness trajectory to be pursued across the cases. Interviews on a three-monthly basis were a rather short interval for most patients to talk about their health status, particularly when no acute crisis has happened. As a result, some patients digress into ‘small talk’ or biographic details without gaining new relevant issues. However, the ongoing analysis enabled us to adapt the interview guide to emerging issues across the cases as well as individual progresses.

Conclusion: The longitudinal design is well suited to explore the experiences and needs of elderly patients with heart failure benefiting greatly from growing confidence. Follow-up interviews could be better adapted to individuals’ trajectories by interim phone calls to monitor any changes.

Funding: Robert Bosch Foundation

Abstract number: PO88
Abstract type: Print Only

Measuring the Quality of End of Life Care Using ICECAP-SCM: A Think Aloud Study
Bailey C1, Kinghorn P.2, Orlando R.3, Armour K.2, Perry R.2, Coast J.1
1University of Birmingham, Health and Population Sciences, Birmingham, United Kingdom, 2Marie Curie Hospice Solihull, Birmingham, United Kingdom

Background: Measuring the quality of end of life with generic health instruments has received criticism amongst palliative care researchers. The ICECAP Supportive Care Measure (ICECAP-SCM) is a self-complete questionnaire developed to evaluate palliative and supportive care. Using attributes of autonomy, love, physical and emotional suffering, dignity, support and preparation, it measures wellbeing in terms of ‘capability’ amongst patients receiving supportive care.

Aim: To determine the feasibility of completion of ICECAP-SCM, amongst people receiving supportive care and their potential proxies. The study explored difficulties in completion, views about the measure and provides a better understanding of proxy completion.

Study design and method: Using the ‘think-aloud’ technique, participants were asked to verbalise their thoughts whilst completing the ICECAP-SCM. Semi-structured interview questions explored participants’ opinions about the measure. All interviews were transcribed verbatim and independently rated for errors. Kappa scores calculated inter-rater agreement. Constant comparative methods were used to analyse the qualitative data. Transcripts were read and re-read, and categories and sub-categories developed to describe emerging themes.

Findings: Measuring the end of life is complex due to the ‘adaptive normality’ that patients experience as their illness trajectory changes. The attributes of ICECAP-SCM...
offer a comprehensive overview of quality of end of life to capture and accurately measure capability. It is easy to conduct in a hospice setting and easily understood by participants, including patients who are very near the end of life. It is perceived as an appropriate measure by patients receiving supportive care to accurately and appropriately record quality of life.

Implications: ICECAP-SCM is offered to measure the quality of end of life care targeting research interventions aimed at improving palliative and end of life care provision.

Abstract number: PO89
Abstract type: Print Only

The Utrecht Symptom Diary for Professionals, a Validation study

Graaf E.D.1, Bloemink W.1, Nijs E.D.2, Teunissen S.1,3
1Academic Hospice Demeter, De Bilt, Netherlands,
2Leiden University Medical Center, Leiden, Netherlands,
3University Medical Center Utrecht, Utrecht, Netherlands

The Utrecht Symptom Diary (USD) is a validated Dutch adaptation of the Edmonton Symptom Assessment Scale. The USD is a self-assessment tool for 11 symptoms: pain, sleeplessness, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnea, fatigue, anxiety, and depressed mood. In addition well-being is measured as a single item. All items are rated on a 0 - 10 rating scale. When patients are unable or not willing to self-report symptoms the USD is not applicable. The USD-Professional (USD-P) was developed, assessing the 11 symptoms, using clinical observations on a 5 point Likert scale (not at all - overwhelmingly). Well-being is assessed on a 0 - 10 rating scale. The USD-P is a feasible instrument in daily hospice care but the validity is yet to be determined.

Aims: To validate the USD-P as a clinical tool to maintain symptom monitoring through the entire illness trajectory.

Method: This clinimetric research study had a quantitative, prospective design. All patients admitted to a hospice from January 2012 to December 2013 were enrolled in this study. Symptoms were measured using the USD concurrent to the USD-P.

The reliability focused on agreement. USD data were categorized using cut-off points. Differences of paired measurements were analyzed.

Validity focused on face-, content-, criterion- and construct validity and internal consistency. Cosmin criteria procedures are planned for statistical analysis.

Results: Complete agreement was achieved in 31 to 51% of the measurements. Agreement within one category was achieved in 73 to 93% percent of the measurements. Further analysis by the Cosmin criteria is in progress. The results will be presented during the EAPC of 2014.

Conclusion: The use of the USD-P improves early recognition and monitoring of symptoms when self-assessment is not feasible. Preliminary results show fair to good agreement of USD and USD-P items. The USD-P optimizes monitoring of symptoms and well-being in the continuum of palliative care.

Abstract number: PO90
Abstract type: Print Only

Addressing End-of-Life in Advanced Cancer Trials - A Systematic Review

Gaertner J.1,2, Weingärtner V.1, Lange S.4, Haasner E.4, Gerhardus A.5, Simon S.T.1, Voltz R.1, Schmacke N.5
1University Hospital Freiburg, Department of Palliative Care, Freiburg, Germany, 2Competence Center Palliative Care, Baden-Württemberg, Germany, 3University Hospital of Cologne, Department of Palliative Medicine, Clinical Trials Unit (BMBF 01KN1106), and Centre for Integrated Oncology (CIO) Cologne/Bonn, Cologne, Germany, 4Institute for Quality and Efficiency in Health Care (IQWiG), Cologne, Germany, 5University of Bremen, Institute for Public Health and Nursing Research (IPP), Bremen, Germany

Aims: Randomized controlled trials (RCT) are among the most important sources of information about the realistic benefit patients may expect from possible treatment options. It is unclear, whether RCT assessing interventions against advanced cancer consider the patients’ end-of-life (Eol) situation. Since this is inevitable for judging the patients’ benefit, this study explored whether Eol and quality of life (Qol) issues are considered in such RCT in advanced cancer.

Methods: Systematic literature review in MEDLINE. RCT including patients with glioblastoma, lung cancer stage ≥IIIb, malignant melanoma stage IV or pancreatic cancer and a median survival ≤24months, published in highly ranked, predefined journals in English were eligible. Available information on incurability of disease, therapeutic goals (prolongation of life (PoL), QoL), endpoints (EP), use and definition of palliative care terminology were extracted and analyzed descriptively.

Results: Of 206 eligible publications, 100 (the 25 latest publications for each entity) were analyzed. Incurability was mentioned in 71/100 publications and 38/100 reported therapeutic goals (PoL 31, QoL 2, both 5). Primary endpoints (EP) were overall survival (53), surrogate parameter (47) or study specific (3) (six RCT defined two primary EP). QoL was a secondary EP in 36 publications but only 31 reported results. Best supportive care was used in 19 publications while Eol, terminal- or advance care were never used. Supportive care /-treatment were common but inconsistently defined. Palliative Care, palliation and palliative therapy were rarely used and never defined.
Conclusion: Though most authors mention incurability of disease, Eol terminology is avoided. Compared to survival and surrogate measures, QoL plays a minor role in study design and reporting. This severely impedes the interpretation of results in the context of Eol.

Funding: The study was funded by the German Institute for Quality and Efficiency in Health Care (GA 12-01).

Abstract number: P091
Abstract type: Print Only

The Role of C - Reactive Protein in Adult Solid Tumor Prognostication
Shrotriya S., Walsh D., Bennani-Baiti N., Aktas A., Estfan B.
Cleveland Clinic Taussig Cancer Institute, Department of Solid Tumor Oncology, Harry R. Horvitz Center for Palliative Medicine and Supportive Oncology, Cleveland, OH, United States

Aims: C-reactive protein (CRP), a non-specific marker of inflammation may help cancer prognostication. CRP is secreted by liver due to interleukin-1 (IL-1), IL-6 and tumor necrosis factor (TNF). It has been linked to shorter survival in some cancers. We examined associations between CRP levels and prognosis in solid tumors.

Methods: Retrospective study of electronic medical records (EMR). Multiple CRP levels at a tertiary cancer center reviewed (2006-2011). Hematological cancer diagnoses were excluded. Survival was defined from the date with highest CRP to date of death. CRP reference range 0-10 mg/dL; low CRP: ≤10 mg/dL; high: >10mg/dL.

Results: N=7716 with solid tumors identified. 48% were males. 83% Caucasian; 12% African American. CRP was >10 mg/dL in 49% and ≤10 mg/dL in 51%. Common cancers with high CRP levels: gastrointestinal (GI) 21%, genitourinary (GU) 19%, breast 16%, lung 13%. The median (range) value in low CRP group was 3 (3 -5) mg/dL and high CRP group was 51(23-107) mg/dL. The risk of death increased by 19% (unadjusted model) and 11% (adjusted) for patients whose maximum CRP was above 10 mg/dL.

Conclusions:
1. Higher median CRP in GI, GU, breast and lung cancers.
2. Risk of death increased for those with high CRP level (>10 mg/dL) after adjusted/unadjusted for other covariates.
3. High CRP was adverse prognostic indicator in GI, breast and genital cancers
4. High CRP value may be an adverse prognostic indicator in solid tumors.

Abstract number: PO92
Abstract type: Print Only

“Is There Anything we Can Do?” Family Caregivers’ Experience Giving Simple Lymphatic Drainage (SLD) - A Qualitative Study
Salomonsen A., Jørgensen B.
Aarhus University Hospital, Det Palliative Team, Aarhus, Denmark

Aim: Lymphedema/oedema is a symptom with significant influence on the quality of life of the palliative patient and family. Caregivers in the family often ask: “Is there anything we can do?” This study evaluates the experience of giving Simple lymphatic drainage (SLD) by family caregivers.

Method: Three qualitative semistructured interviews with two spouses and a friend of a patient were conducted using an open interview guide. The relatives were recruited from a palliative care team. The interviewer was a lymphedematherapist.

Results: Three main themes were identified: experiences in the family relation, experiences in relation to professionals and recommendations to other family caregivers. To be able to do something active, physical and effective for the sick body of a relative is positive and important to the family caregiver. It is a rewarding and meaningful activity and although energy consuming adds to the quality of life. In giving SLD you are together creating a “room” of silence, presence and intimacy where thoughts are few and where there is room to feel. The experience of having done what you could is remembered in the process of grief. Family caregivers want to participate in giving SLD with the possibility of renouncing not knowing how it may affect them. There are varieties in the need for support from professionals. Often it will be sufficient with a home visit by the lymphedematherapist informing about aims and the practical instruction in SLD accompanied by a written instruction and the possibility for follow-up. The family caregivers should not be left alone with SLD.

Conclusion: Family caregivers recommend giving SLD to other relatives in similar situations. To be able to help in a meaningful way which creates a good time for patient and relative is a good combination and remembered in the process of grief.

Abstract number: PO93
Abstract type: Print Only

Palliative Care Case Management in Primary Care: A Descriptive Study about the Flexibility, Duration and Content of Care
van der Plas A.G.M.1, Francke A.1,2,3, Jansen W.1, Vissers K.4, Deliens L.1,2,5, Onwuteaka-Philipsen B.1,2
Background: In case management an individual or small team is responsible for navigating the patient through complex care. Case management can have many appearances, but in palliative care case management flexibility of care, duration of care for as long as needed, and attention to physical, psychological, social, and spiritual wellbeing (the four domains of palliative care) are considered central points. The objective of this study is to describe the number, duration and content of contacts the case manager has with patients and/or informal carers, and the time span between first and last contact.

Method: Twelve of the 20 existing palliative care case management initiatives in primary care in the Netherlands were involved in this study. Case managers completed a questionnaire for every contact they had with a patient and/or informal carer.

Results: For 738 included patients, there were 4278 recorded contacts between the case manager and the patient and/or informal carer. The median number of contacts was 4, with a range from 1 to 36 contacts per patient. Home visits were done between zero to 22 times per patient, and lasted 48 minutes (median). Contacts by telephone occurred zero to 19 times per patient and lasted 30 minutes (median). The time between the first and last contact ranged from zero days (with one or two contacts in one day) up to almost 2 years. Topics most discussed during contacts were physical complaints, psychological issues, life expectancy and incurability of illness. Spiritual aspects and possible medical complications were least discussed. Information on care services and illness was mostly given.

Conclusion: Case management in primary care is delivered flexible with regard to the number and duration of contacts. Time between the first and last contact was also variable. Content of care covered the four domains of palliative care, with physical aspects most discussed and spiritual aspects the least.

Abstract number: PO94
Abstract type: Print Only

Decision Making at the End of Life (EOL): Exploring the Process for Patients, Families and Community Healthcare Professionals
Brogan P., McIlfatrick S., Hasson F.
long term care facilities. In October 2010 a unique hospice has been inaugurated, meaning that palliative care is now implemented in all different settings.

The aim of our study was to find out where and under which circumstances this care is delivered. The results concern mainly hospital wards and the hospice, as here a 3 digit ICD 10 registration of all patients is requested.

The general data are the following: 44 «palliative» beds are listed in the palliative units in the whole country for a total population of some 550000 people. (88 beds per 1 million inhabitants). In the hospital palliative wards some 5500 days of hospitalisation were found and in the hospice 4380 days (a total of 9830 days).

More specific data in the hospice show that the annual admissions are 92 patients compared to some 240 in the hospitals. The mean length of stay was 52 days in hospice and 49,8 in hospitals. The main pathologies treated: 70 % for cancer in hospice and 89% in hospital wards.

In conclusion, the specificity of the hospice can clearly be shown on the data analysed: the palliative hospital wards are very specific for pure cancer patients and the hospice has focused on cancer and end-stage respiratory or cardiovascular diseases including elderly stroke patients. In all departments people with dementia tend to be less often taken into consideration because of some psycho-motor agitation.

We suggest that the palliative care teams should treat these patients either at home or in the long term care facilities.

Abstract number: PO96
Abstract type: Print Only

Characterization of the Population Attending Outpatient Palliative Care Oncology

Crovador C.1, Trevisani D.M.2, Ito C.T.3, Canola I.3, Rodrigues L.F.3

1Barretos Cancer Hospital, Center of Research Support, São José do Rio Preto, Brazil, 2Barretos Cancer Hospital, Palliative Care Unit, Barretos, Brazil, 3Barretos Cancer Hospital, Center of Research Support, Barretos, Brazil

Objective: To describe the characteristics of the population attending outpatient palliative care oncology.

Method: This was a descriptive study, from which data were collected from medical records of patients attending an outpatient palliative care cancer during the period from 02 January 2013 to 10 October 2013. The variables collected included: age, type of cancer, the latest assessment of performance status (PS) recorded in the medical records prior to the date of data collection, and the time elapsed between the last of the PS and the date of data collection.

Results: A total of 943 medical records of these 44 % were urologic malignancies, followed by cancers of the head and neck (40 %), hematologic (37 %) and digestive (36 %). It was observed that patients with better PS had a time interval between the query that was registered PS and the date of data collection larger than that of patients with worse PS. The average was 115 days for patients with PS / ECOG 0 and 35 days for PS / ECOG 4. There is also a larger number of patients (n = 471) aged 60-79 years, and these had mostly PS / ECOG 1 (36 %) in their last evolution of records that contained PS, followed 31% PS / ECOG equal to 2. Stands out in this age group, most care for patients with digestive cancers (15 %), followed by gynecological / breast (24 %). For the age group 40-59 years (n = 331), the majority had PS / ECOG 1 (40 %) in their last evolution of PS on record, highlighting, even at this age the gynecological cancer (12 %), followed by gastrointestinal tumors (25 %).

Conclusion: It was noticed that there is a routine part of most professional register the PS in medical developments, since this information was not present in all developments. Thus, the systematic registration of PS and other parameters of clinical evaluation of the patient in palliative care can guide better care planning.

Abstract number: PO97
Abstract type: Print Only

Death in the Words of Patients with Cancer

Omidvari S.

Health Metric Research Center, Iranian Institute for Health Sciences Research, ACECR, Mental Health Research Group, Tehran, Iran, Islamic Republic of

Aims: One of the most often expressed preoccupations of patients with cancer is death. This study explores the subject “death” from the point of view of patients with cancer.

Methods: A qualitative study, using semi structured individual in-depth interview and purposive sampling, was carried out by a psychiatrist in a major cancer hospital in Tehran, Iran. Interviews went on until data saturation. The interviews were audio-taped and the data were coded and classified on the basis of the area and subject.

Results: In total, 24 interviews were done. The study findings revealed various pivots, some of which are as follows:

- Since based on religious beliefs the human being does not interfere with the time of death, so it needs no anxiety.
- Since having disease is a way to get cleaned up from sin, so we should not fear death
- Since all the human beings eventually die, death is not a factor causing distress
- Since everybody, and me too, dies one day, one should not fear death
- Since the real life is in the other world, thinking of death does not cause anxiety
Abstracts

- Since death is a matter full of mystery, it causes fear
- Dying is something like sleeping, so it is comfortable
- Death is preferred compared to loss of dignity, disability, loss of independence, and disfigurement
- Death is good because the money spent on the treatment of the disease can be spent on the family’s every day needs if I die
- Worrying about the afterlife and the position of the patient in the other world
- Worrying about being unable to complete life tasks or responsibilities before death time
- Worrying about what will happen to dependents after my death (financially, who will take care of my children, they may endure a lot of emotional distress, and so on)
- …

Conclusion: Although a part of findings indicates a positive attitude towards death, which in turn needs more exploring, it seems death is a source of anxiety in some patients.

Abstract number: PO98
Abstract type: Print Only

Is it Different or Not? - Transfer for Paraplegics Caused by Traumatic Spinal Cord Injury or Caused by Advanced Cancer with Vertebral Bone Metastasis

Abe P.K.
Chiba Prefectural University, Rehabilitation, Chiba, Japan

Clinical question: Clinical picture of paraplegics looks like as same between caused by traumatic spinal cord injury and caused by vertebral bone metastasis with advanced cancer. But there are differences between them about symptoms such as pain, fatigue and muscle loss with advanced cancer. It is a crucial clinical issue for palliative care for advanced cancer patient when the patients transfer from bed to wheel chair. It was basic skill for their activities of daily living. Then I studied differences between traumatic paraplegia and paraplegia with advanced cancer with vertebral bone metastasis comparatively.

Subjectives and methods: From 1972 to 2012, I selected 72 articles by database called Ichushi in Japanese about paraplegia caused by traumatic spinal cord injury. Then I compared with 36 articles about paraplegia caused by vertebral bone metastasis with advanced cancer.

Results: When paraplegics transfer from bed to wheel chair, push up movement is key point for traumatic paraplegics. However, paraplegics with vertebral bone metastasis are contraindicated to push up, because of pathological fracture of bone metastases, severe pain of bone metastasis and so on, weakness of muscle and fatigue with cancer cachexia in particular.

Discussion: Traditional way of transfer for paraplegics caused by traumatic spinal cord injury are done by push up movement basically by getting stronger muscle power. However, the other paraplegics, especially advanced cancer patient with vertebral bone metastasis are contraindicated push up, because of danger of pathological fracture, severe pain of bone metastasis and so on, weakness of muscle power caused by sarcopenia and fatigue by cancer cachexia. Therefore, it is quite different between traumatic paraplegics and paraplegics with vertebral bone metastases with advanced cancer at transfer movement. This is quite important to approach clinically for transfer from bed to wheel chair.

Abstract number: PO99
Abstract type: Print Only

Nurses’ Perception about Palliative Care in the Home: Advocating for the Well-being of the Family

Baliza M.F.1, Poles K.2, Bousso R.S.1, Santos M.R.1

1University of São Paulo, São Paulo, Brazil,
2Universidade Federal de São João del Rei, São João del Rei, Brazil

Background: The palliative care aim to assist patients and families that have to face the impossibility of cure and irreversibility of the clinical condition. The end of life care can be offered in various contexts, such as hospital, hospices and the patient’s own home. Often, the care in the hospital can not ensure the needs of the patient and family, since they are in a different socio-cultural environment. The aim of this study was to understand the perception of nurses from the Brazilian health care system in relation to palliative care in the home.

Methods: A descriptive, exploratory study with a qualitative approach conducted with nine nurses from the Brazilian health care system. Semi-structured interviews were conducted and data were subjected to content analysis.

Results: The various dimensions of care in the home context were identified, along with the performance and limitations of nurses in the care of the patient and his family at end of life. The capacity to establish a bond, by the proximity to people who receive their care, is a remarkable point of the action of these nurses with patients and families in end of life situations. Also, nurses believe they have a very important role in advocating for the well-being of the family in end of life care. Nurses ensure relatives are sufficiently informed to discuss the patient’s condition with the doctors during their daily care.

Discussion: Nurses share information and check understanding in order for relatives to better articulate their
concerns and wishes to doctors and effectively take part in any discussions about the patient. The nurses consider the patient and his family as the unit of care, they have the opportunity to share solidarity, experiences and learning, not only from a professional standpoint, but above all, from a human one.

Abstract number: PO100
Abstract type: Print Only

„Different Mentality, Different Culture - But Are Individual Like Every Patient” - Palliative Care for Patients with Turkish and Arabic Migration Background in Germany

Jansky M., Friedemann N.
University Medical Center Göttingen, Clinic for Palliative Medicine, Göttingen, Germany

Introduction: People with migration background are a vulnerable patient group facing various barriers to health care and difficulties in care. Studies about palliative care for patients with migration background in Germany do not exist.

Aim: We aim to assess care related issues for patients with Turkish and Arabic background from the health care professionals (HCP) perspective in specialized palliative care.

Method: All HCPs in specialized palliative care in Lower Saxony, Germany, were invited to take part. Data was collected through a self-developed questionnaire with open and closed questions. Open questions were analyzed using content analysis; closed questions were analyzed descriptively with SPSS.

Results: Participants (n = 55) were mostly female nurses between 40 and 60 years old. Only one team had a member with migration background. One fifth had not cared for a patient with migration background in the last 12 month (19.6 %, mean: 3.7 patients). Most stated to care for fewer patients than they assumed need palliative care (84.6 %). They attributed this to patients’ extensive social networks and their cultural background, or to language problems and insufficient knowledge about palliative care. One third expected cultural differences, their lack of knowledge and resulting uncertainty to be a challenge in providing palliative care for this patient group. Further challenges included difficulties in communication and dealing with the family. Most institutions had not implemented guidelines (80.0 %) and only 29.1 % had access to resources like interpreters or education.

Conclusion: People with Turkish or Arabic migration background are underrepresented in both staff and patients. HCPs perceive those patients as culturally different and lack resources to care for them adequately. Further research should emphasize on patients’ and families’ needs for palliative care, improving access if necessary, as well as implementation of helpful resources for HCPs.

Abstract number: PO101
Abstract type: Print Only

An Online Survey to Prioritize Research Questions in an Analytic Framework Derived from the SUNDIPS (Studies to Understand Delirium in Palliative Settings) Program

Lawlor P.G.1, Ansari M.2, Davis D.3, Hosie A.4, Momoli F.5, Kanji S.2, Bush S.3

1Bruyere Continuing Care, Division of Palliative Care, Dept of Medicine, Dept of Epidemiology and Community Medicine, University of Ottawa, Bruyere and Ottawa Hospital Research Institute, Palliative Medicine, Ottawa, ON, Canada, 2Ottawa Hospital Research Institute, Ottawa, ON, Canada, 3University of Cambridge, Institute of Public Health, Cambridge, United Kingdom, 4University of Notre Dame, Sydney, Australia, 5Bruyere Continuing Care - Palliative Care Unit, Division of Palliative Care, University of Ottawa, Bruyere Research Institute, Ottawa, ON, Canada

Context: SUNDIPS generated research questions relate to epidemiology (Q1-9), management (Q10-14) and outcome prediction models (Q15-18) of delirium in Palliative Care (PC) settings.

Aims: To prioritize 18 pre-specified research questions arising in the SUNDIPS analytic framework for further research on delirium in PC settings.

Methods: We used multidisciplinary input from delirium researchers and knowledge users at an international delirium study planning (SUNDIPS) meeting, literature searches, and epidemiological expertise to generate research questions and map them onto an analytic framework for clinical care in PC settings. An online survey of meeting participants was conducted to assign an importance level to answering either a research question or any one question in a domain: Q1, Q2-5, Q6-7, Q8-9, Q10-14, and Q15-18, respectively. The importance was rated 0=N/A, not applicable/ unable to rate, 1=not at all, 2=slightly, 3=moderately, 4=very, and 5=extremely important. The criteria used to rate importance were

(A) need to determine the burden and impact of disease in relation to delirium;
(B) need to inform decisions in clinical practice where there is controversy or uncertainty;
(C) need to estimate the economic cost and/or resource utilization associated with delirium;
(D) known need to address this knowledge deficit; and
(E) potential impact of the answer on clinical practice.

Results: 28/30 (93%) participants rated the research domains and their associated question/s according to the 5
criteria of importance (A-E), generating an aggregate total of 140 ratings per domain. In summary, for each research domain or question(s), a posthoc created combination category of either “very important or extremely important” represented the modal response, and ranged from 80.7% for Q10-14 to 56.5% for Q6-7.

Conclusions: Our survey confirmed the importance of questions identified in the SUNDIPS analytic framework of delirium research.

Abstract number: PO102
Abstract type: Print Only

Advanced Lung Cancer. Poorer Prognosis as Functional Status Declines

Barallat Gimeno E.1, Canal-Sotelo J.1, Nabal Vicuña M.2, Trujillano Cabello J.3

1UFISS-CP HUAV-GSS, Lleida, Spain, 2UFISS-CP HUAV, Lleida, Spain, 3University of Lleida, Basic Sciences, Lleida, Spain

Introduction: Lung cancer is the most common cancer worldwide and is associated with significant mortality. Even if in recent years there have been important developments in the techniques to diagnose and in the treatment options available lung cancer patients still face poor survival.

Methods and population: 76 consecutive advanced lung cancer patients, were recruited between June and September 2011. Data related to age, gender, diagnosis and mental status were obtained. Functional status was assessed by the use of the Barthel test (BT), Karnofsky Performance Scale (KPS) and the Palliative Performance Scale version 2 (PPSv2). Prospectively the date of death was recorded.

A 30-days survival analysis and a classification tree based on the CHAID (Chi-squared Automatic Interaction Detector) methodology were performed in order to identify which variables were associated with the 30-days survival interval.

Results: Male 54 (71%), Mean of age 70 years (female 56 years). No statistical differences were observed when comparing 30 day survival with age (p=0.566) or gender (p=0.773) . Kaplan Meyer survival curve showed significative statistical differences when comparing 30-day survival with PPSv2 subgroups (p=0.000), with KPS (p=0.000) and BT (p=0.000).

The BT ≤ 20 in this group of advanced lung cancer patients is a sensible prognostic factor with a survival rate of 14.3% at 30 days. When BT ≤ 20 is associated with age > 70 years, survival falls to a 0%.

Conclusions: In our population the average of 30-days survival is 65.8% being the association between BT and age a good indicator of bad prognostic at 30 days. However, the low number of patients included in this study limits the results.

Abstract number: PO103
Abstract type: Print Only

Integration of Medical Oncology and Palliative Care Procedures in Various Institutional and Economical Settings - Validation Process of Perceived Key Intervention-palliative Cancer Care

Mosoiu D.1,2, Predoiu O.3, Nedelcu M.3, Magaya-Kalbermatten N.4, Strasser F.4

1Hospice Casa Sperantei, Educatie, Brasov, Romania, 2Transylvania University, Medical Faculty, Brasov, Romania, 3Hospice Casa Sperantei, Brasov, Romania, 4Cantonal Hospital, St.Gallen, Switzerland

In the care of incurable cancer patients medical oncologists play a sentinel role both in tumour directed treatment and in identifying palliative care needs and offering appropriate treatment. The aim of IZERZO project (5 Romanian and 1 Swiss partner) is to develop tailored educational & clinical interventions and test their feasibility for cancer patients in oncological settings. One tool used in the project is the Perceived Key Intervention-Palliative Cancer Care.

Aim: To have a validated Romanian and German version available for Perceived Key Intervention-Palliative Cancer Care (with three subversions Patient Perceived, Family Perceived and Staff Perceived KI-PCC).

Methods: The tool was developed by the research team in English and is looking at perceived interventions concerning illness understanding, symptom management, decision making, spiritual care, professional and family support. Special attention was given to formulation of questions to accomodate the non-disclosure culture widely spread in oncology settings in Romania. Forward&backward translations were done by health care and non-health care professionals. Expert review was performed with the project consortium team members. Cognitive debriefing: focus groups with patients and staff were conducted and individual meetings with family members. Proof reading was done by sending the validation reports to Swiss partner responsible of this step from validation process.

Results: KI-PCC tool was validated and agreed to be used as part of initial research stage in the project to design a reality map for care of cancer patients in oncology settings. Patients, family members and staff appreciate the tool as improving the quality of care. 3 subscales are available in Romanian and German.

Abstract number: PO104
Abstract type: Print Only

The Occupational Therapy Process for People Living with a Life-limiting Illness

Faddy K.A., Bye R.A., Cook C.
University of Western Sydney, School of Science and Health, Occupational Therapy, Penrith, Australia

**Introduction:** Occupational therapists are part of the multi-disciplinary healthcare team who treat people with a life-limiting illness in Australia. However, there is limited evidence to guide their assessment and treatment processes with people with a life-limiting illness, leaving therapists with a lack of clarity regarding the scope of their practice and the depth of their role in this area. Further investigation is required to first identify the scope of occupational therapy practice in this clinical area, and to secondly improve therapists’ knowledge of their scope of practice in order to provide quality occupational therapy care at the end-of-life.

**Aim:** This study aimed to identify the occupational therapy processes implemented when working with people with a life-limiting illness.

**Methods:** A national survey of Australian occupational therapists working with people with a life-limiting illness was completed. Recruitment occurred over during April 2012, using a purposive, snowball sampling technique. Descriptive data was analysed using SPSS, while qualitative analysis was completed using grounded theory methods.

**Results:** Findings state the occupational therapy processes of 144 occupational therapists working with people with life-limiting illnesses. Referral, assessment, goal setting, intervention, outcome measurement, and follow-up practices are discussed and establish the current scope of practice for occupational therapists working in this area. Findings also report therapists’ perceptions of their role, the most common goals set with this client group, and the clinical reasoning behind their assessment and intervention decisions.

**Conclusion:** Findings provide therapists with the occupational therapy processes used by therapists when working with people with life-limiting illnesses. These findings have implications to the expansion of the occupational therapy role with this client group at national and international levels.

**Abstract number:** PO105

**Abstract type:** Print Only

**The Move from Home to Hospice Care: A Retrospective Analysis of Carer Experience**

*Dunsmore-Dawson J.A., Rodriguez A.M., King N.*

University of Huddersfield, Behavioural Sciences, Huddersfield, United Kingdom

**Aims and design:** The move from home to hospice care has been identified as a juncture in caring and a significant life event for the informal carer, that impinges on them in idiosyncratic ways. The aim of the current study was to illuminate the salient features of the move into hospice care from home care, from the carer’s perspective. We explored the experience of seven different spousal carers of patients who received end of life care in two hospices. Influenced by the work of van Manen, this research utilised interpretive phenomenology, with data analysed using the Template Analysis approach.

**Findings:** Findings suggest that carers underwent important changes to their ‘being in the world’ during the accommodation and restructuring of their position in the new caring arena. Their appraisals of the meaning of ‘home’ were challenged by illness as well as the change in caring setting, as were their ways of thinking with regard to the rhythm, tempo and value of the time. Our analysis characterised their experience as one of the “slipperiness of time”. An important observation was that the experiential trajectories of carers - and their associated needs - were not necessarily in parallel with the illness trajectories of patients. For example, where carers had family holiday plans that were dashed due to the sudden realisation of remaining time, or where carers wanted to maintain ownership of care and struggled relinquishing roles once partners were in the hospice setting.

**Conclusion:** It is important that service providers do not assume that carer experiences can be framed simply in the context of the patient’s illness trajectory. Future research needs to examine the dynamics and complexities of carer-patient relationships in the move from home to hospice care. Longitudinal studies following dyads from initial contact with the hospice through to admission and beyond would be particularly valuable.

**Abstract number:** PO106

**Abstract type:** Print Only

**Concept of Euthanasia, Are All Doctors Using the Term with the Same Meaning?**

*Cuervo Pinna M.A.*

SES, Palliative Care, Badajoz, Spain

**Background and objectives:** The decriminalization of euthanasia (E) and physician assisted suicide (SMA) generate an ongoing debate. The terminological confusion is one of the main difficulties of agreeing on medical practices. We analyze whether the terms of E and SMA are used with the same meaning by doctors.

**Materials and methods:** We conducted a qualitative research through focus groups (FG) of physicians. We carried out two GF, and we did not proceed to a third party by objectifying saturation. The sessions were tape recorded and transcribed by two experts in qualitative methodology. We used the Atlas.ti software. We were advised by the Group “Health Care at the end of life” of the WTO.
**Results:** It was developed a concept map, after analysis of categories and codes. The terminological confusion lays in:

1. The mixture of etymological, functional and social concepts,
2. not to eradicate the term “Passive” E,
3. the equation of E with SMA,
4. the confusion with the equivalent “wish to hasten death” and
5. the difficulty of differentiating sedation with E.

There was consensus on some aspects:

(a) Full voluntariness,
(b) the condition of terminal illness and
(c) the condition of unbearable symptoms.

**Conclusions:** Conceptual variability persists regarding the E, especially striking to observe the survival of the concept of passive euthanasia. It seems convenient to have a common language to assign a precise meaning to words to help doctors in their practice.

**Abstract number:** PO107
**Abstract type:** Print Only

**Nurse Preference for Spiritual Well-being Assessment Tools**

*Windon G.*

Nightingale House Hospice, Chaplaincy, Wrexham, United Kingdom

Good spiritual care is essential to good patient care, yet the assessment of spiritual well-being has always been a balance between trying to tie down something many regard as indefinable in a meaningful way and the needs of the healthcare profession to have evidence based practice.

Despite a large number of spiritual well-being assessment tools existing and being written about, no published tool yet exists which is in general use in the UK for the initial assessment of spiritual well-being in patients by healthcare staff who are not specialists in spiritual care.

Research has shown that nurses believe spirituality and the spiritual care of patients to be important, but it has been shown that in the United Kingdom very few nurses use any spiritual well-being assessment tool. This study looks at why nurses do not use spiritual well-being assessment tools by asking a sample of nurses to fill in two such tools and then comment on how they found them. A total of 21 nurses completed the questionnaires and seven were interviewed. The two instruments used were the Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being Scale, which is a tool originally aimed at the research context and is validated, the other is a new tool devised for the purpose, the Spiritual Well-being Assessment Tool.

A consideration in this study is how and if the nurses psychological type profile affects their preference towards spiritual well-being assessment tools and how the psychological type profile of nurses in the study compares with that of the general United Kingdom population.

Results of the study conclude that nurses would value spiritual well-being assessment tools, but are wary of them, perhaps because of their own psychological preferences. The Spiritual Well-being Assessment Tool is found to have promise as a tool for the initial assessment of spiritual well-being to be used by healthcare staff.

**Abstract number:** PO108
**Abstract type:** Print Only

**Pediatric Palliative Care at Home: Parental Perceptions**

*Pinho-Reis C.*, *Capelas M.L.*, *Coelho P.*

1 The Catholic University of Portugal, Institute of Health Sciences, Porto, Portugal, 2 The Catholic University of Portugal, Institute of Health Sciences, Lisboa, Portugal

**Background:** According to the World Health Organization, Pediatric Palliative Care (PPC) is the active total care of the child’s body, mind and spirit and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Although PPC can be provided in every location where the child is, parents very often choose home as the best place for their child to receive end-of-life care.

**Aim:** To know the state of the art regarding to parental perceptions about pediatric palliative care at home.

**Methods:** Review of the literature published in the period 2003-2013, with research in PUBMED, MEDLINE, CINAHL, ISI and Academic Search Complete with abstract, references and full text available. The keywords used were “nutrition”, “palliative care”, “parents” and “children”. Twenty-four articles were found and analyzed.

**Results:** Analysis indicated the concept of palliative care is still poorly understood by parents. What affects parents the most is the withholding/ withodrawing artificial nutrition/ hydration and the place of death. Parents are also emotionally, financially and physically affected by the burden of caring for children with life-threatening or chronic conditions requiring complex care at home. Parents indicated the need for clear and honest information about their child’s condition and prognosis in order to play an active role in decision-making. Parents also required access to, and advice from, multidisciplinary health professionals when caring for their child at home. Despite of all, parents preferred to care for their child at home...
wherever possible throughout the palliative care trajectory of their child’s disease.

**Conclusion:** Care for children and their families should be coordinated by a multidisciplinary team and integrated with the treating at home in order to give holistic care, focused on the needs of children and parents, thus providing a dignified death.

**Abstract number:** PO109
**Abstract type:** Print Only

**Outcome Quality of Pain Management on a Palliative Care Unit as Result of a Certification Process**

Hofmann G.1, Klammer M.1, Jahn-Kuch D.1, Bitsche S.1, Edelsbrunner M.1, Verebes J.1, Siegl A.1, Kuba S.1, Sandner-Kiesling A.1, Samonigg H.1

1Onology Division and Palliative Care Unit, Department of Internal Medicine, Medical University of Graz, Graz, Austria, 2Department of Anesthesiology, Medical University of Graz, Graz, Austria

**Aims:** It is well known that pain is one of the leading symptoms in palliative care units (PCUs). To improve pain control in the patients of our PCU, we participated in a certification program regarding implementation of standards in documentation, assessment and treatment of pain as the first PCU in the german-speaking world. It was possible to improve the process quality and structural quality regarding pain assessment, documentation and time to treatment leading to an earlier and better pain control for patients. But nevertheless, the outcome quality of these interventions had to be investigated. So we did the following patient survey.

**Methods:** From 29.6.-4.7.2012, 33 patients at our PCU were included in this investigation. A modified questionnaire including 11 items regarding intensity and control of pain, efficacy of therapy as well as learning the Ceytcom e.V. datacenter and compared to the results of other conventional wards that had finished the certification process.

**Results:** 14 female and 19 male subjects took part in this survey. Mean age was 68 (range 57.2-80.3). Pain at rest (NRS) was indicated mean 1.8 (range 0-3.5), pain on movement 3.3 (range 1.0-5.6) and maximum pain 4.8 (range 2.0-7.5). Efficacy of pain therapy was evaluated with a school grading system from 1-5, where 1 was excellent and 5 no efficacy. The patients rated mean 1.8 (1.0-3.0). Level of information and satisfaction of the patients was satisfying and very good in comparison to conventional wards, as well.

**Conclusion:** It could be demonstrated that scientific surveys about the quality of output regarding pain management in patients at PCUs are possible and lead to valid and comparable data. Since shortcomings in pain management occur in a lot of fields of medical care, the research of output quality in pain management remains a big issue and should be investigated further.

**Abstract number:** PO110
**Abstract type:** Print Only

**Combination of CysC and CRP May Be Useful Serum Markers to Predict Remaining Life Time in Palliative Care Patients**

Feldner K., Nibling G., Holdt L.M., Teupser D., Lorenz S.

Ludwig-Maximilians University Munich, Interdisciplinary Center for Palliative Care, Munich, Germany

**Aims:** Lack of clarity about palliative care patients’ prognoses poses a huge burden on both patient and family, and can lead to difficulties in advanced care planning. While certain serum markers were identified as valid predictors of life expectancy in elderly citizens, their significance in a palliative care setting is unknown. The aim of our study is to identify prognostic parameters of life expectancy in patients at a palliative care unit (PCU).

**Methods:** In this prospective study, blood samples were collected from 100 patients in our PCU from 08/01/2012 to 3/30/2013 regardless of the patients’ underlying disease. Survival time was recorded and serum analyses were performed for 43 patients who already passed away. Serum parameters include cathepsin s (CatS), interleukine 6 (Il6), cystatine c (CysC), CRP, blood count, LDH, LDL/HDL ratio and cholesterol. Clinical data comprise basic demographic data, Karnofsky performance score and cardiovascular risk factors. All parameters were correlated with survival time by means of univariate (uCR) and multivariate Cox regression models.

**Results:** A strong correlation was seen between survival time and serum levels of CysC, Il6 and CRP (uCR: all p < 0.001; Spearman-Rho: CysC: -0.540, CRP: -0.500, Il6: -0.539), but not CatS (uCR: p = 0.320). Clinical parameters including Karnofsky index did not reach statistical significance. In a multivariate cox regression model, CysC and CRP were significantly correlated with survival.

**Conclusion:** In summary, our results indicate that a combination of CysC and CRP may prove to be a valid combination of parameters to calculate life expectancy in palliative care patients considering clinical status. Furthermore, Il6 is a valid predictor on its own. Confirmation of these results in a prospective multi-center study holds out the prospect of a reliable tool for advanced care planning in palliative care patients.

**Supported by:** A Grant from the Friedrich-Baur-Stiftung (Altenkunstadt, GER).
**Abstract number:** PO111
**Abstract type:** Print Only

**Creation of a Tool for Withholding and Withdrawing Life-sustaining Treatment Decision in the Emergency Room**

David G.1, Chirac A.2, Rieg N.1, Schott A.-M.3, Bohe J.1, Carpentier F.4, Jacob X.1, Rhondali W.2,3, Filbet M.3

1Hospices Civils de Lyon, Lyon, France, 2Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 3Hospices Civils de Lyon, IMER, Lyon, France, 4Centre Hospitalier de Grenoble, Grenoble, France, 5MD Anderson Cancer Center, Palliative Care, Houston, TX, United States

**Background:** Active treatment withholding and withdrawing decisions in the emergency room (ER) must be taken collegially according to ethical and juridical statements. Specific tools can support this process and our main goal was to create and validate such a tool.

**Methods:** We created a first version of a tool to help for treatment withholding and withdrawing decisions inspired by similar documents from literature. Every items of this tool were then assessed by a group of experts (ER physicians and nurses) using the Delphi method to reach a consensus.

**Results:** Thirty-four experts from eleven ER (academic, regional centre) were included and participate to the first round and twenty-seven to the second round. From the eighty-two-item tool, sixty-five items reach a consensus during these two rounds and were kept to constitute the final version of the tool.

**Conclusion:** We have been able to create a tool to help for treatment withholding and withdrawing decisions adapted to the guidelines for end of life patients' management in the ER. This tool has been validated using a Delphi method by similar documents from literature. Every items of this tool were then assessed by a group of experts (ER physicians and nurses) using the Delphi method to reach a consensus.

**Abstract number:** PO112
**Abstract type:** Print Only

**PALLI-study: Development of an Instrument for the Identification of People with Intellectual Disabilities (ID) who Are in Need for Palliative Care**


1Erasmus MC, Intellectual Disability Medicine, Rotterdam, Netherlands, 2Radboud UMC, Expertise Center Palliative Care, Nijmegen, Netherlands, 3Radboud UMC, Healthcare for People with Intellectual Disabilities, Nijmegen, Netherlands

**Background:** According to the definition of the WHO, early identification of physical, psychosocial and spiritual problems is an important aspect of palliative care. Professional caregivers in the care of people with intellectual disabilities (ID) experience many barriers in the identification of people suffering from these problems. Quality of palliative care is expected to benefit greatly with early identification of needs.

**Purpose:** The purpose of the PALLI-study is to develop an instrument that will help caregivers to identify people with intellectual disabilities who are in need for palliative care.

**Study population:** 90 ID physicians and general practitioners (GPs) who provided medical care to a patient with ID who did not die suddenly will participate in a survey and interviews. Eight ID physicians, eight GPs, and eight palliative care specialists will participate in three focus groups.

**Study design:** A retrospective survey, interview and focus group study.

**Methods:** ID physicians and GPs filled in a retrospective questionnaire about the process of palliative care provided to a deceased patient with ID. Questions include the cause of death, signals en symptoms that led to the identification of palliative care needs and the barriers and facilitators for identification. Factors associated with early identification of palliative care needs will be identified. Twenty physicians will be interviewed. Items relevant for identification of palliative care needs will be generated from the survey and interviews, and the item list will be prioritised in the focus groups. The resulting draft identification instrument will be pilot tested for feasibility.

**Results and interpretation:** The final identification instrument will be presented at the conference.

**Funding:** This research has received funding from The Netherlands Organisation for Health Research and Development.

**Abstract number:** PO113
**Abstract type:** Print Only

**Myths, Challenges and Strategies to Improve the Evidence Base in Palliative Care**

Aoun S.1, Nekolaichuk C.2

1Curtin University, School of Nursing and Midwifery, Perth, Australia, 2University of Alberta, Edmonton, AB, Canada

The adoption of evidence-based hierarchies and research methods from other disciplines may not completely translate to complex palliative care settings. The heterogeneity of the palliative care population, complexity of clinical presentations and fluctuating health states present significant...
research challenges. The overall purpose of this presentation is to explore the debate about the use of current evidence-based approaches for conducting research, such as randomized controlled trials (RCTs) and other study designs, in palliative care. Three primary objectives are:

(a) to describe key myths about palliative care research;
(b) to highlight substantive challenges of conducting palliative care research, using case illustrations; and
(c) to propose specific strategies to address some of these challenges.

Myths about research in palliative care revolve around evidence hierarchies, sample heterogeneity, random assignment, participant burden and measurement issues.

Challenges arise because of the complex physical, psychological, existential and spiritual problems faced by patients, families and service providers. These challenges can be organized according to six general domains: patient, system/organization, context/setting, study design, research team and ethics. A number of approaches for dealing with challenges in conducting research fall into five separate domains: study design, sampling, conceptual, statistical, and measures and outcomes. Although RCTs have their place whenever possible, alternative designs may offer more feasible research protocols that can be successfully implemented in palliative care. Therefore, this presentation will highlight ‘outside the box’ approaches that would benefit both clinicians and researchers in the palliative care field. Ultimately, the selection of research designs is dependent on a clearly articulated research question, which drives the research process.

Abstract number: PO114
Abstract type: Print Only

Narrative Analysis of Dying with Motor Neurone Disease

O'Toole S.1, Kemple M.2

1University College Dublin, School of Nursing, Midwifery & Health Systems, Dublin, Ireland, 2UCD, Nursing, Dublin, Ireland

The aim of this study was to document the constructions of dying with MND provided by individuals who had witnessed the death of a relative with MND. A narrative approach was used to address the research question: “What are the constructions of dying with MND provided by family members who witnessed the death of a relative with MND?” A combined thematic, structural and performative analysis of narratives was conducted in order to describe the broad patterns within and across the sample and variations within individual narratives.

The constructions of dying with MND by those who witnessed the death of a relative with the disease, although characterised by plurality and diversity, were constructions of suffering. These narratives did not reveal accounts of choking or suffocation at the time of death. While almost all of the narratives related to accounts of dying quickly, peacefully and without pain, they were interwoven with experiences of suffering that occurred during the long trajectories of dying related by these research participants.

Suffering was theorised as being of both physical and iatrogenic in origin and was related to the intermeshed components of the physical manifestations of MND, the systems of health care, and to the individuals within these systems, upon which the dying person and his or her family were dependent. This study contributed to existing knowledge by focusing on relatives’ narratives of dying and, in doing so, revealed detailed constructions in which dying with MND was viewed as encompassing the entire disease trajectory.

Abstract number: PO115
Abstract type: Print Only

Single Point Organization: Coordinates Resources and Professionals to Save Money and Yields High Levels of PC Activity

Garcia-Baquero Merino M.T.1, Pinedo F.2, Hernandez J.3

1Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 2Subdirección General de Servicios de Sistemas de Información, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain

Aims: Single coordination of Specialist Palliative Care (SPC) services is said to reduce budgets, optimize benefits to patients, establish better communication within professionals and increase PC related activity and enhance society’s PC perceptions.

Method: The first PC service in this region was set in 1990, over the following 15 years, services slowly increased until 2005 when the first Strategic Plan came into being. The increase in professionals and teams was greater than ever. In 2008 the Regional PC Coordinator was appointed.

General SPC activity increased straightaway: publications; professional meetings; consensus documents; new organizative and assistential models; non professional meetings round PC.

More important, numbers of interdisciplinary training courses increased to train thousands of generalists and the importance of SPC extended throughout the hospitals, health centers and Nursing Homes in the area.
All data related to professional meetings, training sessions, research and clinical activity were collected from the weekly Palliative Care Regional Coordination Office data base.

**Results:** The study demonstrates the enormous amount of data and activity that can be collected to further PC and how rigorous management of data relating to events, meetings, workshops, lectures, etc over five year help configure the picture of regional PC development.

**Conclusions:** A central point of organization for SPC in a large, populated region helped extend pc services, and activity. The most significant change was doubtless the radical change in society perceptions and its ease to accept PC not as a culture of death but as a philosophy of care and being with those suffering.

**Abstract number:** PO116
**Abstract type:** Print Only

**How to Implement Palliative Care in Nursery Homes: Report on a Pilot Project in Four Institutions in Essen, Germany**

_Kloke M., Degner M._

Kliniken Essen-Mitte, Department for Palliative Care, Essen, Germany

**Background:** There is strong evidence form the literature that there is a dramatic underdiagnosing and undertreatment of the palliative care needs of inhabitants of nursing homes. This can be attributed to the deficits in the palliative education of caregivers as well as to the insufficient concepts of delivering palliative care to non-cancer geriatric patients.

**Aim:** Development and analyses of a concept of implementing palliative care in nursing homes being piloted in four nursing homes with 860 inhabitants.

**Methods:** Description of the elements and tools of the implementation process. Defining a catalogue of quality indicators for the realization of palliative care in the homes.

**Results:** The implementation process encompasses several elements: in-house trainings, on the job trainings (bedside teaching), curricular education as well as structural and organizational measurements (e. g. adapting the documentation system to particular palliative care requirements). The existence of the so-called geriatric palliative care team consisting of trained palliative care nurses and a palliative care appointee in each nursery home seems to be the key of sustainability.

**Conclusion:** A prerequisite of a successful implementation of palliative care in nursery homes is a proved concept and strategy. Education of the staff and adaption of structure and organization to palliative care requirements are key elements.

**Abstract number:** PO117
**Abstract type:** Print Only

**Correlation between Spirituallity and Coping Responses of Patient with Terminal Illness in RSUP Dr. Sardjito Yogyakarta**

_Hukum A.J.A., Rahmat I., Suseno P._

¹Universitas Gadjah Mada, Nursing Programme, Yogyakarta, Indonesia, ²Universitas Gadjah Mada, Medical Programme, Yogyakarta, Indonesia

**Background:** Patients terminal experiencing physical and psychological problems. The patient suffered physical damage in the form of damage to body functions and cause great pain. The health of patients who declined very rapidly, severe pain that is felt increasingly serious psychological stress in patients. Terminal patients had lost his source of strength to rise. Meanwhile, the spiritual is the most important form of supportive, as much as 85.7% of patients said that the spiritual is an essential requirement.

**Purpose:** Knowing the relationship between the level of spiritual and coping responses in patients with terminal illness in the hospital of. Dr. Sardjito Yogyakarta.

**Methods:** The study used cross sectional method. Sampling method in this study is purposive sampling with the sample of 37 respondents. Spiritual level of the respondents assessed using instruments Spirituality Index of Well Being Scale while the coping responses of respondents was measured using the Brief Cope Scale, accumulate data were analyzed using chi square test and contingency coefficient.

**Results:** The results of the analysis using chi square test between the spiritual level with the coping responses generate a significance value (p) of 0, 036. Meanwhile, the results of the analysis using contingency coefficient indicates the correlation (r) of 0.325. This suggests that there is a significant association between the level of spiritual coping response (p = 0.036) with a relatively low level of relationship (r = 0.325).

**Conclusion:** There was a significant association between levels of spirituality and coping responses in terminal patient with low level of correlation.

**Keyword:** Patient terminal, Spirituality, Coping

**Abstract number:** PO118
**Abstract type:** Print Only

**Evaluation of the Efficacy of Psychosocial Teams’ Intervention: A Randomized, Open, Controlled, Multicentre Phase III Study**

_Mateo D., Martínez-Muñoz M., Limonero J.T., Maté J., González-Barboteo J., Gil F., Buisán M., Pascual V., Gómez-Batiste X._

¹Catalan Institute of Oncology, University of Vic, The ‘QUALY’ Observatory, WHO Collaborating Centre
Research aims: To evaluate the efficacy of the psychosocial teams’ intervention within the Program for the Comprehensive Care of Persons with Advanced Diseases from “la Caixa” Foundation (PCCPAD-CF) on levels of emotional distress in people with advanced disease and moderate or severe emotional distress as measured by the Detection of Emotional Distress (DED) scale.

Study population: People with advanced disease and moderate (DED<9) or severe (DED≥13) emotional distress, candidates to be attended by the PCCPAD-CF, being ≥ 18 years old and giving informed consent.

Study design and methods: A randomized, open, controlled, multicentre, phase III study. It is planned to randomize 80 subjects in a 1:1 ratio to Arm A: psychosocial intervention every 3 days (days +2 and +6) during a period of 7 days in combination with conventional intervention or Arm B: conventional intervention. Psychosocial intervention will consists of attending subject’s emotional distress through psychotherapeutic techniques depending on the needs of each patient. Conventional intervention will consists of non-specific psychosocial intervention offered by healthcare carers. DED scale will be administered to all enrolled subjects at days +2 and +6.

Method of statistical analysis: Primary efficacy endpoint is the proportion of subjects with DED≤9 at 7 days after completed intervention. Test Z for two proportions will be used to determine if hypothetic difference between population proportions differs significantly from that observed in the samples. An interim analysis of data will occur when reached half the planned recruitment (40 subjects).

Results: Recruitment currently ongoing. It is expected that results from the interim analysis will be available in June 2014

Conclusion: A study to evaluate efficacy of psychosocial teams’ intervention within PCCPAD-CF has been designed and implemented.

Source of funding: This project is developed within the PCCPAD-CF, Spain

Abstract number: PO120
Abstract type: Print Only

Improving End of Life Care for Patients with Dementia

Whitfield A.M.1, Cross G.2, Parkes N.2

1Blackpool Teaching Hospitals NHS Foundation Trust, Palliative Medicine, Blackpool, United Kingdom, 2Trinity Hospice, Blackpool, United Kingdom

Introduction: Dementia is predominantly a disease of later life but there are at least 15 000 people under 65yrs who have the illness. Symptom relief is often missed as these patients are unable to communicate effectively.
Aims of the project:
- Improve the quality of end of life care for people who are diagnosed with dementia admitted to hospital
- Increase the awareness of staff caring for these patients
- Promote advance care planning for people with dementia
- Support families of people suffering from dementia with decision making

Methods: A flow chart was designed and coloured to reflect the local end of life care model. There was close liaison with trust staff about developments in dementia care within the acute setting and teaching materials were developed to train staff on caring for patients with dementia in their last days of life.

Results: The acute trust collated results from the dementia screening tool used to assess every patient over 75yrs; it demonstrated an increase in knowledge for staff in trust to recognise dementia as a terminal disease.

Discussion: The project aims to support patients with dementia from diagnosis to bereavement. The work was a collaboration between the acute trust and local hospice services. Work streams were formed to develop care pathways, integrated working and shared learning. The trust adopted the Butterfly Scheme which the CNS team promote when visiting patients with dementia and raise awareness of importance of advanced care planning for these patients.

Conclusion: Improving the knowledge of staff around caring for patients that are dying who have dementia improves their ability to effectively observe and manage symptoms, improves the quality of care and job satisfaction whilst improving outcomes and relieving distress for patients and families.

Abstract number: PO121
Abstract type: Print Only

Palliative Care and End of Life Care in Residential Care Centers

De Vlieger T., Leuris I., Wens J.

1Palliative Network Antwerp, Antwerp, Belgium, 2University of Antwerp, Antwerp, Belgium

Aim: To explore the actual palliative care (PC) organization in residential care centers (RCCs), aiming to improve collaboration and support with the local palliative network.

Method: Survey with 32 multiple choice questions sent out to 80 RCCs in the Antwerp region. Three different stakeholders per RCC (coordinating physician [cor], policy coordinator [pol] and PC reference person [ref]) were asked to fill in the questionnaire.

Results: 58 RCCs (73%) responded yielding 134 surveys itemizing 37% pol, 35% ref and 28% cor respondents.

Though most RCCs claim to have a vision (79%) or policy text (90%) concerning PC, it is less clear if residents and families are familiar with it. Where almost all RCCs (93%) have a trained ref in PC, only in 44% of the RCCs a tangible job description for this ref is present. Almost half of RCCs (45%) state that most of their floor staff had some education in PC. Though most of cor (79%) had some additional education in PC, 31% of the pol and 32% of the ref did not know this. Anyway, 84% of cor are involved in making the RCC’s palliative policy.

Where 75% of RCCs claim they have conversations about advanced care planning with their residents, a guideline concerning palliative sedation or euthanasia is often lacking.

There’s a great trust in knowledge, experience and expertise of the RCC’s staff in supporting terminal ill residents and their families. Though, support from the palliative network is often (82%) required, specifically regarding symptom control, education of personnel, advanced care planning and reasoning with the treating physicians.

Conclusion: Though positive scores on support that is given to residents and families, deficits in policy and guidance concerning palliative sedation and euthanasia are mentioned as most problematic in RCCs. Working side by side with the palliative network seems more important than ever for the RCCs to assure the best possible care towards palliative and terminal residents and their families.

Abstract number: PO122
Abstract type: Print Only

PROLONG: Identification of Patients with COPD with a Poor Prognosis and Implementation of Proactive Palliative Care (Study Protocol)

Duenk R.G., Engels Y., Heijdra Y., Verhagen C., Dekhuijzen P.N.R., Vissers K.C.P.

1Radboud University Nijmegen Medical Centre (RUNMC), Anesthesiology, Pain and Palliative Care, Nijmegen, Netherlands, 2Radboud University Nijmegen Medical Centre (RUNMC), Lung Diseases, Nijmegen, Netherlands

Background: Proactive palliative care is not very common for patients with Chronic Obstructive Pulmonary Disease (COPD). Important barriers in the provision of proactive palliative care for patients with COPD are: the identification of patients who have a poor prognosis and the organisation of proactive palliative care dedicated to the COPD patient. Based on recent literature a set of indicators is developed to identify patients hospitalized for acute exacerbation COPD (AECOPD) who are at risk for post-discharge mortality. Once identified a multi disciplinary approach to proactive...
palliative care by a specialized palliative care team will be offered.

**Objective:** The objective of the PROLONG study is:

1) to assess the discriminating power of a set of indicators to start proactive palliative care for patients with COPD;
2) to assess the effects of proactive palliative care for patients with COPD on the wellbeing of these patients and their informal caregivers.

**Study design:** A controlled study will be performed with hospital as cluster. In total 6 hospitals will participate, 3 intervention hospitals and 3 control hospitals. The study population consists of patients with an AECOPD admitted to a hospital and their informal caregivers. All patients receive standard care (usual care) by the pulmonary team. Only patients in the intervention hospitals scoring positive on two or more criteria from the set of indicators for bad prognosis will also meet with a specialized palliative care team on a regular base.

**Expected results:** We expect the set of indicators to predict higher mortality within 1 year for patients hospitalized for AECOPD. We also expect that proactive palliative care for these patients with COPD may: increase the quality of life, decrease the number and length of acute hospital admissions and ICU admissions, prolong survival and decrease the level of overburdening of their informal caregivers.

**Source of funding:** ZonMw, the Netherlands

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**Interventional Therapy for Post Mastectomy Pain Syndrome**

Góraj E.J.¹, Tchórzewska-Korba H.²

¹Cancer Center Institute, Palliative Care, Warsaw, Poland, ²Cancer Center Institute, Physical Therapy, Warsaw, Poland

**Introduction:** Post mastectomy pain syndrome (PMPs) is caused by irritation of intercostobrachial nerve and cutaneous branch of T1-2 (pain and filling disturbances in the area of axilla, medial part of arm and chest wall on the operated side). Worsen on shoulder movement.

**Goal:** Assessment of effectiveness of the interventional methods for PMPS.

**Method:** 130 patients treated in Department of Physical Medicine and Rehabilitation.

- Group I – 30 patient referred to the Pain Clinic (unsatisfactory results of rehabilitation). 12 arranged the visit.
- Group II (100) continued physiotherapy.

**Evaluation tools:** Modified McGill-Melzack questionnaire, Kułakowski and Mika test for mobility assessment, Numeric Rate Scale (NRS) pain assessment.

Localization of pain group: upper arm, scapula, shoulder, armpit, phantom pain.

Character of pain: sense of tightness, burning, dull, sudden, radiating sharp.

**Results:** In group I 12 decided for interventional treatment, 18 continue physiotherapy.

- Pain score before treatment was 5.7 after 3.0.
- Influence for everyday life in patient mild, 5 considerable degree.

Treatment: Termolesion of peripheral nerves -6, steroid to the epidural space- 3. Three patients preferred non-invasive methods.

Group II was taught to changed motor habits. The averaged pain score ≤NRS 5.

**Conclusion:**

1. Interventional therapy was more effective and should be applied more frequent and in early stage of pain as a part of a preventive strategy.
2. When pain score is ≤NRS6 it is sufficient to change motor habits to reduce pain.
3. One should increase the awareness of interventional technique treatment.

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**An Exploration of Sleep Quality in Patients with Life Limiting Illness**

Kemple M.E.¹, O’Toole S.²

¹University College Dublin, Nursing, Midwifery and Health Systems, Dublin, Ireland, ²University College Dublin, Nursing, Dublin, Ireland

Many chronic, life-limiting conditions increase the likelihood of sleep problems. Consistently, numerous research studies have demonstrated that sleep deprivation reduces wellbeing, alters emotional states, impairs both functional and cognitive activities negatively affecting performance.

The aim of this qualitative study was to explore patient’s quality of sleep in the community setting. Data from interviews with patients with life limiting conditions were thematically analysed. Tired but not sleepy emerged as the predominant lens through which patients dealt with their main concern which was the loss of feeling rested and refreshed. The loss of feeling rested and refreshed evoked three responses: Dealing with it, Framing in the context of individual illness and Finding solutions.

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**Considering the Scientific Nature of a Qualitative Research: The « Midazolam and Sedation Study » Example**
Leboul D.1, Peter J.-M.2, Royer V.3, Faivre-Chalon D.4, Aubry R.4, Guirmand F.1, Richard J.-F.1

1Maison Médicale Jeanne Garnier, Paris, France, 2Université Paris Descartes, Paris, France, 3Ecole des Hautes Etudes en Sciences Sociales, Paris, France, 4CHRU de Besançon, Besançon, France

Context: Because of their holistic approach to the ill person, Palliative Care (PC) practices are complex. This complexity stems from the theoretical and experiential knowledge from the various disciplines (medical, human and social sciences) that these practices require. The production of scientific knowledge is crucial for establishing the quality and legitimacy of these practices.

Objectives: The research process requires to:
- demonstrate the strict methodical and systematic approach to producing PC knowledge
- discuss the scientific nature of results.

Example: We draw on a study titled “Using midazolam and sedation in PC which paradox between care practice and the meaning of caring?” This qualitative study was undertaken with care and medical PC Unit teams in two locations. The purpose of the study was to understand how caregivers adopt the use of midazolam in care practices and how they appreciate its effects; and understand their representations of sedation in PC.

A rigorous research process: We will present: The research project (problem, conceptual framework, specific questions and research hypotheses).
- The methodology (strategy, survey and data analysis tools).

Science-like criteria: To determine the scientific nature of this study, we will examine the terms of interdisciplinary collaboration among researchers, how methodological approaches supplement each other, the confrontation of different data disciplinary analyses and the comparison of significant results in relation to criteria of reliability, credibility and transferability.

Conclusion: A research undertaking based on a comprehensive approach and a qualitative methodology can produce scientifically validated knowledge. In PC, this type of research contributes to improve the quality of care practices. It also contributes to the development of palliative medicine as a discipline and to its integration within academia in France.


Abstract number: PO126
Abstract type: Print Only

Development and National Use of a New Standardised and Validated Questionnaire for Bereaved Relatives’ Evaluation of Palliative Care

Nylandsted L.R.1, Neergaard M.A.2, Petersen M.A.1, Groenvold M.1,4

1Bispebjerg Hospital, The Research Unit, Department of Palliative Medicine, Copenhagen, Denmark, 2Aarhus University Hospital, The Palliative Team, Aarhus, Denmark, 3Aarhus University, Research Unit for General Practice, Aarhus, Denmark, 4Copenhagen University, Institute of Health Science, Department of Public Health, Section of Health Services Research, Copenhagen, Denmark

Background: According to the WHO definition the aim of palliative care is to reduce suffering and improve quality of life among patients with life-threatening illness and their families through assessment and treatment of symptoms and problems. There is a lack of solid knowledge about the quality of palliative care in the last part of life.

Aims:
1. To develop and validate a questionnaire for bereaved relatives’ evaluation of the quality of palliative care in the patient’s last months of life.
2. To investigate the relatives’ evaluation of the quality of palliative care in palliative teams/units and hospices.

Methods: Based on the literature, previously used questionnaires, and interviews with bereaved relatives and experts a list of topics relevant to the quality of palliative care was developed. This list was presented to 100 bereaved relatives who were asked to indicate which topics they found most important. A questionnaire will be chosen or constructed covering the most important topics in a way that allows an overall rating of the palliative trajectory as well as separate evaluation of the palliative care in hospitals, at home, by palliative teams/units, and hospice.

In 2014, the questionnaire will be sent to 1,500 bereaved relatives to patients who have been in contact with palliative teams/units or hospices during their last 3 months of life.

Conclusion: The project is expected to give significantly better possibilities for research-based evaluation of all aspects of palliative care during the last months of life. The study will identify the areas that need improvement and will identify risk groups consisting of those patients and relatives who do not obtain satisfactory results despite palliative care. This knowledge will be useful for future efforts to improve palliative care.

Abstract number: PO127
Abstract type: Print Only

Suffering Perceived by Patients from an Acute Palliative Care Unit (APCU)

Lacasta-Reverte M.A.1, Alonso A.2, Vilches Y.2, Diez E.2, Manrique T.3, Feliu M.2

1Ecole des Sciences Sociales, Paris, France, 2University Hospital, The Palliative Team, Aarhus, Denmark, 3Aarhus University, Research Unit for General Practice, Aarhus, Denmark, 4Copenhagen University, Institute of Health Science, Department of Public Health, Section of Health Services Research, Copenhagen, Denmark

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Abstract number: PO128
Abstract type: Print Only

Suffering Perceived by Patients from an Acute Palliative Care Unit (APCU)
Background: Some authors define suffering as a complex affective state, cognitive and negative feeling characterized by the sensation to feel threatened because of the depletion of personal and psychosocial resources that allow them to deal with this threat.

Objective: To assess the subjective perception of suffering in palliative patients and its relationship with other variables.

Method: Retrospective and descriptive research. Were used visual numerical scales (EVN 0-10) of suffering and effort, subjective perception scale of time (short, long and normal) and Hospital anxiety and depression scale (HADS). Statistical analysis: Spearman correlation coefficient, Mann-Whitney’s Test and Chi squared test.

Results: 144 palliative’s patients (93 male) participated in the study. The average age was 70 (SD=13). 73% of patients complained about strong-moderated suffering, 23% slight suffering, 76% strong moderated effort and 22% slight effort. 22% of patients showed anxiety symptoms and 52% depressive symptoms. For the 19%, the days were short, for the 35% days seemed to be normal and for the 46% days seemed to be long. 83% of patients felt to be helped by their family, 37% by religion/spirituality. Data show strong correlation between effort and suffering (p<0,01). There is no relation between suffering and time perception (p>0,05). There is a significant relation between effort and gender, as well as suffering and gender (p<0,05). There are significant differences between HADS-A/D pre-post in the APCU (p<0,001).

Conclusions: Palliative patients have a high suffering level, depressive symptoms and they need to do a strong effort to cope with their current clinical situation. Women show stronger suffering and effort than men. The main patients’ cope resource is their family. The effort variable seems to be an important and useful indicator to assess the suffering in clinical environment.

Abstract number: PO128
Abstract type: Print Only

“We Can’t Do it without you...” Using A Theoretical Model to Explore the Relationship between Volunteering and Independent Hospice Sustainability in the UK

Scott R.C.
Researcher and Independent Consultant, Dunblane, United Kingdom

Volunteers are often told that their hospice would not be able to continue without them. This is the first study of its kind to examine the relationship between volunteering and organisational sustainability. A new theoretical model was developed and tested in independent hospices in the UK to explore the impact of volunteering on four key organisational sustainability factors: governance, service delivery, hospice economy and community engagement.

Purpose of the research: The purpose of this research was to test the Theoretical Model of Organisational Sustainability by: exploring the influence of volunteers on four key organisational sustainability factors: governance, service delivery, hospice economy, and community engagement; exploring how volunteering is understood by senior staff, volunteers and trustees in hospices; considering the relationship between volunteering and independent hospice sustainability in the UK.

Method: A self-administered online survey was sent to hospices across the UK. Three separate questionnaires were developed one for senior staff, one for trustees, and one for volunteers. Questionnaires contained both Likert Scale and free text questions. 32 hospices took part with responses from 286 respondents.

Findings:

§ Hospices are dependent on volunteers for sustainability
§ Volunteers are viewed recognised as a strategic resource
§ Volunteers are crucial to the delivery and quality of services
§ Volunteers seen as integral to the professional team
§ Volunteers are vital to the hospice economy
§ Volunteers help to reduce the fears associated with hospices
§ Volunteers help to reduce taboos about death, dying and bereavement
§ Volunteers perceive their involvement differently to senior staff and volunteers

Conclusions: This study has demonstrated for the first time the strategic significance of volunteering to independent hospices in the UK and may also apply to similarly structured organisations in other countries.

Abstract number: PO129
Abstract type: Print Only

Decreased QOL with CYP 2D6 Poor Metabolizer or Intermediate Metabolizer in Japanese Cancer Patients by Duloxetine Administration for Chemotherapy Induced Peripheral Neuropathy

Takigawa C., Kondou C., Mori S., Suzuki T., Sato M.
KKR Sapporo Medical Center, Palliative Medicine, Sapporo, Japan

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§ Volunteers perceive their involvement differently to senior staff and volunteers

Conclusions: This study has demonstrated for the first time the strategic significance of volunteering to independent hospices in the UK and may also apply to similarly structured organisations in other countries.
**Background:** Many guidelines and new RCTs recommend the administration of anticonvulsants (gabapentin) and/or antidepressants (duloxetine) for pharmacologic management of chemotherapy induced peripheral neuropathy (CIPN). When cancer patients are in depressive status, we prescribe antidepressants as first line of treatment. Most of antidepressants are metabolized by Cytochrome p450 oxidase (CYP). Duloxetine is metabolized by CYP2D6. CYP2D6 poor metabolizer is 10%, intermediate metabolizer is 40% in Japanese population. We experienced decreased QOL due to serious sleepiness after administration of duloxetine.

**Aim:** Side effects and efficacy of duloxetine in cancer patients were investigated at single palliative care center.

**Methods:** From Oct.1 2012 to Aug31 2013, patients records were investigated followed factors.

1. Number (No.) of duloxetine prescribed patients.
2. No. of cancer patients who prescribed duloxetine.
3. No. of duloxetine administration in CIPN patients
4. Prescriptions in detail
5. Side effects from duloxetine administration
6. Genetic investigations of CYP2D6 in patients who got serious side effects

**Results:** No. of patients who prescribed duloxetine were 50 patients. 7 of 50 were cancer patients. There were 5 CIPN patients who are administrated by duloxetine. 4 of 7 stopped administration of duloxetine because of serious sleepiness. The result of genetic investigation, there are 3 CYP2D6 intermediate metabolizers and 1 poor metabolizer. Prescriptions were over 7 kinds of drugs including opioids in 4 patients.

**Conclusion:** CYP2D6 is key enzyme in palliative care medication. Careful attentions are needed for using drugs metabolized CYP2D6 in Japanese patients.

**Abstract number:** PO131
**Abstract type:** Print Only

**Uncertainty Theory as a Approach for Addressing Symptoms in Palliative Care**

**Garcia Navarro E.B.**
Hospital Juan Ramon Jimenez, Huelva, Spain

**Introduction:** The theory of Uncertainty developed by Mishel Merle1, who defines it as the inability of the subject to determine the meaning of the events related to a disease, and occurs in situations where you make decisions, unable to assign definite values to objects and events and accurately predict consequences due to lack of information and knowledge. Uncertainty, as a cognitive state, occurs when an event is not adequately structured or categorized because the patient information on the event in question is scarce. These events causing uncertainty can be the greatest source of stress, increasing patient emotionality and causing physiological reactivity, increasing the sensation of pain. In this paper we aim to describe as the unpredictability of the onset, duration and intensity of symptoms and the lack of communication and coping of patients and family is associated with the perception of uncertainty.

**Methodology:** Qualitative exploratory study with a phenomenological approach using composite techniques,
Finally cease.

A collection of bodily processes that maintains homeostasis takes place at a set point in time, when the last process in the cascade is interrupted. This allows the model to capture a broad basis of individual variation in the timing of death that fulfills the aim of a universal definition and that under it, all human beings are correctly allocated as alive or dead. A definition that is a universal definition and that under it, all human beings are correctly allocated as alive or dead would not capture the deep, fundamental nature of death.

For most of human history there has been no particular importance of establishing the exact time of a person’s death, only whether the person is alive or dead. With modern medical advances however more precise answers are looked for.

For a definition of death to succeed is important that it is a universal definition and that under it, all human beings are correctly allocated as alive or dead. A definition that pronounces someone whom the majority of society would clearly call alive as dead would not capture the deep, fundamental nature of death.

This paper initially examines the most commonly proposed positions on when a human being dies those of Cardiopulmonary Death, Whole Brain Death, Brainstem Death and Higher Brain Death and for each describes scenarios that provide counter-intuitive results. Intuition is used as a benchmark as this is what our patients most commonly use.

The second part of the paper seeks to establish a definition of death that fulfills the aim of a universal definition from the basis of ‘human being’ being defined as possessing of human DNA and based on Olsen’s Animalism. This allows the model to capture a broad basis of individuals and to maintain personal identity throughout a lifetime.

The argued for position is that death is an event that takes place at a set point in time, when the last process in the collection of bodily processes that maintains homeostasis finally cease.

That this conclusion will interfere with clinical practice concerning organ transplantation is considered, but countered with the argument that there has been a conflation of the normative question of when it is permissible to remove a person’s organs for transplantation with the metaphysical question of what is death.

**Abstract number:** PO132  
**Abstract type:** Print Only  

**When Does a Human Being Die?**

**Schofield G.**  
Imperial College London, Division of Surgery and Cancer, London, United Kingdom

For most of human history there has been no particular importance of establishing the exact time of a person’s death, only whether the person is alive or dead. With modern medical advances however more precise answers are looked for.

For a definition of death to succeed is important that it is a universal definition and that under it, all human beings are correctly allocated as alive or dead. A definition that pronounces someone whom the majority of society would clearly call alive as dead would not capture the deep, fundamental nature of death.

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**Abstract number:** PO133  
**Abstract type:** Print Only  

**Long-life Close Relations Influence Patient-doctor Interactions in Palliative Care/Hospice**

Zaporowska-Stachowiak I.A.,  
Stachnik K.,  
Luczak J.

1Poznań University of Medical Sciences University Hospital of Lord’s Transfiguration, Department of Pharmacology/Palliative Medicine In-Patient Unit, Poznań, Poland.  
2University Hospital of Lord’s Transfiguration, Clinical Psychology, Poznań, Poland.  
3University Hospital of Lord’s Transfiguration, Palliative Medicine In-Patient Unit, Poznań, Poland

Adult relations with strangers stem from one’s existing or former relationships with family and close friends. The type and amount of attention a baby gets from its guardians determines its interpersonal interactions and mental stability in the future (prototype hypothesis). Sense of safety and trust in the external world affect the perception of new situations and challenge management. Emotional support is vital for a patient’s physical and mental condition.

In palliative care, a close, trusting relation with one’s doctor has a positive impact on the patient’s quality of life.

**Aims:** To determine whether the kind of patient’s long-life relationships influence patient-doctor relations (PD) in palliative care.

**Methods:** Patients: 30 (aged 36-80 ± 23, 20 F/ 10 M, 13 married, 17 single) advanced cancer patients in palliative care. Revised Adult Attachment Scale (Collins, 1996)-Close Relationships Version Questionnaire was used to assess three attachment dimensions: close (C), depend (D), anxiety (A) in the participants. Additionally, questions assessing PD were posed.

**Statistical analysis:**

**Independent variables:** score in a given attachment dimension,  
**dependent variables:** type of relationship with the doctor,  
**confounding variables:** sex, age, marital status (all controlled). Multiple regression linear model was used to estimate the dependence of patient-doctor relations on the subject’s preference towards a given dimension.

**Results:** There was a statistically significant (p=0.01) influence of A on PD (Pearson’s correlation -.442). 83.3% of patients had good/excellent PDs, but low A scores...
Abstract number: PO134
Abstract type: Print Only

Palliative Care in Nursing Homes: A Qualitative Evaluation of the Content Comprehensiveness and the Practical Usability of the interRAI Palliative Care Instrument

Hermans K.1, Spruytte N.1, Cohen J.2, Van Audenhove C.1, Declercq A.1

1KU Leuven, LUCAS, Center for Care Research and Consultancy, Leuven, Belgium, 2Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium

Research aims: Nursing homes are important palliative care settings for frail older persons. By means of comprehensive geriatric assessments (CGAs), an appraisal can be made of the different palliative care needs of nursing home residents. The interRAI Palliative Care (interRAI PC) instrument is a CGA which assesses the diverse needs of older adults requiring palliative care in all healthcare settings. Examples of results are Client Assessment Protocols (CAPs) and Scales. Based on these outcomes, care plans can be evaluated and adjusted. This study aims to evaluate the content comprehensiveness and the practical usability of the interRAI PC instrument for use in palliative care in Belgian nursing homes.

Study population: Care professionals in Belgian nursing homes.

Study design and methods: Care professionals of ten nursing homes fill out the interRAI PC instrument during one year for all nursing home residents with palliative care needs. After six months, focus groups and interviews will be organized to determine whether items are lacking or unnecessary. The usability of the interRAI PC instrument for use in Belgian nursing homes will be evaluated. Close and dependent dimensions do not affect PDs cardinally. Low attachment-related anxiety facilitates them significantly.

Results on interviews and focus groups will be organized to determine whether items are lacking or unnecessary. Based on the results of this study, we will be able to adjust and optimize the content and the usability of the interRAI PC instrument for use in Belgian nursing homes.

Conclusion: Adult attachment-related features shape PD, contrary to sex, age or marital status.

Abstract number: PO135
Abstract type: Print Only

Bupivacaine Paravertebral Blockade for Patient with Unbearable Cancer Pain in Palliative Care - A Solution in Case of Ineffectiveness of Systemic Step III Opioids

Zaporowska-Stachowiak I.A.1,2, Kowalski G.1, Kotlińska-Lemieszek A.3, Łuczak J.3, Kosicka K.4, Głowa F.4, Hoffmann K.5

1 Poznań University of Medical Sciences, Department of Pharmacology, Poznań, Poland, 2 University Hospital of Lord’s Transfiguration, Palliative Medicine In-Patient Unit, Poznań, Poland, 3 Poznań University of Medical Sciences, Department of Physical Pharmacy and Pharmacokinetics, Poznań, Poland, 4 Poznań University of Medical Sciences, Department of Internal Medicine, Metabolic Disorders and Arterial Hypertension, Poznań, Poland

Severe cancer pain may be difficult to control using WHO principles. Dose-limiting adverse effects and/or ineffectiveness of strong opioids may require invasive pain treatment. Pharmacotherapy is potentially toxic in high risks patients with advanced cancer.

Aims: To evaluate:

- effectiveness and safety of bupivacaine lumbar paravertebral blockade (PVB) in cancer pain treatment, not controlled with systemic strong opioid, in patient with risk factors for drugs’ toxicity
- the effect of mode of administration (continuous infusion: CI or boluses: B) on the bupivacaine plasma concentration.

Methods: We present a 71-year old female in-patient (Karnofsky 40) with breast cancer, admitted to hospice due to L-S backbone and both legs pain of neuropathic and bone origin. Concomitant renal impairment, arterial hypertension, heart failure (NYHA II), complex therapy were risk factors for drugs’ toxicity. Formerly, Fentanyl (F) TD 75μg h-1, Morphine sulfate (MF) s.c. 40 mg d., Acetaminophen 1500 mg p.o. d. didn’t control pain, MF caused confusion. Switch to F s.c. CI improved mental awareness but not pain control. Co-administered bupivacaine in CI (0.25%, 5 mL/h) or in B (10 mL of 0.125-0.5% solution) was used for lumbar PVB.

Results: Efficient pain control was obtained with bupivacaine PVB given in B (0.09 mg/kg/h) only. The requirement for F lowered by 85%. Patient’s social functioning improved. Bupivacaine in CI (0.20 mg/kg/h) was not effective. Bupivacaine elimination was slower during CI than B (t1/2 = 7.80 vs. 2.64 h). Total drug serum concentrations remained within safe range (22.9-927.4 ng/
mL) during the whole treatment course. Bupivacaine side effects were absent. **Conclusion:** Bupivacaine PVB in B (≤ 68.75 mg/12h) provided for effective and safe analgesia in advanced cancer patient with risk factors for drugs-induced toxicity, PVB in CI (≤ 150 mg/12h) was safe but not effective. The effectiveness of PVB in lumbar region was dose- and volume-dependent in the case presented.

**Abstract number:** PO136  
**Abstract type:** Print Only  
**Effect of Subacute Administration of Subcutaneous Morphine in the Neuronal Apoptosis in the Brain Cortex of Male CF-1 Mice**  
*Quilodrán Peredo J.A.*  
Universidad de Chile, Programa de Anatomía y Biología del Desarrollo, Santiago, Chile

The prevalence of moderate to severe chronical pain is high in the oncologic and no oncologic patient, and the gold standard of treatment for the pain management is the administration of opioids, especially morphine. Therefore it is necessary to study its toxic effect at a central nervous system, especially its cell death mechanism. In the present investigation it was studies the effect of subacute administration of subcutaneous morphine in the Neuronal Apoptosis in the brain cortex of male CF-1 mice. For this purpose 4 experimental groups were used: negative control, positive control (pain), vehicle control and the experimental group (morphine 10% 0.6 ml every/6 hours per 48 hours). After 48 hours they were euthanasied in order to remove their brains and then they were sliced, which were fixed and stained with routine technique (H&E), to morphologically analize the cell death. Besides, it was performance immunochemistry stained with anticaspasa 3 antibodies to demonstrate the cell death mechanism via apoptosis. In the slices it was counted the number of death cells from a total of cells in a determinated area, for obtaining the density of apoptotic cells in each groups. Results indicate the presence of a significative difference in the apoptosis level from the experimental group, in comparison with negative control group, however the difference is greater in the positive control group versus experimental group and even greater versus negative control group. Dead cells were positive in anticaspasa 3 antibody stain.

Results suggest the existence of a neurotoxic effect via apoptosis in the cerebral cortex of the morphine, nevertheless is significantly fewer in comparison with pain group, which would confirm the benefits of active analgesic therapy. It allows to know new toxicity mechanism and theoretically it would permit develop a safer and effective long term therapies.

**Abstract number:** PO137  
**Abstract type:** Print Only  
**Evaluation of Hospital Deaths for Patients Referred to Community Palliative Care Services**  
*Wijeratne A., Spencer L.*  
Princess Alice Hospice, Esher, United Kingdom

Community specialist palliative care teams are involved in supporting palliative care patients to live and die at home. Some patients however are admitted to hospital during their last days of life and a survey was carried out evaluating 43 patients who died in 3 hospitals who had been referred to one hospice community specialist palliative care team.

**Aim:**
1. To gain an overall picture of why patients referred to the hospice died in the acute sector  
2. To assess with the information available whether any of these admissions to hospital or deaths in hospital could have been avoided  
3. To make recommendations based on these findings for future practice

**Findings:**
- 86% patients were aged over 70 years  
- 11.6% living alone and 60% of these patients had no package of care at home  
- Only 5% admitted from nursing homes - the majority from their own place of residence  
- Only 14% patients had a Do Not Attempt Cardiopulmonary Resuscitation order prior to admission  
- 42% of patients had advance care planning discussions prior to admission  
- 31% patients died within 48 hours of admission  
- Average length of stay for all patients was 11 days with a total of 399 days  
- The commonest reason for admission was shortness of breath (54%) followed by infection and deterioration (26%), and then pain (16%)  
- 2 patients had spinal cord compression, 1 had a CVA and 1 had a trial of BIPAP  
- 44% admissions were out of hours  
- The hospital specialist palliative care teams saw 67% of these patients and 96% were within 2 days of referral  
- 40% of admissions were thought to have been inappropriate, and 37% of these avoidable

**Recommendations:**
- Better advance care planning with clear ceilings of care in the community
Better communication between community services and use of electronic care coordination systems with clear care plans

Early recognition of dying patients in hospital and referral to hospital specialist palliative care teams to facilitate most appropriate place of death

Abstract number: PO138
Abstract type: Print Only

Experiences with the Ars Moriendi Model for Spiritual History-taking: A Mixed Methods Approach

Vermandere M., Warmenhoven F., Van Severen E., De Lepelere J., Aertgeerts B., RITUALL (Research In The Ultimate Aspects of Life, Leuven)

KU Leuven, Department of General Practice, Leuven, Belgium

Background: Many patients with advanced disease desire their health care providers (HCPs) to provide spiritual care. Lack of training, confidence, and appropriate language are barriers preventing many HCPs to initiate spiritual conversations.

Purpose: To explore experiences of HCPs with the Ars Moriendi Model (AMM) as a tool for spiritual history-taking in palliative home care.

Patients and methods: Nurses and general practitioners (GPs) performed a spiritual history-taking guided by the AMM in patients with an incurable, life-threatening disease. HCPs completed a questionnaire after the history-taking to collect their early impressions. Four to six weeks after the spiritual history-taking, they participated in a semi-structured interview to investigate their experiences with the AMM more in depth, and to report on possible changes in their relationship with the patient. Statistical analysis on ordinal scale scores was performed using a proportional odds model. Semi-structured interviews were recorded, transcribed, and thematically analyzed by two independent researchers using NVivo 9.0 software. Quantitative and qualitative results were compared using a convergent parallel mixed methods design to observe whether quantitative and qualitative findings were confirmative.

Results (available in January 2014): […] nurses and […] GPs participated in the study. Until present, questionnaires and semi-structured interviews of 18 health care providers (15 nurses and three GPs) were collected. We expect to present data of 20 participants. Preliminary results show that the AMM can give HCPs inspiration and courage to perform a spiritual history-taking. The questions of the model were often tailored to individual patient needs. Most HCPs acknowledge that talking about spiritual needs and resources positively influenced the patient-provider relationship, and that they will continue addressing spirituality with future patients.

Conclusion: [will follow after full analysis]
The education and empowerment of the family is essential to enable the caregiver to take care and monitor the patient. However, there are aspects related to self-care and management of the therapeutic plan that sometimes involve greater need for information and training of the caregiver.

**Aim:** To identify what are the needs and difficulties of patient’s caregiver after discharge from palliative care unit.

**Study population:** Palliative care patient’s caregivers of a Portuguese oncological palliative care unit.

**Methods:** A form was applied to 50 patient’s caregivers in the first outpatient clinic visit after discharge from palliative care unit for six months (from April 1st to September 30th). Data were processed in SPSS program.

**Results:** The management of the therapeutic plan and the patient’s positioning and mobilization raise greater need for training.

**Conclusion:** To provide written information and early training enable caregiver to meet the patient’s needs more effectively. An education programme will be planned.

**Abstract number:** PO141

**Abstract type:** Print Only

**Colourful Life of Hospice Volunteers in Europe**

**Pelttari L.**, **Scott R.**

1Dachverband Hospiz Österreich, Vienna, Austria, 2non, Dunblane, United Kingdom

**Introduction:** Volunteers in some countries in Europe have historically had a long involvement in hospice and palliative care. Many services depend on the volunteering contribution to enable them to deliver the range and quality of services that they provide. Volunteers have an important role to play and they bring a unique quality to the care of patients and their families. Volunteers are less focussed on the patient’s medical condition and bring an important social dimension to care in a medical environment. However, volunteers, may not always be acknowledged as a part of the professional team, or their skills and expertise recognised. With a demand for hospice and palliative care steadily increasing, volunteers will have a significant role to play in the delivery of services in the future.

A new Task Force has been established to explore the role of volunteers in hospice and palliative care in Europe. This project will involve practitioners in volunteer management in hospice and palliative care, managers of hospice organisations, volunteers and academics drawn from different European countries.

The aim of the task force is to explore:

- The roles undertaken by volunteers in hospice and palliative care
- Management of volunteering
- Training of volunteers
- Challenges for volunteers, managers and organisations
- Identify numbers of volunteers in each participating country

**Approach:** This will be a participative project with task force members involved in the development of data collection methods. Working through existing networks in Europe level, the aim of the work is to hear from practitioners and volunteers in hospices from a range of countries about their experiences of volunteering today. The voices of volunteers will be particularly important.

**Outcomes:** The outcomes are intended to highlight the important contribution made by volunteers to hospices, to develop knowledge and understanding and to improve and develop practice.

**Abstract number:** PO142

**Abstract type:** Print Only

**Creative Self-expression Therapy (CSE) in Palliative Care**

**Orlova T.V.**

Moscow Clinical Oncology Hospital #62, Department of Palliative Methods for Outpatient Palliative Care, Moscow, Russian Federation

The aim of research: The development of a short variant clinical psychotherapy method: the Creative Self-Expression Therapy (CSE), originated by prof. M. Burno (Russia), that improve the quality of emotional and spiritual life for cancer patients in the IV stage. Results are based on the complex research of 100 patients suffering from advanced generalized cancer. Such psychotherapy method is applicable for most terminal cancer patients who usually feel defensive, invalid, deficient, bitter at the end of life. The essence of this method gives the possibility for patients during the terminal stage of their illness to increase the valuable positive feeling of his/her personal individuality and enlarge their adaptability to illness according to their own individual natural characterological features, that promotes the better quality of life to patient personally and his loved ones.

**Specific features:**

1) Special methodology of creative communication with Nature and Art, adapted to weak cancer patients.

2) Raising emotional, motivational sphere and the level of understanding and view of one’s life, feeling unique nature of patient’s personality, helping to positively sum up his/her life with dignity, adapt to feeling of the end of life.

3) The use of psychotherapy approaches, helping terminal patients to analyze different characters and their demonstrations via creative self-expression,
that, as a result, help them to better understand their own unique character and accept their own personality and relations with their loved ones.

4) Positive dynamics of several clinical and psychopathological indicators demonstrate the raising of quality in their psychic life: patients express better mood, the fear of death disappear or become less, they stop blaming themselves, accept the value of their life and relations with their loved ones.

Abstract number: PO143
Abstract type: Print Only
Anticipatory Care Planning: Understanding the Impact of Planning for Future Care

Mcglinchey T.¹, Saltmarsh P.¹, Mason S.¹, Gambles M.¹, Bancroft R.², Corcoran G.¹, Ellershaw J.E.¹
¹Marie Curie Palliative Care Institute Liverpool (MCPCIL), University of Liverpool, Liverpool, United Kingdom, ²Royal Liverpool and Broadgreen University Hospital NHS Trust, Liverpool, United Kingdom

Background: Advance Care Planning (ACP) is important in improving care for people nearing End of Life (EOL). ACP can enable people to die in their place of choice, coordinate care, reduce unnecessary hospital admissions and burdensome interventions.

Research is needed to inform our understanding of how ACP works in practice. Accordingly, a two phased study is currently engaged in the Care Home setting in the North of England, which seeks to:

1. Develop a consensual process for ACP.
2. Assess the impact that ACP discussions have on all participants; residents, relatives/friends and Health Care Professionals (HCP).

Phase 1 findings indicated that existing definitions of ACP are complex, with practical and conceptual understanding varied. A recommendation for this study was that the term Anticipatory Care Planning (AnCP) would be used.

Phase 2 of this project is now underway.

Aim: To examine the lived experience of residents in care homes, their relative/friends and HCPs, who have been engaged in discussions about AnCP.

Method: Interpretive phenomenology underpins the research methods employed; in-depth semi-structured interviews with residents (where possible), relatives/friends of care home residents and HCPs are being undertaken using a longitudinal case study design:

Initial interview after first AnCP discussion
Follow up interview at 3 monthly intervals
Post bereavement interview with relative/friends and HCP.

Results: Qualitative data derived from the interviews will be discussed under the following emerging themes:

- Timing and content of discussions
- Variances in understanding and purpose of AnCP
- Emotional impact of engaging in discussions
- Confidence in care delivery in Care Home setting.

Conclusion: Conclusions will inform the developed AnCP protocol and contribute to the ongoing debate and understanding around the broader concept and impacts of Advance Care Planning.

Abstract number: PO144
Abstract type: Print Only
Determination of the Palliative Care Practices of the Nurses Working in the Gynecological Oncology Units

Uslu F., Terzioglu F.
Hacettepe University Faculty of Nursing, Obstetrics and Gynecology Nursing, Ankara, Turkey

Research aim: This study aims at determining the palliative care practices of the nurses working in the gynecological oncology units.

Study population: The population comprised of all of 65 nurses who work in three state and three university hospitals where the palliative care is rendered in the gynecological oncology units.

Study design and methods: This is a descriptive study. The research data was collected by means of face-to-face interviews through the semi-structured questionnaires from June 30 2012 to September 30, 2012.

Method of statistical analysis: The package software SPSS 19.0 was used to analyze the research results on the basis of the descriptive statistics (quantity, percentage).

Results: It was determined that the participants got knowledge on the palliative care by 47%, whose mostly used the on-job training courses (71%). The participant patients with gynecologic cancers more frequently had such symptoms as “pain” (100%), “nausea and vomit” (92.5%) and fatigue (86.2%). The participants with pain symptom was by 95.5% found to use analgesics on prescription, while the entire participants with nausea-vomit symptom used antiemetic drugs on prescription, and the bed rest was suggested for 87.5% of those with fatigue symptom. The participants were determined to take care of the ethical rules on the end-of-life care, as a portion of 73.8% abstained from talking about death with the patients and their families. The participants were however determined to support by 66.2% the claim “the patient has the opiodic phobia” in palliative care practice, while 80% of them declined the claim “the people has not enough knowledge on the palliative care, and the patients do not have an adequate demand for the support therapy”.

Interpretation: In line with the research results, it was suggested for the pre-graduate and on-job curricula to
Fentanyl (FEN) is considered to be a WHO step III opioid of first choice for patients with renal failure. The use of transdermal fentanyl (FEN TD) in this population, including dialysed patients, has not been reported until now.

**Aims:**
- to demonstrate that FEN TD can be an effective and safe step III opioid in patients on long-term hemodialysis,
- to determine the effect of dialysis on plasma concentrations of FEN and main metabolite norfentanyl (NOR).

**Methods:** We present four patients (aged 56-86, Karnofsky score 30-90) undergoing intermittent hemodialyses, with chronic cancer or non-cancer pain. FEN TD was introduced as the first step III opioid or after switch from morphine, which had caused severe toxicity. Two types of polysulphone dialyzers: Elisio 170H,1m² (E) or Heli- xone FX50,1m² (H), were used. The efficacy and adverse effects of treatment were assessed. FEN and NOR plasma concentrations were quantified by liquid chromatography-mass spectrometry on one or two days of dialysis in each patient. The study was approved by the Ethics Board and informed consents were obtained.

**Results:** FEN TD (12.5-50 µg/h) provided satisfactory and well tolerated analgesia in all patients, within the period of 11 days to 40 months (NRS 0-2/10). Dialyses did not impair analgesia. FEN plasma concentrations ranged between 0.2-3.8 ng/ml, and declined by 38-68% during dialyses in 2 patients, as opposite to other two (with the use of E or H, respectively). NOR concentrations decreased by 16-86% during dialyses in all patients, however when compared between two days of blood samplings, a 4.5-18-fold increase of NOR concentrations with longer use was found. FEN concentrations increased by only 34-105% between two study days and indicated a relevant conversion of FEN to inactive NOR, which prevents its accumulation and toxicity with chronic use.

**Conclusion:** FEN TD can provide effective and safe analgesia in patients with renal failure on dialysis, also in chronic use.
Considerably heavy to make those decisions, without the
to decide on treatment cessation, some relatives find it
Therefore, when faced with the inability of the patient
is called: considers too much or not enough the family.
or in shortage. For example, a first "deviance criteria"
were digressing from the philosophy, either in excess
identification of fifteen deviant clinical situations that
Results and interpretation:

and social sciences.

followed by an in-depth analysis by drawing from human
analyses were performed to achieve objective 2.
Method of analysis: Data analysis was performed by
doing a content analysis using NVivo software. It was then
by an in-depth analysis by drawing from human

Results and interpretation: The results allowed the
identification of fifteen deviant clinical situations that
were digressing from the philosophy, either in excess
or in shortage. For example, a first “deviance criteria”
is called: considers too much or not enough the family.
Therefore, when faced with the inability of the patient
to decide on treatment cessation, some relatives find it
considerably heavy to make those decisions, without the

Qualitative variables will be described with frequency and
quantitative variables by mean and standard deviation.
It will be calculated the mean of the score of the quality
of life measured by the SF-12 questionnaire on Mental
Healthcare and the Duke Social support scale with 95%
CI. Logistic regression will be used to adjust for prog-
nostic factors. Confounding factors or factors that might
alter the effect recorded will be taken into account in this
analysis.

Results and conclusions: We started collecting data few
weeks ago; we expect to have at least 100 patients by the
end of April. With the results we will have a view of the
situation of our bereaved in order to evaluate the factors
that can influence the quality of life during the process of
grieving.

Abstract number: PO147
Abstract type: Print Only

Deviant Practices in Palliative Care: What and why?

Blondeau D.
Université Laval, Sciences Infirmières, Québec, QC, Canada

The objectives were to define what constitutes a deviant
palliative care practice and to identify factors that con-
tribute to its emergence.

Study population: Different caregivers working in palli-
tive care relatives who attended, in the context of palliative
care, a person until his/her death.

Study design and methods: This is a qualitative study,
since no empirical data is available right now. First, individ-
ual interviews were conducted among fifteen caregivers
and sixteen relatives of a deceased person (objective 1).
Second, disciplinary focus groups on deviant clinical situ-
atations were performed to achieve objective 2.

Method of analysis: Data analysis was performed by
doing a content analysis using NVivo software. It was then
followed by an in-depth analysis by drawing from human
and social sciences.

Results and interpretation: The results allowed the
identification of fifteen deviant clinical situations that
were digressing from the philosophy, either in excess
or in shortage. For example, a first “deviance criteria”
is called: considers too much or not enough the family.
Therefore, when faced with the inability of the patient
to decide on treatment cessation, some relatives find it
considerably heavy to make those decisions, without the
support of professionals (excess). The results allowed the
identification of a predominant explanation, the organi-
zational factor. For example, and more precisely, there is
the shortage of human resources, turnover of employees,
heavy workload and the absence of beds in palliative
care. Another factor named axiological can explain the
misdemeanor.

These results suggest a real deviance from the original
approach in palliative care. They bring us to conclude that
the humanization of care and the search for the quality of
life of end-of-life people can, in certain circumstances, be
seriously compromised.

Project funded by: The Social Sciences and Humanities
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Abstract number: PO148
Abstract type: Print Only

Dying at Home: A Decision in Palliative Care, an
Integrative Review

Covelho P.¹, Costa T.¹, Pinho-Reis C.¹, Capelas M.-L.²
¹The Catholic University of Portugal, Institute of Health
Sciences, Porto, Portugal, ²The Catholic University of
Portugal, Institute of Health Sciences, Lisboa, Portugal

Introduction: Palliative care allow to develop social
policies and innovative health, focused on the needs and
preferences of patients, combining scientific knowledge,
skills and attitudes to promote the excellence of care.
Also promote a holistic care which improves the com-
fort and quality of life of the patient and family, through
an approach of the problems associated with life-
threatening diseases, preventing and relieving suffering
by early identification and assessment of pain and other
physical problems, psychological, social and spiritual.
Care the patient at home is important to respect the pre-
ferrances of patients and to provide humanized end-of-
life care.

Aims: To demonstrate the need to integrate palliative care
in home care.

Methods: Review of Literature in databases (CINHAL,
MEDLINE, ISI). The search was guided by the follow-
keywords: “palliative care”, “die at home” and “preferences”.
As inclusion criteria we defined: English-language
articles published after 2003, in full text, with abstract and
references available and, analyzed by experts.

Results: We found a total of 45 articles which show
that 51 % of patients prefer to die at home but someti-
mes that it is not possible. Palliative care enable early
intervention in the illness trajectory as well as persona-
lized care aproaching effectively the needs of patients
and families, providing an improved quality of life and
reducing the need for hospitalizations, painful and dis-
proportionate.
Conclusion: It is essential to develop home palliative care teams (HPCT) to deliver quality care and implement interventions, given the management of symptoms, assessment and care planning, monitoring, preparation and support in bereavement. Given the guidelines of the EAPC, it is needed one HPCT per 100 thousand inhabitants. To achieve this goal is vital to have health professionals with specializes education and training in palliative care.

Abstract number: PO149
Abstract type: Print Only

A Retrospective Review of Patients Initiated on Oxycodone at a Tertiary Cancer Treatment Centre

Wung M., Shahaney S., Branford R., Droney J., Ross J.
Royal Marsden Hospital, Sutton, United Kingdom

Morphine is recommended first line for the treatment of moderate to severe cancer-related pain in worldwide and national guidelines. Other strong opioids i.e. oxycodone are available and are appropriate for use in certain cases. Some patients do not respond to morphine due to poor analgesia or side effects. In these cases an opioid switch to oxycodone is recommended. Morphine and oxycodone are similarly efficacious, but on a population level there is substantial interindividual differences in response. Local expert opinion issued specific guidance about appropriate prescribing of oxycodone.

Aims: This was a retrospective case note review evaluating the prescribing of oxycodone for palliative care patients at a cancer treatment centre according to local, regional and national guidelines.

Methods: Sample size was 50, comprising of consecutive prescriptions of oxycodone from October - December 2012.

Results: 27 were female and 23 are male, with a mean age of 58.66 years (SD 15.4). Most patients had new prescriptions of oxycodone (n = 43). 23 patients received first line oxycodone prescriptions, often made without evidence of specialist involvement. Incorrect oxycodone prescriptions were generally from non-specialist teams (n = 9). Patients who have no specialist team involvement usually did not have written documentation that their opioid switch had been reviewed (n = 15). If specialist teams were involved, prescriptions concurred with local guidelines and a greater proportion of opioid switches were reviewed. Of those switched to oxycodone, half had been trialled on morphine before switching (n = 22). Reasons for the switching was poorly documented.

Conclusions: Poor documentation regarding reason for oxycodone use and review and incorrect prescribing were more common when specialist palliative care was not involved.

Abstract number: PO150
Abstract type: Print Only

How to Develop a National - All-capturing - Minimal Data Set for Palliative Care: A Dutch Initiative

1Comprehensive Cancer Center the Netherlands (IKNL), Rotterdam, Netherlands, 2Comprehensive Cancer Center the Netherlands (IKNL), Utrecht, Netherlands

The demand for palliative care (PC) is increasing, mainly because the scope of PC has expanded from patients with end-stage cancer to all cancer and non-cancer patients in every stage of their incurable disease. On top of that, PC is becoming more prominent in healthcare due to the aging population with more people developing a life threatening illness.

Today, little information is available about the quality of PC, partly because of the challenge to recognize patients in need for PC. Several initiatives have been carried out ranging from data collections in specific settings/diseases to national datasets such as the Swedish national quality register in end-of-life care and the American Minimal dataset for nursing home residents. These initiatives are a great step forward to gain understanding of the care provided but still limited to specific settings or a specific time period (e.g. last week of life).

Recent studies show that to give insight into the quality of care, a data set should provide

1) information about the whole period when PC could be provided; and
2) about all patients in need for PC (e.g. not restricted to patients who actually receive PC). The time has come to develop such a dataset without possessing too much burden on persons who collect the data, e.g.
3) It has to be a minimal data set. In cooperation with several Dutch organisations we plan to design and pilot such a dataset in 2014.

Our existing registration databases and the recently launched PC care module will be our starting point: We plan to combine prospectively collected data with retrospective data to ensure capturing all patients in need for palliative care. Furthermore, we plan to include all settings and to focus on three different time-points: the start of the palliative phase; the terminal phase; and the dying phase. To do this, we encourage recent national initiatives focused on caregivers documenting on PC. Retrospective and prospective data will then go hand in hand.
Abstract number: PO151
Abstract type: Print Only

Impact of an Interactive Model of Advance Care Planning Education on Health Care Staff Within the Care Home Environment

Howard J.M.¹, Phillips S.¹, Saltmarsh P.², Ellershaw P.J.²

¹Marie Curie Palliative Care Institute Liverpool (MCPCIL), Learning and Teaching, Cancer Research Centre, Liverpool, United Kingdom. ²Marie Curie Palliative Care Institute Liverpool (MCPCIL), Liverpool, United Kingdom

There are 17,510 registered Care Homes (UK). Many residents in Care Homes are frail and vulnerable with multiple morbidities to include dementia. Timely, consistent, well-managed end of life care (EoLC) support in Care Homes should enable more residents to die where they would choose; supported by the process of advance care planning. Key areas have been identified for workforce development including communication skills and advance care planning. Challenges include access to high quality core EoLC education for staff. This may affect quality of care and place of death of residents in Care Homes. To evaluate the impact of a pilot model of education related to the processes of advance care planning on registered and unregistered nursing staff in 5 Care Homes A bespoke interactive pilot model of education was developed and implemented within five Care Homes and delivered to both nursing and healthcare assistant staff. A social constructivist approach to learning was undertaken, requiring participants to build on existing knowledge, constructively critique current practice, attitudes, values and beliefs. Staff perception of the impact of the teaching programme was evaluated using standardised evaluation forms. The 2 sessions were delivered sequentially to a total audience of 50. This comprised of 35 Healthcare Assistants, 6 Registered General Nurses and 9 Managers. The social constructivist approach was received well and encouraged staff engagement. “I liked the way we were allowed to share our different experiences”. “Now I have more knowledge about how we are doing” “I can’t wait to come to session 2”. Staff demonstrated increased awareness of their individual and team roles related to key elements of advance care planning. “This will enhance my practice in so many ways”. Whilst anecdotal evidence demonstrates the positive impact of this approach through Facilitator observation and student evaluations it is recommended that a more formal evaluation of the model is undertaken.

Abstract number: PO152
Abstract type: Print Only

A Total Pain in the End of Life: A Perspective in the Context of Home

Costa T.¹, Coutinho A.², Capelas M.L.³, Coelho P.¹

¹The Catholic University of Portugal, Institute of Health Sciences, Porto, Portugal. ²Obra Diocesana de Promoção Social, Porto, Portugal. ³The Catholic University of Portugal, Institute of Health Sciences, Lisboa, Portugal

Introduction: Considering the pain is one of the concerns present in the day-to-day of palliative care health professionals, and that fit these functions to assess/approach and reassess pain, making therapeutic decisions, it seems essential to increase knowledge about pain, specifically total pain.

Aims: To understand the factors that contributed to the total pain in the case study and highlight the importance of personalized care/holistic.

Materials and methods: We did a case study of three elderly men in the end of life, that were in their own home.

Conclusion: For an appropriate intervention is critical to control the physical pain and other concomitant symptoms, as well as all other factors that cause social, psychological and spiritual suffering. It is imperative that the symptoms are identified and evaluated to meet the real needs of patients/families considering partnership of all stakeholders in the triad.

Abstract number: PO153
Abstract type: Print Only

Trends in Colorectal Cancer Mortality in England and Implications for End of Life (Terminal) Care

Verne J., Fleming S., Pring A.

Public Health England, Knowledge and Intelligence South West, Bristol, United Kingdom

Introduction: Colorectal cancer is the underlying cause of about 13,000 deaths per year in England accounting for 3% of all deaths and 10% of cancer deaths. We examined patterns of death from colorectal cancer over a decade.
Methods: Mortality records for England, collated by the Office of National Statistics, selecting a cohort based on underlying cause of death or contributory causes of deaths 2001-11 including colon cancer (ICD10-codes C18) or rectum and recto-sigmoid cancer grouped as rectal cancer (C19, C20). Trends in mortality were analysed by gender and age. Co-morbidity at death was estimated for each person using a modified Charlson score inferred from the conditions recorded on the mortality record.

Results: The total number of deaths from colorectal cancer has remained stable between 2002 and 2011 but deaths from colon cancer have decreased (8,804 to 8,037) and rectal cancer deaths have increased (4,198 to 4,834). The proportion of people dying from colorectal cancer who are aged 85 or older has increased for colon cancer from 21% to 27% and for rectal cancer from 19% to 23%). The people dying aged 85 years or older had on average the most co-morbidities.

Discussion: As populations age, more elderly people will die from colorectal cancer. Older adults have specific end of life challenges due to multiple co-morbidity especially dementia which may complicate their stoma and palliative care management. The influence of age and terminal rectal as opposed to colon cancer on types of care needed will be discussed.

Abstract number: PO154
Abstract type: Print Only

‘Mens Sana in Corpore Sano’: A Sound Mind in a Healthy Body
Shah S.1, Shipman K.2, Gardiner F.2, Milne H.2
1Auckland City Hospital, Palliative Care, Auckland, New Zealand, 2Auckland City Hospital, Auckland, New Zealand

Aim: To explore perceptions of spirituality and spiritual care of health care professionals working at Auckland City Hospital, New Zealand.

Background: Health has been defined by the World Health Organisation as ‘a state of complete physical, mental and social well being and not merely the absence of disease or infirmity.’ Current health care systems use primarily bio-medical models focused on medical and surgical treatments with less importance on beliefs and faith although these are recognised as important aspects of healing. The Maori philosophy of health in particular is based upon a holistic model of Taha wairua (spiritual dimension), Taha hinengaro (mental dimension), Taha tinana (physical dimension) and Taha whanau (social/family dimension).

Auckland City Hospital is New Zealand’s largest public hospital and clinical research facility providing specialist services for the country with over 7,000 staff serving a culturally diverse population of 444,100.

Method: An online survey of all health and social care professionals working at the hospital is to be undertaken using the internationally validated 17-item Spirituality and Spiritual Care Rating Scale by Wilfred McSherry plus five additional questions to explore health care professionals’ perceived:

- responsibility in assessing and addressing patient’s spiritual care needs
- confidence in assessing and addressing patient’s spiritual care needs and
- preferred learning methods and tools to help professionals with the above.
- Basic demographic data will also be collated as part of the survey.

Results: Data from the survey will be analysed using Statistical Package for Social Sciences.

Conclusion: It is anticipated that preliminary results from the online survey will be used to inform an educational strategy on spirituality and spiritual care for all health and social care staff working at the hospital as well as further developmental work on spirituality assessment tools.

Abstract number: PO155
Abstract type: Print Only

The Palliative Care Nurse Concept. A New Concept to Realize the Routine Integration of Palliative Care and Medical Oncology: Report on a One Year Experience
Kloke M.1, Bartschat T.1, Stevens S.2, Becüwe B.1, Stahl M.2
1Kliniken Essen-Mitte, Department for Palliative Care, Essen, Germany, 2Kliniken Essen-Mitte, Department for Medical Oncology and Hematology, Essen, Germany

Background: The integration of palliative care and oncology has become a desideratum of modern oncology since J. Temel succeeded in demonstrating a live prolonging effect of concordant palliative and oncology treatment. Nevertheless, due to the shortage of financial and human resources the principle of the two noses cannot be realized in routine oncology. Therefore, the problem of integrating palliative care and oncology on a day to day basis from the beginning, needs to be resolved. That’s why the Department of Medical Oncology and Hematology and Palliative Care started the so-called palliative care nurse concept (PCNC). Each inpatient was screened using the Distress Thermometer at least once a week by an highly experienced palliative care nurse. The PCN discusses the results with the pt and initiated appropriate interventions.

Aims: Creation and implementation of an effective method of integrating palliative care and oncology - to evaluate the type of palliative care intervention (e.g. pain
and symptom control, psychosocial support, organizing home care, patient’s last will) - to assess the medico economic outcome.

**Methods:** Analysis of counseling records and activities during the first year of the project.

**Results:**
- The PCNC is highly accepted both by professionals as well as by the pts.
- There is a strong indication that underdiagnosing and undertreatment of palliative care needs can be reduced by the involvement of a specialized palliative care nurse into routine work.
- The acceptance of palliative care by the cancer patients and his or her relative can be increased and the prejudices can be reduced.
- The medico economic advantages are reflected by the increase of remuneration by the health insurance.

**Conclusions:** The involvement of a specialized palliative care nurse only dedicated to the assessment of and response to the palliative needs of inpatients of a medical oncology ward improves the quality of patient’s care and has some medico economic advantages.

**Abstract number:** PO156
**Abstract type:** Print Only

**Emergencies and Palliative Care: Current Situation and Ways of Improvement**


1Assistance Publique Hopitaux de Marseille - Aix Marseille University, Palliative and Supportive Care Mobile Unit, Medical Oncology, Marseille, France, 2Aix Marseille Université, Public Health, Marseille, France

**Aims:** Emergencies team and palliative care team ways of thinking could be opposed at first sight. Do emergency situations exist for patient in palliative care? How to manage them at home or with team not prepared to work in emergency? Do emergency departments (ED) provide adapted care for patients approaching end-of-life?

**Aims of this work are:**
- studying management of patients in palliative care state in ED,
- studying management of emergency situations for patients in palliative care,
- identify areas of improvement

**Methods:** To study current situation, we

**Results:** The majority of people approaching death explicitly state that they want to die at home, and eventually die at hospital.

Emergencies and Palliative care: both fields seem to present opposite frame of mind, although they are intricated.

Emergencies situations, foreseeable, appear among patients in palliative care, whether they are real or felt as real. At home medical teams and carers might be overwhelmed as “relief should be always an emergency”.

Emergencies departments are not well adapted to treat this kind of patients and their relatives. They suffer from lack of training, informations, time, interdisciplinarity, links between hospital and out of hospital, capacity to accomodate patients. Palliative mobile team impact is positive as the other “tools” (palliative care network, identification file for patients in palliative care, mobile palliative care emergencies team, emergency medical protocols and kit at home...).

**Conclusion:** Hospitalisation and management of patients at the end-of-life by emergency medical services is presenting a challenge to our society. Communication, anticipation, training and technical improvements are required.

**Abstract number:** PO157
**Abstract type:** Print Only

**The Use of Lasertherapy in the Treatment of Oral Mucositis in Palliative Care Patients - A Case Report**


1Barretos Cancer Center, Palliative Care Unit, Barretos, Brazil, 2Barretos Cancer Center, Barretos, Brazil

**Aims:** LBF, HR 0614879, female, white, married, 40 years and two months old, coming from Dourados, Mato Grosso do Sul, Brazil, carrier of ductal carcinoma metastatic breast cancer. The patient was submitted to a bilateral mastectomy with placement of silicone prosthesis, and on January 25, 2007 started the chemotherapy, radiotherapy and hormone therapy associated. The patient was sent to the Palliative Care in August 2013, and started the treatment with corticosteroids, evolving to an autoimmune process that resulted in the development of severe oral mucositis, grade IV. Oral mucositis is a severe complication that occurs in 85-100 % of cancer patients and 60-70 % of patients with advanced cancer. The Department of Dental Sciences of
Implement a Regional Strategy Using SWOT Analysis and Using the Results to Improve Palliative Care Systems

García-Baquero Merino M.T.1, Ruiz Lopez D.1, Luengo González R.2, Izquierdo Botica F.1, Blasco Amaro J.A.1

1Coordinación Regional de Cuidados Paliativos, Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain, 2Consejería de Sanidad, Comunidad de Madrid, Madrid, Spain

Background: Relevance and necessity of creating efficient and effective care systems in the palliative care (PC) sphere requires research to evaluate needs related to professionals’ material resources, management and coordination.

Aim: Analysis of needs perceived by the professionals working within different palliative care levels environments in our region.

Methodology: An integral assessment was carried out, which included a questionnaire designed to assess material and human resource; number and category of patients receiving care; and referral and common pathways to bring together PC services. The questionnaire also provided information on the perceived needs of staff through open ended questions in a SWOT analysis and asked participants to suggest strategies for the coordination improvement in PC systems. Data was collected through interviews by the same researcher during 4 months.

Setting/participants: Questionnaire, answered by health care professionals from all PC services within a 6 m people region.

Results: 41 working groups, involving both public and independent home and hospital care-consulting teams and bedded units. Results obtained provided an outline for 18 improvement strategies to exploit internal strengths and external opportunities while confronting internal weaknesses and external threats.

Conclusions: SWOT analysis is a useful and relevant tool in the healthcare field, although its use has yet to be widely implemented. In our case, the results obtained from the resource questionnaire together with the analysis of the answers in the SWOT analysis, later defined the main strategic lines which would subsequently conform the “Regional PC 2010-2014 Strategy”.

Abstract type: Print Only

Loss of Faith in God among Indian Palliative-care Patients

Gielen J.1, Bhatnagar S.2

1Catholic University Leuven, Research Unit Theological Ethics, Faculty of Theology and Religious Studies, Leuven, Belgium, 2All India Institute of Medical Sciences, Anaesthesiology, Pain and Palliative Care, Dr. B.R.A. Institute Rotary Cancer Hospital, New Delhi, India

Aim: India is renowned for its profound religious and philosophical thought. Yet, the day-to-day religious life of many Indians revolves around devotion to a personal God. A terminal illness might pose a serious challenge to faith in God. We wanted to know how this faith fares among Indian palliative-care patients.

Study design: We opted for an ethnographic approach (participant observation). Fieldwork was undertaken from February until October 2012 at a palliative-care unit of a tertiary cancer hospital in North India. 31 patients formally consented to participate in the study. Research notes were made on the basis of the presenting author’s repeated interactions with the patients, their relatives and the treating physicians and nurses, and observations on the ward. The researchers had access to the patients’ medical files. The notes were analysed using conventional content analysis.

Results: Commonly Hindu, Christian, Muslim and Sikh patients expressed their faith in a loving God who helps his devotees and would eventually also cure the patient’s disease. This faith was not rarely actively nurtured by relatives who fearing that loss of hope for a cure would hasten the patient’s death attempted to prevent the patient from considering death as an imminent possibility. In this way, the combination of a specific religious faith and contextual factors made acceptance of diagnosis and prognosis difficult. Moreover, the fact that the hoped-for cure did not materialize, at some point made patients to wonder in despair whether God had forsaken them or did not exist.

Conclusion: Faith in God can be a source of hope and consolation for Indian palliative-care patients. However, under certain circumstances this faith can lead to a crisis which may substantially contribute to a patient’s emotional burden in the last stage of his or her disease. These observations should be taken into consideration while treating and counseling patients of Indian origin in palliative care.
Abstract number: PO160
Abstract type: Print Only

Signs and Symptoms at the End of Life of Children and Adolescents with Cancer and Palliative Sedation at the Institute of Oncology Pediatric in Brazil
Moraes C.V.B.1, Bonfietti D.R.2
1Instituto de Oncologia Pediatrica, UNIFESP, Oncologia Pediatrica, São Paulo, Brazil, 2Instituo de Oncologia Pediatrica, UNIFESP, Pediatric, São Paulo, Brazil

Children with advanced cancer also develop a number of physical symptoms, many times this symptoms are refractory to treatment, them palliative sedation is an important therapeutic for severe symptoms as dyspnea and bleeding.

Palliative sedation is defined as the use of drugs to reduce consciousness as much as necessary to alleviate one or more refractory symptoms.

Although it is practiced on a daily in hospitals and hospices, there has been limited research on pediatric palliative care and palliative sedation em children and adolescent.

This research evaluated the medical records of patients in palliative care retrospectively and evaluate the place of death, the signs and symptoms present in the last 72 hours of life, and the need for sedation to control symptoms that were considered refractory.

Medical Records were evaluated retrospectively in the period from January 2012 until September 2013, patients in palliative care were evaluated, 54 patients, aged between 1 year and 1 month to 26 years old. The most common symptoms at the end of life were pain, dyspnea, and seizures. The most common symptom that was refractory to treatment and required sedation palliative was dyspnea.

The most widely used drug for sedation were midazolam.

Although little is known about the feasibility and effectiveness of palliative sedation in children. The present report concerns children and adolescents with end-stage cancer and severe, treatment-refractory dyspnea and other symptoms cared for by our specialized pediatric palliative care team (in a hospital of treatment for cancer).

Abstract number: PO161
Abstract type: Print Only

Integration and Incorporation of Palliative Care (PC) in Healthcare (HC) System-experience of Former Soviet Countries
Rukhadze T.1,2,3, Lekashvili T.1,2
1Georgian National Academy for Palliative Care - Practical, Educational and Research Resource Centre, Tbilisi, Georgia, 2Iv. Javakhishvili Tbilisi State University (TSU), Tbilisi, Georgia, 3Georgia National Association for Palliative Care, Tbilisi, Georgia

Beginning of XXI century showed remarkable increase in global aging, together with rising incidence and prevalence of cancer, AIDS and chronic illnesses. All these have led to huge numbers of incurable patients, requiring the relevant complex medical and social care due to symptoms and suffering from their illness. A new direction in public health, called PC, serves to this very aim.

The population of every Country can be divided into three main groups: “Healthy”, “Potentially Treatable Patients” and “Advanced Chronic Patients”. Evidently, the HC system must also have three principal directions: Prevention, treatment and PC; If any of the listed directions is omitted, the HC system can’t be considered as perfect, for in this case, the corresponding part of the society becomes deprived of the HC service.

The interviewing of PC services from 7 former soviet countries was performed. The level of their competence, experience, knowledge, tools using for care and opioids availability were evaluated by specially designed questionnaires. The respective database was created and analyzed.

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 in Soviet Period also have prevented the right understanding of this issue.

In most former soviet countries PC still on very basic level of development. The clear understanding of the substance, role and place of PC still remains one of the most essential hindrances on the way of its incorporation in National HC System.

Abstract number: PO162
Abstract type: Print Only

Hoffmann Method(HM), a Welcome Unknown: Bridge, Bond and Support for Elderly People and their Families within EoL Process
Hoffmann Munoz -Seca C.1, Garcia-Baquero Merino M.T.1,2, Salinas T.1, Acolado A.1, Gallego C.1
1Hoffmanelderly-Healthcare Innovations, Madrid, Spain, 2Coordinación Regional de Cuidados Paliativos, Consejeria de Sanidad, Comunidad de Madrid, Madrid, Spain

Background: Palliative Care and Care of the Elderly have much in common and have learnt much from each other.
over time. Today, as they formalize alliances to care for an aged population, ambulatory services start having an important part to play, specially to strengthen Palliative Neurology.

**Aim:** To introduce to the SPC audience the Hoffmann Method and its ten year trajectory caring for the elderly—both healthy “seniors” and those with serious challenges due to the normal process of aging and different pathology—in Day Centres within their very localities.

**Methodology:** Regular monitoring by means of well-established pathways incorporate initial multidisciplinary assessment, electronic documentation, weekly meetings, monthly reports for families and six monthly re-assessments to complete the cycle, produces significant physical and cognitive improvement impulse social dimension activities contributing to sustain quality of life even in very advanced illness. The therapeutic plan is a system based on active cognitive stimulation that aids to modulate brain neuroplasticity. Great importance is given to those issues that can disempower carers: skin care, hydration, oral nutrition and mobilizing.

**Results:** A network of Day Centres run by highly motivated interprofessional team offers a wide range of physical. Mental emotional health services as well as initiatives dedicated to hygiene, leisure and manual, care for thousands of people over a number of years, becoming part of their very active last years. Well informed families engage in the process in an active way which leads to a Wall-less program as they continue the good work at home.

**Conclusion:** HM—a scientific process—makes social death thing of the past. Our elderly and their loved ones don’t live waiting for death but, rather it arrives while they are busy making plans, achieving objectives and hoping.

**Abstract number:** PO163  
**Abstract type:** Print Only

**Are Palliative Care Contents of Interest among Health Workers in a Rural Area in Western Catalonia? Our Experience in an Update Program**

**Canal-Sotelo J.1, Villalba-Fernandez E.2, Camarasa-Barbosa M.2, Larré-Ferrer N.2, Larré-Ferrer N.2, Oliver-Ventaja R.2, Medialdea R.3, Baldomá-Campos G.2**

1UFISS-CP HUAV-GSS, Lleida, Spain, 2Hospital Jaume d’Urgell, Balaguer, Spain

**Introduction:** Several different professional categories are involved in delivering good quality of care at the end of life. In our area (considered as a rural area) there are several settings where palliative care skills are needed in order to look after patients: Home, nursing homes, long term stay hospital, primary health care, home care teams, are between them. And professionals need to update knowledge in specific areas.

In order to spread knowledge and to update those skills, our hospital started on 2010 a programme based on three main activities.

1. One day yearly up to date sessions (from June 2010)
2. Display sessions on the net through the local TV and the hospital website (from June 2011).
3. To upload the content of the formation sessions on a PDF format in the hospital website (from June 2013).

**Methodology:** Descriptive study over the profile (gender, profession, place where skills are displayed) of the professionals that have assisted to the formation sessions over the period 2010 - 2013.

**Results:** A total of 480 participants have joined the updating sessions being the 2010 the one with the lowest inscriptions (n=95) and the 2012 the most popular (n=139). Female participants accounted the 86.5% of the total (n=415). 39% of assistants worked in a nursing home (n=183), 32% in a sociosanitary hospital (n=155). 15% worked in a primary health care centre (n=75). 8% of assistants were students (n=40) and 6% worked in a tertiary hospital (n=27). 34.3% were nurses (n=165) and the 38.3% were nurses auxiliaries (n=184).

**Conclusions:** Palliative care curricula is of interest among health workers in our area. The main objective of providing a continued update opportunity has been achieved.

**Abstract number:** PO164  
**Abstract type:** Print Only

**Multiprofessional Training for Practice and Research in Palliative Care in Undergraduate and Postgraduate Programs**

**De Carlo M.M.R P.1, Lima R.A.G.d.2, Lima N.K.C.3**

1Ribeirão Preto Medical School, University of São Paulo, Department of Neuroscience and Behavioral Sciences, Division of Occupational Therapy, Ribeirão Preto, Brazil, 2School of Nursing of Ribeirão Preto, University of São Paulo, Ribeirão Preto, Brazil, 3School of Medicine of Ribeirão Preto, University of São Paulo, General and Geriatric Medical Clinic, Ribeirão Preto, Brazil

**Introduction:** The philosophy of palliative care (PC) assumes that their teams are multidisciplinary and interdisciplinary in the care of patients with cancer and non-cancer.

**Objectives:** Analyze the vocational training initiatives and scientific education in undergraduate and postgraduate research to doctors, nurses and occupational therapists at the University of São Paulo - Campus Ribeirão Preto.

**Methods:** Descriptive analysis of training initiatives for working and research in PC in undergraduate courses in
Medicine, Nursing and Occupational Therapy and post-graduation.

**Results:** There are theoretical and practical training in graduate courses in many disciplines and research projects, besides assistance activities in different contexts. In the School of Nursing and in the Medical Course, the PC disciplines are electives and in the Occupational Therapy Course, content of palliative care are developed in the compulsory disciplines, in training period and through undergraduate research. In post-graduate courses, trained doctors doing medical residency have internships in the area of PC in two university hospitals. Topics of Palliative Care are included in the professional development program and in the specialization course of Occupational Therapy Hospital. In the School of Nursing, we have a discipline of Palliative Care Cancer and many researchs projects.

**Discussion:** To train professionals able to work in in PC, it is necessary to live the experience of interdisciplinarity. The initiatives are still few, but have grown rapidly.

**Conclusion:** This study indicates the need for multidisciplinary training for the work and research in PC, with differences according to the condition of graduation or postgraduation, and also according to the specific indicators for vocational training in different courses and units where they are inserted. It is essential that the training of health professionals for CP include learning and practicing effectively done as a team.

**Abstract number:** PO165
**Abstract type:** Print Only

**Medical Futilities: Differences between Publicized Exposition and Reality. Example of Brain-damaged Patients**

*Devalois B.*

Service de Médecine Palliative, CH René Dubos, Pontoise, France

For the last 20 years or so, conflicts on life-support for brain-damaged patients have become the object of widespread media coverage. By focusing public opinion on the alleged physicians’ unreasonable obstinacy, these publicized cases impact social debates on life-support. By these, they justify claims for the legalization of assisted suicide, specifically the practice of termination of life by lethal injection.

Via a conducted survey of the various caretakers and families involved in this type of situation, we propose an analysis based on different feeling of potential unreasonable obstinacy. The reasonability or not for life-sustaining treatments (LST) can often be perceived differently by physicians (P), caretakers (C) and families (F). Each one can think these LST are reasonable (R) or unreasonable (U), and so have to be maintained or to be withdrawn.

In such a perspective, 6 different cases can be identified: PR/CU/FU; PR/CR/FU; PR/CU/FR; PU/CU/FR; PU/CR/FU; PU/CR/FR. Publicized cases always involve a conflict between the physicians in charge and the families who view the situation as unreasonable (PR/FU). Nonetheless, evidence shows that in the real life, roles are often reversed, and the families are in fact the ones demanding the use of unreasonable care (PU/CU/FR).

A typical example of this is a recent case that became the object of legal proceedings in France.

As it turns out, the publicized filter does not reflect the true reality of cases involving unreasonable care. Specific procedures could help in notifying the existence of such situations. The role of nurses (and their assistants) appears to play an essential part as “watch-dog” for medical futilities. The model we develop for brain-damaged patients should be very helpful for other medical futilities situations. Then it should be necessary to add a forth player (but not the least): the patient himself. Since 2005, the French Law give always the last world to him.

**Abstract number:** PO166
**Abstract type:** Print Only

**Teletransmission Improve Safety and Efficacy for PCA Pump in Homecare Cancerous Pain Patients**

*Devalois B., Jugan C., Trouillet M.*

Service de Médecine Palliative, CH René Dubos, Pontoise, France

PCA pumps allow painful patient to control basal and breakthrough pain. Initially used in post-operative pain, it’s now a serious alternative to control pain for cancerous patient at home, but these devices are under-used. Physician (often in hospital) prescribed the parameters for the morphinic infusion (PPD=prescribed pump datas). Home nurses (HN) have to program PPD and to monitor how patient use bolus (PUD=patient use datas). If pain control is insufficient, HN inform physician, this one modify PPD, then contact HN to reprogram the device. A long time and some mistakes can occur during these exchanges. So, teletransmission between at-home pump from at-hospital physician can be very helpful for better use.

With teletransmission, PDD and PUD are transmitted via GSM network to a specific server. They could be consulted in real time by the physician via protected internet site. By the way, physician can check if PPD are right programmed and if PUD analysis make necessary to modify PPD. It’s also possible to check the battery level and the end-bag hour to optimize change and filling.

It’s only one device in the European market with such a possibility for teletransmission (Micrelcare®). We used it since May 2012 for more than fifty cancerous painful patients at home. In our experience, teletransmission can
dramatically improve safety and efficacy. Mistakes in HN programming the prescribed parameters can be avoided. Daily Consulting PUD, allows physician to quickly adapt the PPD for a better efficacy and best pain control without patient have to come back to the hospital. Causes of failures for at-home PCA are several (not waited events, inefficacy …). Teletransmission decrease all of them and increase number of “days with PCA and without pain at home” for all our patients.

We conclude that more widespread use of teletransmission is an important challenge for the next years to improve better pain control for at-home cancerous painful patients.

Abstract number: PO167
Abstract type: Print Only

Can a Novel Diuretic Tolvaptan Improve the Edema of Advanced Cancer Patients?

Akashi N.1, Okamoto Y.1, Takei K.2, Nakagawa S.1, Tanaka I.1, Mita A.1, Shindo K.2
1Ashiya Municipal Hospital, Pharmacy, Ashiya, Japan,
2Ashiya Municipal Hospital, Palliative Medicine, Ashiya, Japan

Aims: Loop diuretics have a limited effect on ascites, pleural effusion and generalized edema of advanced cancer patients and these are ineffective in improving the symptoms. Tolvaptan is a novel diuretic with a new mechanism of action, selectively binds to the vasopressin V2 receptor and inhibits reabsorption of water and it has potential clinical benefits for the treatment of edema if the effect of loop diuretics is insufficient. Therefore the effect of Tolvaptan on generalized edema of patients with advanced cancer has not been studied.

Methods: All patients with cancer who used Tolvaptan during their hospital stay between September 2012 and August 2013 were enrolled. The medical records for the duration of Tolvaptan use were reviewed retrospectively. The data of patients included gender, age, primary cancer site, indications of Tolvaptan, dose of Tolvaptan, duration of Tolvaptan administration, reason for discontinuation of Tolvaptan administration, adverse event, and so on.

Results: During the study period, a total of 31 patients received Tolvaptan. Among these, 25 patients were for the treatment of leg edema and 14 were for the treatment of ascites. The median Tolvaptan dose was 7.5 mg and the median duration of administration was 10 days. The average thigh circumference before the administration was 43.7±3.4 cm and it also decreased to 39.9 ±4.5 cm after the administration. The most common reason for discontinuation of Tolvaptan was improvement of symptom and the discontinuation of therapy due to adverse event was only one patient whose serum potassium was modestly increased. The physician subjective symptom improvement of edema was achieved 16.5%. However, the patient subjective symptom improvement of edema was 9.9%.

Conclusion: To clarify the benefit of Tolvaptan use in advanced cancer patients, further study such as, increase the study patients and determine the potential factors that contribute to symptom improvement of edema should be undertaken.

Abstract number: PO168
Abstract type: Print Only

Differences in Clinical Symptoms Experienced by Palliative Care Inpatients within the Last 48 of Life: A Pilot Study

Rhondali W.1,2, Behagel G.1, Berthiller J.3, Ledoux M.1, Dubois S.1, Ravallec F.1, Filbet M.1
1Hospices Civils de Lyon, Centre de Soins Palliatifs, Lyon, France, 2MD Anderson Cancer Center, Palliative Care, Houston, TX, United States, 3Hôpital Saint Thomas de Villeneuve, Aix en Provence, France, 4Hospices Civils de Lyon, IMER, Lyon, France

Background: Identification and information about impending death can prevent from aggressive or inappropriate care in the last hours of life. Our aim was to explore differences in clinical symptoms within the last 48 of life of palliative care inpatients.

Methods: This was a prospective observational study of consecutive inpatients in the palliative care unit. From a list of 46 symptoms created by a multidisciplinary group of palliative care professionals, we obtained a final list of 24 symptoms. Assessments were systematically conducted on the day of admission and every single day the team checked for any deterioration of the patient’s condition.

Results: 108 patients were admitted to the unit and 83 patients were included. The most common symptoms within the last 48 hours were anorexia (70%), pressure ulcer (59%), and skin discoloration (57%). We found changes in the last 48 hours for pressure ulcer (p<0.001), skin discoloration (p<0.001), cold extremities (p<0.001), mottling on the knees (p=0.002), cyanotic extremities (p<0.001), anorexia (p=0.002), anuria (p<0.001), fixed stare (p=0.006), dropping of the lower jaw (p<0.001), dyspnea (p=0.02), pauses in breathing (p=0.02), death rattle (p<0.001), and fever (p<0.001).

Conclusions: Our findings show that there were significant differences in symptoms during the last 48 hours. After anorexia, the most frequent clinical signs during the last 48 hours were signs of local peripheral shutdown. These results need to be confirmed by multicentric longitudinal studies with larger samples.
Abstract number: PO169
Abstract type: Print Only

Romanian-Swiss Research Program IZERZO: Protocol Development of the “Reality Map of Integrated Oncology and Palliative Care (PC) in Romanian Cancer Centres”


1Cantonal Hospital St. Gallen, Oncological Palliative Medicine, Oncology, Dept. Internal Med & Palliative Centre, St. Gallen, Switzerland, 2The Oncology Institute “Prof. Dr. I Chiricuta”, Cluj-Napoca, Romania, 3Spiralul Judetean de Urgenta, Alba Iulia, Romania, 4Institute of Oncology, Bucharest, Romania, 5Hospice Casa Sperantei, Brasov, Romania, 6Regional Oncologic Institute, Iasi, Romania, 7CTU, Cantonal Hospital, St.Gallen, Switzerland

Background: The integration of PC in routine oncological care remains challenging, particularly in resource-restricted, culturally diverse, and regulatory/legal dispersed settings like Romania. We aim to collect a reality map about the implementation of Key-Interventions Palliative-Cancer-Care (KI-PCC) and specific outcome quality indicators (QI). We also hypothesize that KI-PCC will predict QI.

Methods: Prospective, longitudinal, multicentre data collection in 5 Romanian and 1 Swiss institution for 6 months or until death with validated tools for PC needs (symptoms [IPOS], quality-of-life [EQ5D]), patients (pts) or family members (fam) perceived KI-PCC, and QI, collected on randomly selected pts in predefined populations having advanced incurable cancer and defined minimal symptom burden. KI-PCC encompass

1. illness understanding and pt education,
2. symptom screening/management,
3. decision making (e.g. cancer tx),
4. coping with life-threatening illness/ end-of-life preparation,
5. support network of pts and fam.

As primary composite endpoint (cEP) 5 defined QI include aggressive anticancer treatment, high symptom burden, repeated ER admissions, aggressive end-of-life-care, and quality of death and dying (QoDD). Co-factors include age, gender, living situation, income, comorbidities, place & type of care, urban/rural, ECOG, anticancer treatment, tumor type, and institution. Appropriate KI-PCC and QI will be reviewed by inter PC-experts before data analysis. The primary analysis will use multiple linear regression (KI-CC versus QI-score, adjusted for co-factors) in 300 pts (20% attrition rate).

Results: We developed KI-PCC assessment and translated / validated KI-PCC and QoDD in Romanian and German. Accrual is ongoing, interim analysis is foreseen 4.2014, final results 6.2014.

Expected impact: The results will provide the basis for implementation of tailored interventions of PC procedures provided by oncologists and other health care professionals.

Abstract number: PO170
Abstract type: Print Only

Design and Development of a “Team Work for Palliative Care” Units Seminar

Noguera A.1, Noguera J.2, Martin Molpeceres E.1, Carrascal E.1, Rocafort J.1

1Hospital CC Laguna, Madrid, Spain, 2Cenyt Consultants, Madrid, Spain

Teammwork is a keystone in palliative care. For a holistic care of the patient and his family it is a must having a multidisciplinary team working in an integrated way, sharing both situational leadership and goal achievement. To date and according to the knowledge of the authors of this work, no specific teaching or learning activities have been designed to develop attitudes, knowledge and skills for team building in palliative care teams.

Aim: To design a specific seminar for the training and development of teamwork skills in a palliative care team which will:

1. Strengthen the understanding and motivation for teamwork in palliative care units (PCU).
2. Stress the need to work with the attitudes, reinforce the knowledge and train the skills to be developed according to the situational influence model suggested.
3. Work with cases and specific role plays for PCU to help the transfer of the learning to the professional reality of the participants.

Methodology: An experienced training consultant with a long record in human resources and team work in the business world, modelling Reality Based Training (RBT) sessions, led a consultative ground study and research along with a medical doctor specialized in palliative care, sharing healthcare activity and clinical meetings with the multidisciplinary team. Five cases for specific teamwork were designed, then evaluated by experts in the different areas (doctors, nurses, psychologists and social workers), and subsequently rewritten according to the feedback received.
**Results:** A seminar for “Team Work in Palliative Care” has been structured, designed and developed with the following cases:

1. Ideal Organization
2. Medical Centre
3. Listening under pressure
4. Conflict management
5. Final case: “Validation”

**Conclusions:** The structure, design and development of a seminar focused in the active education and training to acquire knowledge and skills for team building to work in palliative care units.

**Abstract number:** PO171
**Abstract type:** Print Only

**Pain Control “Hemibody Technique” for the Treatment of Multiple Bone Metastases in Cancer Patients Included in the Palliative Care Program**

Ramos Villaran E.1, Muñoz Carmona D.1, Uceda Torres E.2, Rodriguez Rodríguez J.N.1, Bayo Lozano E.1, Sanchez Segovia J.1

1Hospital Juan Ramon Jimenez, Radiotherapy Oncology, Huelva, Spain, 2Hospital Juan Ramon Jimenez, Palliative Care, Huelva, Spain, 3Hospital Juan Ramon Jimenez, Hematology, Huelva, Spain

**Introduction:** Patients oncologicals palliative with dissemination of the disease oncological constitute 37% of the patients oncologicals of Spain according to the WHO. These patients are submitted to wide pharmacological consistent treatments in opioids, helping and other analgesic medicaments to relieve the pain (sharp, chronic or neuropathic). Sometimes the list of medicaments that these patients have for the control of the pain is endless besides that there is information that up to 25% of the oncological patients in situation of terminal die with an inadequate control of the pain.

**Aims:** The fundamental aim of this work has been to value the impact of the irradiation hemiborporal with Hemibody’s Technology to the only dose for those patients with dissemination of the disease (MO) and the repercussion that has on the pain, quality of life and managing medicament opioids in the same ones.

**Material and method:** From July, 2012 until August, 2013, 35 patients were submitted to RT of wide field according to the described technology. The administered dose was to 6 Gy for the top hemicuerpo and 8 Gy for the low hemicuerpo.

**Results:** Unlike the classic treatment of radiotherapy for bony metastases, with the technology of irradiation hemiborporal, the response to the pain (initial EVE final-EVA) was 100%. The patients with initial EVE of 10 (14%) the response posttreatment was EVE 3, initial EVE of 9 (14%) improved up to EVE of 2; initial EVE of 8 (71%) they improved even one EVE of 1. All the patients improved in his Performance Status, on having improved the painful clinic and this one reverberated positively in his quality of life.

**Conclusions:** The irradiation hemiborporal of wide field or Technology Hemibody in patients with multiple bony metastases in an alone session, it reduces the pain and the need of analgesic medicaments during the period of remaining life, with low toxicity and good tolerance.

**Current Practice of Artificial Nutrition and Hydration in Dying Cancer Patients - A Retrospective Chart Review**

Bükki J.1,2, Unterpaul T.1, Lorenzl S.1,3

1Ludwig Maximilians Universität, University Hospital, Campus Grosshadern, Department of Palliative Medicine, München, Germany, 2Hospice DaSein, Mobile Palliative Care Team, München, Germany, 3Ludwig Maximilians Universität, University Hospital, Campus Grosshadern, Department of Neurology, München, Germany

**Background:** The questionable benefit of providing artificial nutrition and hydration (ANH) at the end of life (EoL) has been described, but little is known about actual policies. Hence, the aim of this study is to evaluate current practice.

**Methods:** Retrospective chart review embedded in a prospective survey of cancer patients who died in medical and surgical wards of a German university hospital. All consecutive adult inpatients hospitalized for a minimum of 7 days before death were included. Evidence of ANH discussions, advance directives (AD), and pharmacotherapy at the EoL were recorded.

**Results:** Of 45 included subjects (30 females, mean age 67 ± 11 years) within a 10 months period, 15 had died on a palliative care unit (PCU), 10 in the Radiation Oncology, 9 in the Hematology, 8 in the Neurology, and 3 in the Ear, Nose, and Throat Department, respectively. In 11 cases, evidence of ANH discussion was found. 15 patients received any kind of enteral or parenteral combined ANH during the last week of life, 2 nutrition only, 22 hydration only, and 6 none of the above measures. In 15 out of 30 patients who were dying in departments other than the PCU, the palliative care inpatient consultation team was involved. 12 patients had an AD completed, of whom 11 declined nutrition and/or hydration. Of these, 8 patients received hydration and 4 nutrition against their documented will. Patients were administered drugs from 3.1 ± 1.7
classes for symptom control and from 2.6 ± 1.6 classes as life-sustaining measures. Nutrition recipients were also administered more life-sustaining drugs. **Conclusion:** Within this sample of patients dying of cancer, most individuals received ANH at the EoL. Evidence of ANH discussion was fragmentary, and ADs were not reliably adhered to. Specific education and routine involvement of Palliative Care services may improve EoL care.

**Abstract number:** PO173  
**Abstract type:** Print Only  
**Is the Recognition of the Dying Phase Masked by the Use of Dexamethasone?**  

van Esch H.J.1,2, Lokker M.E.1, van der Heide A.1, van Zuylen L.1  

1Erasmus Medical Centre, Rotterdam, Netherlands,  
2Laurens Cadenza, Rotterdam, Netherlands

Communication with patient and family to mark the last phase of living and the start of the dying phase is important to provide patients with as much comfort as possible and to prevent complex or prolonged mourning of relatives. We describe four patients in a hospice setting in whom we were not able to mark the start of the dying process and who died relatively unexpectedly. Until the last day, they were not bedbound, but still walking around and they ate and drank relatively well. They showed no signs of reduced consciousness. All four deaths could not be attributed to a cardiac arrest, pulmonary embolism or sepsis. Both the family and the care team were overcome by patients’ rapid deterioration and death, which resulted in reactive instead of proactive communication and in three of the four cases in prolonged mourning of relatives. There was only one characteristic all patients had in common: the use of dexamethasone. It made us wonder, if the use of dexamethasone can mask recognition of the dying phase.

Dexamethasone is widely prescribed in palliative care, though evidence for its use is weak and inconclusive. In three studies, the frequency of its use until death was found to be between 50 and 70%. Dexamethasone is used for specific indications such as cerebral metastases and bowel obstruction, and nonspecific indications such as poor appetite, nausea and poor well-being. The effects of dexamethasone are focused on a number of physiological processes. As a result, patients may feel better and stimulated.

We searched the literature for evidence that the use of dexamethasone masks the recognition of the dying phase, but found no studies which support or reject this hypothesis.

We conclude that there is need for further exploration of the effects of dexamethasone in the dying phase.

**Abstract number:** PO174  
**Abstract type:** Print Only  
**Does the Use of the interRAI Palliative Care Instrument Improve the Quality of Palliative Care in Nursing Homes?**  

Hermans K.1, Spruytte N.1, Cohen J.2, Van Audenhove C.1, Declercq A.1  

1KU Leuven, LUCAS, Center for Care Research and Consultancy, Leuven, Belgium, 2Vrije Universiteit Brussel & Ghent University, End-of-Life Care Research Group, Brussels, Belgium

**Research aims:** The interRAI integrated Suite of Instruments is a set of comprehensive geriatric assessments (CGAs) to support assessment and care planning in mental health, disability services and aged care. The interRAI Palliative Care instrument (interRAI PC) was developed as part of the interRAI Suite of instruments. InterRAI PC is a CGA which evaluates the diverse needs and preferences of adults requiring palliative care in all healthcare settings. Given that nursing homes are playing an increasing role in caring for older adults with palliative care needs, the aim of this study is to determine whether the use of the interRAI PC instrument improves the quality of palliative care in nursing homes.

**Study population:** Nursing home residents with palliative care needs.

**Study design and methods:** A case-matched control study for complex interventions will be conducted. Variables will be used for matching ten experimental nursing homes to ten control nursing homes. Unlike the control nursing homes, the experimental nursing homes will fill out interRAI PC during one year for all residents receiving palliative care. To assess the quality of palliative care in the experimental and control nursing homes, both groups will fill out the Palliative Care Outcome Scale (POS) before and after the intervention period for all nursing home residents with palliative care needs. The quality of palliative care will be compared before and after the intervention and between the experimental and the control groups.

**Results:** The pretest POS-results on the quality of palliative care in ten experimental and ten control nursing homes, will be available for presentation from December 2013.

**Discussion:** Based on the results of this study, we will be able to determine whether the use of the interRAI Palliative Care instrument improves the quality of palliative care in nursing homes.

**Abstract number:** PO175  
**Abstract type:** Print Only  
**Palliating Social Media in Palliative Care**
Taubert M.¹, Gupta S.², Jason B.¹, Watts G.², Radbruch L.³
¹Velindre Cancer Centre, Palliative Medicine, Cardiff, United Kingdom, ²Cardiff University, Cardiff, United Kingdom, ³University of Alberta, Edmonton, AB, Canada, ⁴Catholic University of Portugal, Lisbon, Portugal, ⁵Nursing School of Coimbra, Coimbra, Portugal

**Background:** Comfort is a complex intervention that represents an holistic condition that is difficult to define, to evaluate and to implement. Scientific evidence has focused particularly on the concept analysis but is rather fruitful in studies to clarify and justify the comfort as an activity and the implementation of comfort measures that could operationalize that act. In this context, the following research questions emerged: What are the activities that define the comfort intervention? What are the effects of comfort intervention in the comfort of the person with cancer in palliative care?

**Aims:** To develop and to evaluate the comfort intervention in a population of cancer patients in palliative care.

**Methods:** The method proposed by the Medical Research Council for the development and evaluation of complex interventions will be followed. In the first phase (Development), the intervention will be defined and conceptualized through a systematic literature review and patients interviews. Subsequently, the intervention will be tested and improved in a quasi-experimental study, in a sample of cancer patients in palliative care (Pilot Study). In the third phase (evaluation), the intervention will be evaluated in a longitudinal and experimental trial. In the final phase (dissemination), the intervention will be monitored and disseminated.

**Results:** The first phase preliminary results’ (still in progress) suggest that comfort is essential to life, not only for the patient but also for their relatives. Comfort interventions are not only therapeutic but also preventive and comfort needs are present in all human life dimensions. Studies focus particularly on physical comfort needs while spiritual comfort is the least studied.

**Conclusions:** This longitudinal study will contribute to improve the patient comfort care and the comfort knowledge, including the concept definition, its attributes and the validation of the most significant and more efficient interventions.

**Abstract number:** PO177
**Abstract type:** Print Only

Covenant Health Palliative Institute: A Model of Community-engaged Scholarship

Fassbender K.¹,², Syme A.², Fainsinger R.¹, Macmillan K.²
¹University of Alberta, Edmonton, AB, Canada, ²Covenant Health, Edmonton, AB, Canada

Integrating clinical, education, research, leadership and administrative best practices through extensive consultation
with regional palliative care programs resulted in the establishment of a bricks and mortar palliative institute. Founded in Canada (1738) by Saint Marguerite d’Youville, the Grey Nuns represent a faith-based approach to the relief of suffering. Nearly three centuries later, faith meets medicine and science to create an institution, built on a solid foundation, and is poised to augment and transform palliative care in Alberta. The Institute is poised to learn from Western Canada’s internationally recognized model of regionally integrated, coordinated and comprehensive palliative care services. By forging strong relationships with universities, government and health authorities, the Institute will transform the financing and delivery of palliative care. Building on local strengths in advocacy, symptom assessment, the science of muscle wasting, health policy and addressing non-cancer needs. Early initiatives include the deployment of end of life pathways, patient satisfaction surveys and advanced care planning. We are currently supporting our partners to establish provincial strategies, including an integrated knowledge translation approach to the development of a provincial palliative program. Finally, the Institute will continue to encourage and nurture national and international collaborations.

Abstract number: PO178
Abstract type: Print Only

Dynamic Modelling to Explore the Transition and Improvement of Quality at the End-of-Life
Forero R.1, McDonnell G.1,2, Hillman K.1

1University of New South Wales, Simpson Centre for Health Services Research, Randwick, Australia, 2University of New South Wales, Centre for Health Informatics, Randwick, Australia

Systems modelling is the application of techniques to address complex problems in order to test new theoretical based constructs to guide research and clinical practice.

End-of-Life has been defined by the WHO as “that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.” A key concept is the transition of goals of treatment from active to palliative care. It has been identified as a pivotal component for improving quality of life at the end-of-life.

The aim of this project is to develop the trans-theoretical model into a formal computational model to run virtual experiments able to explore the dynamics of the timing, preparation and consequences of end-of-life decisions. The trans-theoretical model of change developed by Prochaska and Diclemente in the early 1980s is combined with the sense of coherence model which was developed by Antonovsky to explain resilience in the face of adversity (from the patient’s perspective) and the Process of End-of-life decision-making, developed by the NSW Government in 2005 to understand the transition from the treatment team’s perspective.

The model has been formulated to run simulations that can help to inform dynamic hypotheses, formulate research questions and guide data collection from patients, families and care providers. This model can also be used to transfer knowledge and educate the general public about these concepts.

Abstract number: PO179
Abstract type: Print Only

Factors Decreasing Anxiety in Preoperational Period: Cancer Patients’ Experiences and Points of View
Omidvari S.
Health Metric Research Center, Iranian Institute for Health Sciences Research, ACECR, Mental Health Research Group, Tehran, Iran, Islamic Republic of

Aims: Preoperational period provokes so much anxiety for patients, especially for those with cancer. Considering effects of anxiety in such a period, alleviating it is very important. Meanwhile, patients’ experiences and points of view can be so helpful for health care providers. This study examines experiences and points of view of patients with cancer regarding factors alleviating anxiety in preoperational period.

Methods: A qualitative study using semi structured in-depth individual interview and purposive sampling was carried out in different wards of a major hospital in Tehran, Iran.

The interviews were continued until data saturation. The all interviews were recorded and transcribed verbatim. Then the data were coded and categorized based on subjects and areas using a thematic variable-oriented analysis.

Results: In all, 24 patients with cancer were interviewed. The study findings indicated themes including “knowledge and performance of medical team members” (e.g., having a supportive relationship with the patient, providing information on the disease and different treatment methods, answering patients’ questions, …), “beliefs and spiritual issues” (e.g., reliance on God, praying, attributing the disease to the paranormal and feeling lack of control, vowing, …), “having sources of support” (economically, emotionally, taking care of patient’s children, helping with doing housework, …), “patient’s internal conversations”, “having history of surgery”, “patient’s coping styles with life events during his life”, “stories about patients with good prognosis”, “taking anti anxiety drugs”, “physical conditions of the hospital”, and “scientific improvements to treat cancer”.

Conclusion: The study findings show that from patients’ points of view and experiences, different factors
can affect their anxiety in preoperational period, some of which are roles that medical team members must and can play.

**Abstract number:** PO180  
**Abstract type:** Print Only

**Palliative Care in Cardiology: A New EAPC Task Force**  
Sobanski P.¹, Alt-Epping B.²

¹Palliativzentrum Hildegard, Basel, Switzerland, ²Universitätsmedizin Göttingen Georg-August-Universität, Abteilung Palliativmedizin, Göttingen, Germany

**Introduction:** Morbidity and mortality due to heart failure (HF) are increasing and will continue to rise. 3% of the population is affected with HF. 5% of HF patients fulfil the criteria of end-stage disease because of symptom load, risk of frequent hospitalisation and death. They suffer from distressing symptoms and need intensive medical services. The best state-of-the-art care is crucial for improving the quality of life of patients, as well as for the optimal utilisation of health care resources. Palliative care (PC) help to cut the costs of medical care by reducing the rate of readmission of patients approaching end of life to intensive care units.

**Aims and objectives of the Task Force:** The goal of the Task Force (TF) is to join efforts and available expertise across Europe to improve the care of patients with advanced HF and to coordinate development. The TF will invite members from cardiology and palliative care representatives, from medical and nursing staff. Ethicists and lawyers will be invited to give support to complex decision making in relation to patients with advanced HF. The needs of patients, caregivers and health service providers will be analysed. Reviewing current evidence and summarising gaps in knowledge and care will help to manage future research. Implementation policies, as well as under- and post-graduate teaching pathways, will be proposed. Meeting of the Initiative Group is planned for Feb. 2014. It is expected to generate priorities in domains: care, ethics, research, policies and education. The work agenda and an invitation to join the Initiative Group can be presented at the EAPC Congress. The TF will be guided by a Steering Committee to enhance the effectiveness. The TF will

1) deliver EAPC guidelines on PC in HF;  
2) stimulate cooperation between the HF Association of European Cardiac Society and EAPC;  
3) stimulate the introduction of palliative care basics into the core curricula for cardiologists, and cardiology basics for palliativists.

**Abstract number:** PO181  
**Abstract type:** Print Only

**Exploring Resilience in Healthcare Professionals Working in Generalist End of Life Care Settings**  
Middleton-Green L.I.

University of Bradford, Nursing, Bradford, United Kingdom

“Lacking compassion” is how numerous reports have described care given to people at the end of life in generalist settings such as care homes and acute hospital wards; grim pictures have been painted of elderly patients with dementia lying in their own excrement. Emphasis is being placed on educators responsibility to enhance the teaching of compassion in pre-registration nursing and medical education.

However, the evidence suggests that it is not compassion which is lacking, but rather that staff can either be facilitated or inhibited from compassion action dependent on modulating effects of micro (internal), meso ( interpersonal) and macro (systemic/organisational) factors in the clinical environment. Quality of care is known to have a direct correlation with the resilience, or equanimity, of the staff involved in the provision of this care, although this has only been shown in certain clinical settings to date; namely, specialist palliative care, accident & emergency, mental health and intensive care. Given that the vast majority of people will die in generalist care settings, this is an area which has been under-researched, and the nature of daily clinical practice is poorly understood.

This presentation will focus on the first stage of qualitative ethnographic study of end of life care in an acute hospital ward in the north of England, reporting on the emerging factors that facilitate and inhibit emotional resilience in healthcare professionals at key stages of the patients’ journey towards death.

**Abstract number:** PO182  
**Abstract type:** Print Only

**Malignant Pleural Effusion Management in a Hospice**  
Ferguson A.¹, Penketh A.², Perkins P.³,⁴

¹Gloucestershire Hospitals NHS Foundation Trust, Gloucester, United Kingdom, ²Gloucestershire Hospitals NHS Foundation Trust, Respiratory Medicine, Cheltenham, United Kingdom, ³Sue Ryder Leckhampton Court Hospice, Cheltenham, United Kingdom, ⁴Gloucestershire Hospitals NHS Foundation Trust, Cheltenham, United Kingdom

**Aims:** We present a case of pleural effusion secondary to malignancy managed with repeated ultrasound-guided aspiration in a specialist palliative care unit. An algorithm
for the management of pleural effusions secondary to malignancy is suggested.

**Methods:** A patient presented to hospital with ascites and was diagnosed with peritoneal mesothelioma in 2002. He underwent radical omentectomy and splenectomy with adjuvant peritoneal chemotherapy. The ascites reaccumulated requiring therapeutic drainage at 2 weekly intervals.

In 2006 a continuous ambulatory peritoneal dialysis catheter was placed to allow repeated daily drainage at home. He describes this intervention as ‘life changing’ and allowing him to regain some sense of control.

In 2010 he developed dyspnoea secondary to a recurrent pleural effusion which meant he required repeated admissions to the Oncology Centre. He declined the option of a having an indwelling drain as he already had the peritoneal drain and did not want a second indwelling drain.

In 2011 he was referred to the local hospice to see if there was anything that could be done to improve his experience of pleural drainage. Using ultrasound guidance pleural aspiration of up to two litres is performed every four weeks. The patient has had eighteen procedures up to August 2013. His stay is 2 hours compared with the 3 days he used to spend in the hospital.

**Results:** This case led the hospice to work with a local respiratory physician to devise an algorithm for management of pleural effusions secondary to cancer. Hospices can be an option for repeated therapeutic aspirations. These may be the best option for patients where pleurodesis is unlikely to be successful; aspirations are thought to be needed infrequently or patient choice.

**Conclusion:** This case highlights that hospices can help in the management of pleural effusions and can give patients a good experience. We believe that they should be considered as an option for this procedure more frequently.

**Abstract number:** PO183

**Abstract type:** Print Only

**Psychometric Properties of Detection of Emotional Distress Scale in Caregivers (DED-C) of Advanced Cancer Patients. Preliminary Results**

Limonero J.T.¹, Mateo D.², Maté-Méndez J.³, González-Barboteo J.², Bayés R.¹, Bernaus M.³, Casas C.³, López M.³, Sirgo A.², Viel S.⁸

¹Universitat Autònoma de Barcelona, Stress and Health Research Group, Faculty of Psychology, Bellaterra (Cerdanyola del Vallès), Spain, ²The ‘Qualy’ Observatory, WHO Collaborating Centre for Public Health Palliative Care Programmes, Institut Català d’Oncologia, Chair of PalliativeCare, University of Vic, L’Hospital de Llobregat, Spain, ³Hospital Duran i Reynals, Institut Català d’Onologia, Psycho-Oncology Unit, Stress and Health Research Group, Faculty of Psychology, Universitat Autònoma de Barcelona, L’Hospital de Llobregat, Spain, ⁴Palliative Care Service, Institut Catalá Oncologia, Bellvitge Biomedical Research Institute (IDIBELL), L’Hospital de Llobregat, Spain, ⁵Corporació Sanitària Parc Taulí, Sabadell, Spain, ⁶Consorci Sanitari de Terrassa, Palliative Care Unit, Terrassa, Spain, ⁷Hospital Universitari Sant Joan de Reus, Grup de Recerca en Oncologia, Reus, Spain, ⁸Fundació Hospital-Residència Sant Camil, Sant Pere de Ribes, Spain

**Background:** Primary caregivers of advanced cancer patients usually have high levels of psychological distress. To alleviate their emotional distress is necessary to assess it.

**Aim:** To determine the psychometrics properties and the clinical utility of the Detection of Emotional Distress Scale in Caregivers (DED-C) of advanced cancer patients attending in a Palliative Care Unit (PCU).

**Participants and methods:** Is estimated that approximately 100 caregivers of advanced cancer patients admitted to five Catalanian PCU (Spain) will participate in this study after give their consent. The caregivers will respond DED-C administered by trained physicians and throughout a semi-structured interview conducted by psychologists responded others tools: Reduced Zarit Scale (RZS), Emotional Thermometer (ET), Anxiety (A) and Depression (D).

**Results:** In this moment we are ready to begin with the phase of data collection and the results of data analysis will be presented in the congress. According previous pilot study we expect to obtain that approximately half of caregivers will have moderate to severe emotional distress. We expect that the cut-off point for DED-C evaluated by means of Receiver-Operating Curve (ROC) suggest that the best ROC curve will be probably a value ≥ 9, with specificity and sensitivity around 75%. We assume that these results follow a similar pattern obtained with a similar tool developed by our team related to the detection of emotional distress of patient with advanced care. Probably also we will find positive and significant statistically intraclass correlations with ET, RZS, A and D.

**Conclusions:** According previous experience we suppose that DED-C will be an useful and easy tool to use for the identification of emotional distress of caregivers of advanced cancer patients being attended in a Palliative Care Units. We propose that the systematic use of DED-C as a screening tool for emotional distress will allow us early specific psychological intervention.

**Abstract number:** PO184

**Abstract type:** Print Only

**A Protocol for the Development of the Palliative Care Outcome Scale for Dementia (POS-Dem): An Intervention for People with Dementia Living in Residential Care Homes**

Ellis-Smith C., Evans C.J., Higginson I.J., Daveson B.A.
King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

**Aim:** To develop and establish the clinical utility of an outcome measure-education intervention to aid long-term care setting staff screen, identify and monitor palliative care problems; and communicate these to primary healthcare staff in order to improve symptom management and quality of life in residents with dementia.

**Methods:** The research protocol draws upon the Medical Research Council framework for developing and testing complex interventions and the principles of outcome measure development.

**Results:** A three-phase study:

1) a systematic review and narrative synthesis in order to adapt the Palliative care Outcome Scale (POS) for people with dementia and develop training and guidance for use;
2) qualitative study involving focus groups, and cognitive interviews, to examine and explore the underlying mechanisms of action and establish the content validity of POS-Dem;
3) a mixed-methods pilot to test and explore the psychometric properties of POS-Dem, understand its acceptability and feasibility for routine use, and establish the underlying mechanisms of action.

**Conclusion:** A programmatic research approach to developing and evaluating a complex intervention in a cross-sector multi-disciplinary setting is required in order to ensure the translation of findings into practice. This novel design allows for the examination of outcome measurement, education, intervention and context phenomena.

**Abstract number:** PO185

**Abstract type:** Print Only

**Advance Care Planning - A Way to Improve End-of-Life Care**

Morret - Raus M.S.

CHU Brugmann, Oncology - Palliative Care, Bruxelles, Belgium

Since the partial depenalization of euthanasia in Belgium in 2002, the number of declared euthanasias increases each year.

The acceptance of euthanasia nevertheless remains a source of polemic.

Some opponents to euthanasia maintain that, when patients benefit from appropriate palliative care, there are no requests for euthanasia.

To clarify that question, we collected the reasons given by 88 consecutive patients in our hospital to obtain active euthanasia between November 2005 and October 2013.

Our results show that pain was involved in only 2 patients decisions.

Abstract number: PO186

Abstract type: Print Only

**Why Do Patients Ask for Euthanasia ? Experience of a University Supportive and Palliative Care Unit in Brussels (Belgium)**

Morret - Raus M.S.

CHU Brugmann, Oncology - Palliative Care, Bruxelles, Belgium

Since the partial depenalization of euthanasia in Belgium in 2002, the number of declared euthanasias increases each year.

The acceptance of euthanasia nevertheless remains a source of polemic.

Some opponents to euthanasia maintain that, when patients benefit of appropriate palliative care, there are no requests for euthanasia.

To clarify that question, we collected the reasons given by 88 consecutive patients in our hospital to obtain active euthanasia between November 2005 and October 2013.

Our results show that pain was involved in only 2 patients decisions.
Symptoms like exhaustion, incapability of eating, uncontrolled dyspnea were found in almost a third of the cohort of patients, associated with concomitant mental suffering.

In the large majority of our patients, the justification of the request was only psychological suffering related to loss of self-sufficiency, feeling of downfall, loss of dignity and despite family, social and care givers psychological and spiritual support.

Our results are concordant with the data of the Belgian Federal Commission for Control and Evaluation of Euthanasia, which collects the notification of all euthanasias in Belgium since 2002.

Abstract number: PO187
Abstract type: Print Only

Introduction of an “Infodesk Palliative Care” in a University Hospital

Rombouts W.¹, Bossuyt I.¹, Menten J.J.²

¹University Hospital, Palliative Care, Leuven, Belgium
²University Hospital, Radiation Oncology and Palliative Care, Leuven, Belgium

Introduction: Palliative care is frequently started too late in diseases, opportunities for a qualified end of life for many patients are missed. An “Infodesk Palliative Care and end of life decisions” (PC&EO) for patients and families was installed to try to overcome this problem.

Material and methods: An eye-catching info stand was installed since October 2013 in a very busy corridor in the university hospital by the palliative support team to bring PC & EO information as close as possible to patients and their families. The initiative was supported by the hospital direction and the palliative reference caregivers of all medical disciplines. Patients and/or families were provided with verbal information, stimulated to make appointments with their regular caregivers to start palliative care conversations. Hospital-made and (inter-)national brochures about symptom control, palliative care possibilities, bereavement and the working of palliative care networks were available. Web-based material and information about legal issues could be provided.

Results: All questions at this info desk from patients/families were prospectively registered and stratified by type, the time in the disease trajectory, was the question to support the patient, the family or both? It was immediately clear that this low threshold initiative filled a gap of information concerning palliative care and end of life decisions for patients and families. This initiative empowered patients & families to start early palliative care conversations with their regular caregivers and the professionals are pleased that they can answer these already well-prepared questions, which makes the conversation for them much easier and more efficient for all of them.

Conclusion: An info desk provides PC & EO information for patients and families in an university hospital and facilitates the early palliative care conversations with the regular caregivers.
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