Welcome to Lleida

Palliative care researchers from all over the world meet in Lleida, Spain, 5-7 June 2014 to showcase and discuss cutting edge research within the field.

Will you join us?

Deadline for abstract submission: 15 October 2013

www.eapcnet.eu/research2014
Foreword

Dear Congress participant,

Welcome to the EAPC World Congress in Prague!

This Congress has all the ingredients that are needed to deliver high quality palliative care wherever you are in the world. Whether this is your first Congress or if you are a regular attendee, I am sure there will be much in the programme to whet your appetite. The beautiful old city of Prague is situated almost in the centre of Europe, where flavours from east and west mingle with those of the north and south.

If I can draw on a cooking analogy, it seems that to produce the best quality meal; it is essential to combine fresh, carefully selected ingredients, mixed with skill and knowledge, presented impeccably in a timely and well paced way, and tempered with love and passion. Moreover, the very best meals are individualised to the palate, preferences and appetite of the person. Likewise, in palliative care situations, the very best care is provided through a combination of knowledge, skills and careful adjustment to the individual needs of patients and their families, with sensitivity to timing (what is regarded as delicious for breakfast might not be so appetising for dinner). Sharing the production of food and eating together is one of the features that make hospices and specialist palliative care units so different from conventional clinical environments like hospitals. I have a memory of visiting hospices in many countries, where the smell of fresh baking permeates the atmosphere, evoking the essence of homeliness.

Family members and other visitors often appreciate opportunities to drink and eat with patients – a normal social ritual – that advanced disease can disrupt or destroy. It can provide opportunities to collectively mark symbolic occasions – birthdays, anniversaries and religious events. For example, a birthday cake may enable family members to gather at the bedside of the patient, including the dying person in the celebration – giving them both literally and metaphorically ‘a taste for life’. It is also one of the ‘simple things’ that family members remark upon as special about palliative care units and hospices compared to busy hospital wards. Palliative care is also building research and clinical expertise in dealing with the distress caused by reduced appetite, anorexia and cachexia which may be features of the final phase of life. In some parts of Africa, palliative care services provide access to essential food for patients and families who would otherwise go hungry.

Sharing food is a profoundly social and cultural experience. Food is culturally imbued with meaning; it is an easy way to learn more about the backgrounds and values of your fellow participants and of the Czech Republic. I hope you will celebrate the opening of the Congress on Thursday 30th May by participating in the Get Together where you can meet with old and new friends.

At the Congress, we will be launching the Prague Charter which calls for the acknowledgement of palliative care as a human right. This builds upon previous EAPC initiatives such as Budapest Commitments and the Lisbon Challenge. We welcome you to join with us in an international united effort to improve access to high quality palliative care.

Professor Sheila Payne
President of the European Association for Palliative Care

Acknowledgements

I want to offer special thanks to Professor Lukas Radbruch who has chaired the Scientific Committee and acknowledge the important contribution of the members of the Scientific Committee. I am indebted to our international advisory board that have provided detailed and insightful reviews on all the proffered abstracts. Special thanks go to the local organizing committee for their commitment to ensuring the success of this Congress. As always, Heidi Blumhuber and Amelia Giordano in the EAPC Head Office in Milano, Italy have supported the Congress. Thank you to our efficient congress organisers, Interplan. Finally I am constantly amazed and impressed by the tireless energy and enthusiasm of our congress officer, Farina Hodiamont, without whom this Congress would not have happened.
Dear Congress participant,

We are looking forward to meeting you in Prague, for the 13th World Congress of the European Association for Palliative Care. The congress theme is “Palliative Care – the right way forward”, and the topic of access to palliative care as a human right will be visible throughout the scientific program as a major thematic thread.

The congress theme refers to the Prague Charter “Palliative Care: a human right” (http://www.avaaz.org/en/petition/The_Prague_Charter_Relieving_suffering), which has been launched by the European Association for Palliative Care (EAPC), International Association for Palliative Care (IAHPC), Worldwide Palliative Care Alliance (WPCA) and Human Rights Watch (HRW). These organizations are working together to advocate access to palliative care as a human right. The Prague Charter will be promoted throughout the congress program. The full text of the Prague Charter can be found on the EAPC Prague Charter website (http://www.eapcnet.eu/Themes/Policy/PragueCharter.aspx).

The Prague Charter urges governments to relieve suffering and ensure the human right of access to adequate palliative care. Please support and sign the Prague Charter, while you are visiting the congress. So far, the petition has been signed by more than 3000 persons, and we hope that this number can be increased considerably during the congress!

The congress programme will discuss the gaps where this human right is not yet available, but also will discuss different models and ways that are available in order to make palliative care available and accessible for everybody who needs it. This discussion touches ethical, legal, economical, medical, and social challenges which all need to be addressed. Plenary lectures will represent the user perspective, teamwork, culturally and economically appropriate palliative care and the full range of palliative care throughout the disease trajectory from early integration of palliative care to symptom control in the final phase of life, and from pediatric palliative care to palliative care in patients with dementia.

The congress theme “Palliative Care – the right way forward” also mirrors the direction palliative care is heading to: forward! Against the background of this forward movement topics such as new developments in symptom control and service provision will be covered.

We are happy to see this forward movement also in the growth of the palliative care community which is mirrored by the increasing number of congress participants and the quality of the submitted abstracts. As always the scientific content of the EAPC congress will be co-designed by the participants themselves, and we are very much looking forward to your input and the oral communication sessions and poster exhibition which will be building on these abstracts.

Over the last years the EAPC congress became a popular and renowned forum for palliative care professionals from all around the world. The internationality as well as the multi-professionalism of this forum calls for a scientific program which is as versatile as the audience it is designed for. We are happy and honoured to take up the task to create this program representing the many-sidedness of palliative care and we hope to meet the various interests of you – the congress participants.

We are looking forward to seeing you in Prague!

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Plenary sessions
Comparing the current development of palliative care (PC) in Europe with our original values and principles, as inherited from C. Saunders and others, one can say that we – as the PC movement – have been widely faithful to our commitments and our dreams and, most likely, beyond. Total pain of terminally ill patients has been, and remains being, taken into account in its four dimensions by interdisciplinary teams. PC structures have dramatically increased and diversified in response to patient and family needs. Clinical research is a major branch of PC commitment. Education has been admitted as an academic discipline and evaluated, both at graduate and post-graduate levels. Three more unexpected developments are noteworthy: 1) the wide adoption by European states of national PC policies; 2) the acknowledgement of PC as a medical specialty; 3) the extension of the field of PC to non-terminal patients, particularly to geriatric patients, and to conditions other than cancer. Among the questions that could be raised, three will be discussed: 1) Does the advent of PC as a specialty detract in some way the diffusion of PC as a common behaviour in every clinical practice? 2) Will the development of national PC policies and official PC organisations lead to a kind of neglect of dying people and of questions about death and dying in society? 3) Are we faithful to our humane condition when we admit, as a historical and social reality, that euthanasia is now an unavoidable fact that will exist beside PC?
Delirium at the end of life: developing the evidence base?

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Background: Delirium in palliative care is prevalent and distressing. Understanding clinical decisions in palliative populations and delirium is crucial. The role of the anticholinergic system is considered important in the pathophysiology of delirium but has not been explored in the palliative population. Therapies need to be subject to robust trials to ensure net clinical benefit.

Methods: The talk will outline four studies and a clinical trial with results to date. The first two studies explored specialist and nurses’ views on delirium management. Anticholinergic medication use as death approaches and the association with symptoms, quality of life, function and health service use was explored. In the third, serum anticholinergic activity and its association with delirium in advanced cancer was explored. A clinical trial of risperidone, haloperidol and placebo in delirium in palliative care illustrates robust designs to determine net clinical benefit of therapies for delirium.

Results: Significant variability in delirium care exists. Anticholinergic medication is associated with reduced function, dry mouth and difficulty concentrating, but not health service utilisation or survival. Delirium occurrence was not associated with anticholinergic medication or serum anticholinergic activity. Comorbid illness severity, benzodiazepine dose and the presence of cerebral metastases on admission predict delirium.

Implications: Some of the variability seen in clinical practice relates to an evidence practice gap with implications for translation of the delirium evidence base into practice; equally, there are some aspects of delirium care unique to the palliative population. Anticholinergic prescribing in palliative care has a potential impact on function, symptoms and quality of life, but not, however, on delirium occurrence. Well-designed and feasible randomised controlled trials can be conducted to evaluate delirium therapies, and this can also be achieved in the palliative population.
The notion of human rights implies that everyone deserves a basic set of universal and inalienable freedoms and entitlements to protect their dignity. European societies have long understood access to healthcare among these. Indeed, medicine and public health embody the best of humanity: intelligence, cooperation, solidarity and kindness. Doctors and healthcare professionals are with us in the most vulnerable moments of our lives – in birth and in sickness – and they also usher us to death. This transition is, perhaps, one of the greatest potential threats of all to human dignity. Terminal illness, if unattended, strips individuals of basic comfort, autonomy and personal freedom. Palliative care restores these dignities, offering pain relief, spiritual comfort and grief support. If healthcare is part of the foundation of human rights protection, then palliative care is a cornerstone, incarnating the principles that underpin the concept of human rights. It enshrines the objectives that modern medicine strives to achieve in all fields: (i) patient-centred care rather than disease-centred cure; (ii) holistic attention to both physical and psychosocial aspects; (iii) interaction with the social and human environment; (iv) coordinated teamwork; (v) objectives based on the patients’ best interests; (vi) humanisation of the relationship between patient and doctor; (vii) comprehensive bioethical perspective; (viii) dialogue-based practice; and (ix) an intense vocational, philosophical and empathetic nature. With all of this in mind, and from a public health perspective, health systems are compelled to include palliative care services in their portfolio of basic health services. Death comes to us all, and all wish to meet it with dignity and peace. Universal, inalienable, egalitarian ... we all deserve the protection that this human right offers to our passing.
The second edition of the EAPC Atlas of Palliative Care in Europe is the result of three years of work of the EAPC Task Force on the Development of Palliative Care in Europe working in partnership with the ATLANTES Research Programme of the Institute for Culture and Society (ICS) of the University of Navarra.

Our surveys have collected data on the national development of palliative care (PC) in 53 European countries from a variety of sources: leaders of PC in each country, experts in national development of the discipline, bibliography and other sources. A peer review process has been implemented in order to improve the quality of the information provided. With a rate of answer of around 85% in the surveys, the Atlas will provide country reports, thematic maps, and more graphic information on a country-by-country basis. The diffusion of data related to the development of PC at a national level is the engine of that very development because it:

a) allows society to estimate whether a country’s citizens receive adequate care when suffering from advanced and terminal illnesses and b) provides a comparison with other countries in that region, so that healthcare professionals, institutions and politicians can plan and make strategic decisions in terms of the nation’s health.

The full second edition of the EAPC Atlas of PC in Europe will be available in PDF format due to its excessive size (approximately 500 pages in length). Consequently, we offer this time a smaller edition (EAPC Atlas of Europe Cartographic Version) in order to present the most important information in thematic maps and one-page graphic country reports. This information will be accessible in multiple formats; for example, via the internet and also in printed format to provide both visibility and credibility. The free availability of maps in diverse formats will enhance the use of the Atlas in professional public presentations and will also be effective in dissemination among politicians and planners. ■
Palliative care for persons with a diagnosis (PWDs) and their families should start at the time of the initial diagnosis, but that does not exclude continuing efforts for aggressive treatment of coexisting or intercurrent medical conditions. Both PWDs and their caregivers need support by explaining the diagnoses and their consequences, and for future planning. Strategies for decreasing the risk of dementia development should be explained, and both PWDs and the caregivers should be referred to support groups and activity programmes if these are available. If pharmacological management is indicated, it should be started as soon as possible. When the dementia progresses to moderate stage, the emphasis should be on management of behavioural symptoms of dementia, which may decrease significantly the quality of life of both PWDs and their caregivers. Environmental and physical causes should be excluded (especially the presence of pain), and a distinction between agitation and rejection of care made. Since both of these syndromes are aggravated by depression, PWDs should be evaluated for the presence of depression and effectively treated. Agitation may be managed by appropriate levels of meaningful activities that are provided as a continuous activity programme. In the severe and terminal stages, the emphasis shifts to medical issues, although behavioural symptoms may continue. Medical interventions should correspond to the goals of care, and both the benefits and burdens of these interventions should be taken into account. Decisions have to be made about cardiopulmonary resuscitation, transfer to an acute care setting, use of antibiotics for treatment of generalised infections, and tube feeding. PWDs should be cared for in a comfortable environment, in the presence of others, and using loving touch for activities of daily living until death (for example, Namaste Care). There is a need for continuous support of professional caregivers and for bereavement support of families after PWDs' death.
Aim: To explore the relevance of team work in palliative care and any evidence of effectiveness.

Background: For many years, it has been recognised that the changing needs of patients can best be met by a team approach, in which a variety of health professionals with different skill can collaborate to meet the range of needs presented by people being treated in the community or hospital. This is especially true within palliative care and is reflected in many of the guidance and strategic documents issued by governments, professional/international bodies, and charitable agencies. A review of the literature, however, indicates that the form and success of that collaboration between professions and disciplines varies and is reflected in the adjectives used to describe the team: multi-, inter-, trans- and so on. Team effectiveness is influenced by the relationships that exist, leadership style, trust and respect between members, and resources; a challenge reflected in the EAPC Mission Statement of the need to ‘promote palliative care in Europe through … multi-professional collaboration’. A team is essentially a group of people brought together for a specific task and who work together interdependently, taking ownership for the outcome. Leadership and clarification of a task are key and will affect the skills mix of the team, and how well they work together and achieve satisfactory outcomes for any interventions made by the team. While the study of teamwork has developed in recent years, little has been done to examine the factors contributing to effectiveness.1

Conclusion: I wish to examine the key components of teamwork in palliative care – factors, which contribute to mentally healthy teams or to dysfunctional teams. I also wish to review some of the studies that seek to examine team effectiveness and offer suggestions for maintaining healthy teamwork within palliative care.2

References
The European Association for Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA), and Human Rights Watch (HRW) have joined together to formulate the Prague Charter to recognise access to palliative care as a human right. The Prague Charter urges federal governments of all developing and developed countries around the world to implement healthcare and social policies that will ensure the relief of suffering through adequate access to patient-centred palliative care, wherever it is needed – whether in hospital, a hospice, home or any other place of care. This short presentation will examine the activities that have led to the creation and launching of the Prague Charter, and will highlight options for future advocacy work.
Integrating palliative and oncology care in advanced lung cancer

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Aim: To improve care for patients with metastatic non-small cell lung cancer through the introduction of ambulatory palliative care at the time of diagnosis.

Methods: Patients were randomly assigned to receive either early palliative care integrated with standard oncological care or standard oncological care alone. Quality of life and mood were assessed with the use of the Functional Assessment of Cancer Therapy Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care and components of palliative care visits were collected from electronic medical records. Quantitative and qualitative methods were used to analyse the data.

Results: Patients assigned to early palliative care had improved quality of life compared with those patients assigned to standard oncological care alone (mean score on the FACT-L scale). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms. Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care, median survival was longer among patients receiving early palliative care.

Initial palliative care visits focused primarily on symptom management and building rapport. Few patients discussed advance directives at the first palliative care visit.

In addition to symptom management, palliative care visits focused on cultivation of prognostic awareness and promotion of positive coping strategies.

Conclusions: Patients with metastatic non-small cell lung cancer who received early palliative care had significant improvements in both quality of life and mood. As compared with patients receiving standard oncological care, patients receiving early palliative care experienced less aggressive care at the end of life and longer survival.
With advances in medical sciences and practice, children with long-term, chronic conditions are often living past the legal limit of childhood, even into their 30s. The differences in service provision by children’s and adult services are highlighted at this time, with many young persons uncomfortable in adult services that are predominantly geared towards older people with a limited life expectancy. Added to this, often difficult decisions regarding care, taken by parents and carers during childhood, legally become the responsibility of the young adult. Dreams of this age group, for loving relationships, studies and work may be unrealistic for many young people facing the challenges of increasing disability and dependence.

Some children’s hospice services have dealt with this by extending their programmes to meet the needs of young adults, with programmes, facilities and resources geared towards improving their quality of life in a way that will be acceptable to them. Some innovative programmes have been developed by transition task forces or teams set up in the UK. Where resources are limited, care is community-based and one programme cares for every age group, the different psychosocial needs of the young adult may not even be considered. This presentation will discuss present trends, existing challenges, innovations in palliative care for young people and proposals for the future.
Aims: Social media help the EAPC’s aim to develop and promote palliative care in Europe through information, education and research. Our blog (www.eapcnet.wordpress.com) aims to connect people interested or involved in hospice and palliative care with short, timely bursts of information from practitioners, researchers and academics working in the field. The blog drives traffic to the EAPC website by highlighting news of task forces, publications, recommendations, and so on. It strengthens communication with our membership; promotes research and other projects published in the EAPC’s official journals; fosters debate, and highlights the global need for palliative care.

Method: In February 2012, we set up a social media team with representation from the Universities of Bonn and Lancaster, and the EAPC board, membership and head office. The blog is merged with the Central and Eastern Europe and Former Soviet Union newsletter, and we strive to achieve a balance of Eastern and Central European content. One person manages the blog, commissioning and editing articles, with the whole team advising, commenting and approving content before publication. The blog is published on a WordPress site linked to the EAPC website, Facebook and Twitter.

Results: So far, 127 posts have been published from 30 countries, with 30,474 views: Europe 73%, Americas 14%, Asia 6%, Oceania 3%, Greater Middle East 2%, Africa 2%. The five most popular posts are:
• What do hospices do or not do?
• On opioids and wisdom
• Use of opioid analogues in treatment of cancer pain
• Deathbed tweets
• Big Five revisited.

Snappy titles, good images and opioids seem to engage readers.

Conclusion: Excellent teamwork and the collaboration of our membership and others help us to reach a worldwide audience. There is substantial participation and goodwill from contributors, and an increasing number of unsolicited posts. Spontaneous debate is growing – a recent post elicited 31 comments from five continents. To encourage more contributions from Eastern and Central Europe we now have limited funds for translation.

PL 4.2

EAPC News: EAPC and social media

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Although palliative care is supposed to address the physical, psychosocial and spiritual dimension of the human person, many of those involved struggle with the last of these four. The spiritual dimension is hard to grasp due to a number of historical and cultural reasons. At the same time, however, we see an increasing interest in this ‘fourth dimension’ of palliative care. Both scientifically and culturally the number of studies and initiatives related to spiritual care are growing rapidly.

In this lecture we will give an overview of the current state of affairs of spiritual care in palliative care in Europe by making three comparisons. These comparisons will help to understand both the problems and possibilities of developing spiritual care in Europe.

1) The first comparison is between times in history. Europe is a multi-cultural phenomenon in transition from modern to late- or postmodern culture. Many of the particularities of this transition directly affect the position of spiritual care in our days. Among these are the decline of traditional belief systems and (religious) communities, an increase in influences from other cultural traditions, the growing impact of the economy and the market on all sectors of society (including care and science) and paradoxes like a call for robust scientific research underpinning policy on the one hand, and deep respect for individual spiritual convictions on the other. In this new situation palliative care has a special privileged position for the development and study of spiritual care, being an interdisciplinary enterprise concerning existential issues in which different types of knowledge meet and often clash.

2) The second comparison is between these types of knowledge. One of the key elements of why spiritual care is so hard to develop in a scientific way is because it is based on types of knowledge that differ radically from scientific knowledge. Historically the study of spirituality was part of theology, using the same methodology as the humanities. Working within one particular tradition it reflected on the lived experience of people belonging to the same belief system. With the development of social sciences in the second half of the 19th century, and the rise of comparative anthropological and religious studies the study of spirituality started to include qualitative research methods. In the context of healthcare, however, the study of spirituality had to adapt to the dominant medical ideal of knowledge which has a preference for quantitative methods. As a result of this there is a great disparity between the ones who are trained specialists in spiritual care but have no empirical research education on the one hand, and the ones who have a research education but are not trained specialists in spiritual care on the other. This results in many problems in terms of understanding each other.

3) The third comparison is between countries in Europe. Spirituality is indissolubly connected with culture and Europe houses many different cultures. As a consequence, again there are great differences between European countries. Although the Catholic South faces different problems than the Protestant North, and although the place of religion in the Western part of Europe has developed differently from in Mid and Eastern Europe, the entire continent shares the same challenge: a reinvention of the way questions of purpose and meaning in life can be integrated in palliative care. Against the background of the work of the EAPC Taskforce on Spiritual Care – which is building a platform for research, education and implementation – some inspiring examples from specific countries will be given of how spiritual care can be developed further in palliative care.
Palliative care (PC) aims to improve quality of life by early identification, impeccable assessment and treatment of symptoms and other needs in patients with advanced and progressive disease. The dying phase has often been claimed to be ‘underdiagnosed’. As a consequence, team conflicts, ‘futile treatment’ and insufficient symptom control were reported. Pain and symptom control in dying patients, particularly in the final phase, have been one of the main foci in PC over many years. Treatment options and standards were established. PC has had, over years, a focus on patients with far advanced cancer. Then the focus changed, on one hand, to an early integration of cancer and non-cancer patients. This comprises a broader spectrum of disease-specific and symptom-guided interventions, with emphasis on preparing patients and their relatives for foreseeable, distressing clinical problems. On the other hand, PC has focused on ‘peaceful’ dying for all patients. But what does this mean? Burdens and suffering of patients and relatives should be minimised. This is what patients and relatives expect from us. Physical, psychosocial and spiritual symptoms should be treated. Up to today, the three-step analgesic ladder is seen as a guide for initiating analgesic drugs and dosages that correspond to the patient’s reported level of pain. Various new opioids and formulations of opioids, and a greater variety of application modes have broadened the range of options. After years of undertreated symptoms, there is now a danger of unreflected application of high doses of strong opioids without a medical indication or the application of sedatives to cope with difficult symptoms at the end of life. Therapeutic decisions must reflect probably conflicting issues of medical indication, ethics and law. This is of particular relevance when treatment preferences of patients are not known or in contrast to those of the carers.
The EAPC Research Network invites all healthcare professionals who see the potential in conducting European multicentre research.

The network can offer:

• An established structure for collaborative research
• An infrastructure to take care of the planning and organisation of large prospective studies, as well as data handling and analysis
• A meeting point for discussion and exchange of knowledge.

Highlights from ongoing research activities will be presented.

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We are all bound by our background, upbringing, family traits, education, life experiences and the community we live in. Even in a relatively homogeneous society, in terms of ethnicity and religion, there are still social class norms and generational differences.

Greater challenges are met when working across different cultures, whether with ethnic minorities, or in a multi-ethnic, multilingual, multireligious society. We have to familiarise ourselves with different behavioural norms, gender issues in role and caregiving, the meaning of food in nurturing and as therapy, and different systems of understanding health and disease processes. We need some background knowledge of the beliefs and religious practices of the patients and families, if they are different from our own. While communicating well is already a skill that needs to be honed by all working in palliative care, doing this without a common language becomes a greater challenge. The ideal of using professional interpreters is often a luxury reserved for well-resourced services working with ethnic minorities and not available to the vast majority of practitioners who are trying to cover a heterogeneous population in emerging palliative care services.

Healthcare provision is necessarily shaped by the resources available. Much of palliative care practice in resource-rich countries is inaccessible or irrelevant in resource-poor places, and adaptation and improvisation are necessary.

A multi-ethnic, multireligious, multilingual palliative care team is a great resource. Diversity becomes a real advantage. Openness and respect for one another, whether colleague or client, can create harmony, where differences are celebrated rather than feared. This is one of the aspects of palliative care where the learning is life-long, which continues to fascinate and is a real source of joy in the practice of medicine.
Parallel sessions

Pain Management in 2013
Gastrointestinal Symptoms
Spiritual Care
Volunteers
Leadership in Palliative Care: From Good to Great
Paediatrics I
Neuropsychiatric Symptoms
Ethics and End-of-life Decisions
Implementing Palliative Care in Nursing Homes
Teaching Session: Planning and Conducting Clinical and Public Health Research in Palliative Care
Innovations in Learning
IMPACT
Neurology
Public Health Perspective
Religious Aspects in Palliative Care
Common Battlefields for Palliative Care and Oncology (ESMO Supported Session)
Developing Collaboration for Palliative Care: Experience and Challenges
Paediatrics II
Dementia
Outcome Assessment in Palliative Care
Access Issues / Access to Care
EAPC Atome Session Title: Regulatory Barriers in Palliative Care Opioid Treatment
From Budapest to Prague - From Commitments to Rights
Palliative Care - Part of the Main or Specialized Discipline?
Nutrition in Palliative Care
End of Life Preparation - Health Literacy in the Community
Palliative Care as a Human Right
EUROIMPACT: How to Be Successful as a Palliative Care Researcher within the European Research Area
Dyspnoea
Parallel sessions

Pain Management in 2013

Abstract number: PS 1.1
Abstract type: Parallel Symposium

Symptom-based Management of Neuropathic Cancer Pain

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A neuropathic pain component can be suggested, if cancer growth leads to compression or infiltration of nociceptive nerve fibres, or cancer treatment such as surgery, chemotherapy or radiation therapy induces damage to the somatosensory system with pain as a direct result of this lesion. Depending on the neurobiological pain mechanisms in action different sensory symptoms may occur. Peripheral sensitization of the nociceptive system, e.g. due to an inflammatory environment surrounding a tumour, will be indirectly reflected by localized hyperalgesia to heat and blunt pressure pain. Central sensitization leads to pinprick hyperalgesia and/or dynamic mechanical allodynia in the affected area. Deafferentation due to neuronal damage is reflected by a decreased sensitivity to all types of thermal or mechanical non-painful or painful stimuli. Using quantitative sensory testing (QST) it is possible to assess the complete somatosensory phenotype of a cancer pain patient. Using the QST protocol of the German Research Network on Neuropathic Pain (DFNF) seven sensory tests are performed to assess thermal and mechanical detection and pain thresholds. Sensory profile of symptom patterns in cancer patients is fostering better knowledge about possible neurobiological mechanisms underlying the pain problem. Based on the literature and recent QST studies about 40% of cancer patients present with a clinical or subclinical neuropathic pain component. The next step will be to compare a symptom-based treatment of neuropathic cancer pain in clinical trials.

Abstract number: PS 1.4
Abstract type: Parallel Symposium

Spirituality and Biographical Pain at the End of Life in Old Age

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It is well recognised that as individuals move into later life, they are less occupied by the demands of paid employment and consequently spend more time in reflection about the life lived. In part this is due to the onset of infirmities, as chronic diseases take their toll on mobility and autonomy. As they enter into the 'stage of dependency', characterised by conditions which deliver decrements of worsening health or what epidemiologists have termed 'long dwindling' there are also a degree of depression. Unchosen solitude and the frustration of a failing body, both prompt recollections of more engaged times and draw attention to the deficits of adult life.

The evidence of my own biographical interviews indicates that the predominant self evaluation is of disappointment, unworthiness and having failed to 'come up to expectation'. When it is accompanied by profound guilt, anger at the health or what epidemiologists have termed 'long dwindling' there are also a degree of depression. Unchosen solitude and the frustration of a failing body, both prompt recollections of more engaged times and draw attention to the deficits of adult life.

The evidence of my own biographical interviews indicates that the predominant self evaluation is of disappointment, unworthiness and having failed to 'come up to expectation'. When it is accompanied by profound guilt, anger at the

Gastrointestinal Symptoms

Abstract number: PS 2.1
Abstract type: Parallel Symposium

Abstract number: PS 2.3
Abstract type: Parallel Symposium

Pharmacotherapy of Chronic Nausea and Vomiting

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Chronic nausea and vomiting are frequent symptoms in advanced cancer patients. The management should be directed at underlying causes, which may be multifactorial e.g. gastrointestinal tumours, oncology treatment (chemotherapy, radiotherapy, surgery), opioid induced bowel dysfunction, metabolic disturbances. Still, the treatment is based on a meticulous assessment comprising detailed history taking and physical examination. Laboratory tests may be useful to detect factors such as anaemia, hepatic dysfunction, and renal impairment. Radio logical investigations may be carefully considered in patients with symptoms of gastrointestinal obstruction. Over 80% of colorectal malignant bowel obstruction (MBO) occurs in 3-6% of patients suffering from advanced cancer and is highest in patients with advanced colorectal cancer (24%). Therefore, the evidence for clinically established pharmacological therapies for constipation and gastrointestinal obstruction in palliative care patients have to be evaluated.
bowel obstruction should be considered for a surgical intervention. However, only minority underwent surgery due to poor prognosis and general condition, dissemination of the tumour, and the absence of the abdominal conservations to patients with symptoms of mechanical bowel obstruction comprises antidiromg and enemas and lysis with naso-jejunal feeding to reduce colicky pain and bowel secretion. An addition of oncostatics and corticosteroids may increase the effectiveness of such regimen. In patients with functional or those with partial mechanical bowel obstruction without colicky pain prophylactic may be used. In case of ineffective prophylaxis of pharmacotherapy and nasojejunal tube may be inserted for a short period of time. For patients in general states parenteral nutrition may be carefully considered.

Spiritual Care

Abstract number: PS 3.3
Abstract type: Parallel Symposium

Spiritual Care - What Does This Mean in a Secular Society?

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The World Health Organization defines health as a state of spiritual well-being as well as physical, psychological and social well-being, and palliative care policy globally includes spiritual care as an essential component. Evidence shows many people with incurable, progressive illness have spiritual needs [1,2] and wish those needs to be considered in a healthcare context [3,4]. Yet patients’ spiritual needs are often neglected [5], healthcare staff struggle with the provision of spiritual support and often confuse spirituality with religion [6], and the very presence of a spiritual aspect of healthcare is debated [7].

Making use of sociological and philosophical perspectives as well as social science, in this paper I examine the extent to which European society truly is ‘secular’ and consider challenges to the provision of spiritual care in healthcare. I argue that spiritual care is a contentious and challenging domain of care for three main reasons:

1. Conceptual confusion regarding what spiritual care is and a consequent lack of understanding amongst healthcare and whose responsibility it is in the multi-professional team;
2. The subjective nature of spiritual care, in which the personal, political and professional collage and we are challenged to bring who we are and what we believe into the clinical context;
3. The limited body of robust evidence to inform the provision of spiritual care.

I also review the gaps regarding patient and care preferences and the nature and effectiveness of spiritual care, highlighting directions for future research.

References:
5. Spinkova M. J Pain Symptom Manage 2013; 45: 589-598

Abstract number: PS 4.2
Abstract type: Parallel Symposium

Ordinary or Peculiar Folk? On the Role of Volunteers in Palliative Care in Czech Republic

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The phenomenon, that people who do right things are peculiar within their society, is well known. Prophets of all ages were refused because they listened weird. Yet today to them “illness” of their age could be diagnosed: they served as a mirror which reflected society around them. Our ambivalent relationship to the prophets has much to do with what we expect to see in the mirror.

In the perspective of palliative care our age is the age of institutions. We believe that at the end of life institutions help us better than a person who has legs, hands, head and soul. In spite of that these beings with head and soul are helping us in their special way.

Volunteers in palliative care aren’t prophets at all, but there is a similarity: they indicate something important about us and often we consider them to be peculiar. In the Czech Republic something else can even be traced down: after fewer than twenty years of freedom, some of our diseases from the period of totalitarian life were used to have the same salar; all hospitals had the same beds, all bakeries had the same shop signs. Whatever stood apart was suspicious.

Volunteers stand apart in many respects: the questions they have faced with whilst they reveal something about our society today: We are harassed and sad - how is it that you are happy? We come home exhausted - how can you work more? We have little money - how is it that you are doing it for free? We only want to see the pretty things - why do you want to see people die? After all at day we need to recover - how is it that this is your job?

Or, after all, do they receive anything? It seems they do, although it is often incomprehensible for many people. In my opinion, the volunteers are ordinary and rich people and our society is enriched by them. They are silent builders of our society.

Volunteers have always formed an integral part of the care offered in hospices across the UK. Without them, hospices could not have continued to do the work that they do. Hospice volunteers report a high level of satisfaction in being there for someone during a difficult time of life. They feel like they are making a significant contribution to the care of the patient and their families. In service they hope others would offer them, were they in need.

Methods: A mixed methods two phase study was conducted. Phase one involved a national survey of volunteer managers based in hospices in the UK. Phase two used organisational case study methodology to investigate how volunteers contributed to the delivery of direct patient and family care associated with adult hospices.

Results: In Phase 2, a total of 205 interviews with volunteers (n=96), managers and staff (n=72), patients (n=29) and families (n=14) were conducted between May - December 2012 at 11 purposively selected hospices in the North West and South East of England, with 14-24 interviews at each site. The majority were undertaken face-to-face, individually and in small groups, and a few were telephone interviews. All were recorded and transcribed and have been edited and coded in NVivo, a software analytics package for qualitative data. The sample had an age range of 21-88, with an overall mean of 66 years. The most common age of staff was that of volunteers and carers were 62 and 63 respectively, with patient mean age was 67 years. The time that participants had been involved with the hospice ranged from two months to 23 years. Qualitative analysis has identified four overarching themes: Impact of volunteering
- Management Practice
- Relationship to the external context
- Role of volunteering in the hospice environment

These will be explained and illustrated by direct quotations.

Conclusions: There remain challenges facing hospices in the recruitment and management of volunteers.
Parallel sessions

Leadership in Palliative Care: From Good to Great

Abstract number: PS 5.1
Abstract type: Parallel Symposium
The Leadership Development Initiative (LDI): My Experience

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As a medical doctor I had never been trained in leadership or management skills during the first 15 years of my hospice program, I felt inadequate in addressing management problems and meeting people in high position. Therefore, I felt fortunate to be selected for the inaugural class of LDI. The program has equipped me with techniques and skills which help me lead and coordinate our team as we expand our services to provide care for increasingly more patients in need. Apart from the formal aspect of LDI, I met wonderful colleagues from all around the globe, who are facing very similar challenges. Their enthusiasm, dedication and honesty constantly recharge my batteries. Their personal experiences shared taught me important lessons. I am proud and deeply grateful to have been a part of the first cohort of LDI.

I have used my new skills and knowledge I’d been equipped with to advance palliative care through introducing new forms of care and academic programs. Still I am aware that Hungary is twenty years left behind compared to developed countries. I appreciate that change needs time and attitudes change slowly. However, programs like LDI with their expert support, clear vision, commitment and humility can give us inspiration to persevere. I see a very challenging twenty years ahead. But I also see a slowly-unfolding transformed cultural picture of death and dying in the minds and practices of Hungarians. Integration of palliative care services across the spectrum of healthcare will reduce suffering and ensure better quality end-of-life care in Hungary. Although, there is a long way to go, if we use every daily opportunity in our lives, we can make a difference.

Abstract number: PS 5.2
Abstract type: Parallel Symposium

Mentorship in Palliative Care

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The Leadership Development Initiative (LDI) at San Diego Hospice and Institute for Palliative Medicine is a 2-year leadership programme, initiated in 2009. The participants in the program are young physicians in palliative medicine with a leading role in their region or country. The LDI include three residential weekly long courses in San Diego as well as continuing education and individual follow up between the courses and a mentor program. The mentors are invited senior palliative care physicians with extensive experience in both clinical medicine and leadership.

Challenges for the mentor relationships - as well as for the programme in general - include the global perspective, the many different cultural, social, economic and other differences between the participants and the mentors. The actual mentoring process follows a structure including a contract, set agendas, reports and evaluation, all based on a common shared value of mutual learning. Specific aspects to this mentor programme such as the assignment of mentors, monitoring at a distance and site visits by mentors will be contrasted to more regular mentoring conditions. Participant and mentor feedback and evaluations will be presented.

Abstract number: PS 5.3
Abstract type: Parallel Symposium

How to Lead to Improve Clinical Programs That Benefit Patient and Family Care

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Providing high quality, needs-based care for patients and families at the end of life is a crucial part of any health system whatever the background reasoning levels are. Such care needs to be within the overall context of health service provision. Within the context of health services as a whole, despite the level of training and dedication of staff, there is the need to ensure that hospice and palliative care services are delivering care as part of the health system. To do this in the most effective way, it is necessary to understand the pressures on the health system and to address systematically these pressures as they intersect with hospice and palliative care. This requires an ongoing conversation with administrators, funders and policy makers. Within the community of hospice and palliative care service provider.

Delivering the highest quality care demands systematic performance measurement focused primarily on patient and family centered outcomes, both while the person is alive and in understanding the long-term outcomes for families and caregivers. Such systems require data collection at point-of-care and, ideally, in the longer term. Improved outcomes can only be achieved by measuring current performance and seeking to respond to areas of poor performance at an organisational level. It is far more likely that poor performance is caused by the way that a team or health system approaches issues rather than the performance of an individual practitioner. Defining and adopting best models of care, and identifying key success factors or barriers in other hospice / palliative care services can create a community of practice in hospice / palliative care that can deliver better care, sooner.

Abstract number: PS 5.4
Abstract type: Parallel Symposium

Leadership in Clinical Research - Local, National and International Considerations

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Clinical research is complex. According to the latest WHO definition of palliative care both physical, psychological, social and existential issues are of clinical importance. It is probably impossible to be heavily involved in all of these areas, even for a large research group. Therefore one needs to prioritise through a democratic leadership process. Furthermore, the leader needs to:

- Have insight and skills in basic research methodologies and clinical practice
- Set up a team of researchers with complementary skills and knowledge
- Assure funding conducting the research programme through
- High quality research applications
- Local and national strategy for funding
- Recruit and motivate staff
- Assure that the research findings are implemented into clinical practice
- Have fun with the research team

Abstract number: PS 5.5
Abstract type: Parallel Symposium

Paediatrics

Abstract number: PS 5.6
Abstract type: Parallel Symposium

The Importance of Respite in Children’s Palliative Care in Ireland

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Aims: Respite in children’s palliative care aims to provide a break from the routine of caring. Frequency, location and type of respite vary according to the child’s age, diagnosis, geographical location and the family’s capacity to meet the child’s care needs. Despite being an integral part of children’s palliative care none of the offered respite is investigated in the literature. The aim of this study is to ascertain the situation and address different aspects of respite in a children’s hospital.

Methods: Utilising multiple, longitudinal, qualitative case study design research and exploratory qualitative research, 9 cases of parents caring for a child with a life-limiting condition were explored. Multiple, in-depth interviews were undertaken with parents identifying children as receiving respite in a children’s hospital. In-depth interviews were also conducted with others identified by parents as having a role in the provision of respite. All interviews were analysed using thematic analysis; Cross-case comparison was also conducted.

Results: Nine families were recruited and followed for two years. A total of thirty-eight in-depth interviews were conducted with parents caring for a child with a life-limiting condition in Ireland. Each interview identified as receiving respite were also interviewed thus providing data relating to the same incidents from differing perspectives. Other sources of data were also used. A cross-case comparison revealed that for all parents utilising respite care, regardless of their child’s age and condition home was the location of choice.

Past experience of in-patient care of their child and trust and confidence carers were key deciding factors. Concerns about home care included the impact on family life, siblings and the concept of home. From a provider perspective home was seen as a challenging environment in which to provide care.

Conclusion: This study identifies the unique respite requirements of Irish parents caring for a child with a life-limiting condition and identifies the factors that enable responsive and family-focused respite

Abstract number: PS 5.7
Abstract type: Parallel Symposium

Comprehensive Palliative Care for HIV Positive Children - the Role of Inter-Professional Teams

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HIV positive children have many and changing needs. This poses an excellent opportunity for health care workers to learn and practice inter-professional teamwork. Team members learn from each other, support each other and the success of one team member motivates the rest. The output is not equal to the sum of the input, it is much more! The aim of this case presentation is to demonstrate how HIV can affect a child’s life and the role comprehensive palliative care can play in the management of HIV.

Godfrey’s mother died of HIV when he was 11 years old. As an orphan he was placed in a children’s home where he developed symptoms of AIDS. He also developed chronic diarrhoea. His pulmonary tuberculosis and cor pulmonale were made in hospital. Due to his HIV he had numerous symptoms that needed medical management. After discharge from hospital Godfrey was placed in Sunflower House, a paediatric palliative care inpatient unit.

A social worker and a palliative care nurse conducted an initial meeting his main problem was that he wanted to stay with his grandmother in a town about 60 km from the hospice. The social worker investigated the situation and addressed it in the best possible way with his input. In Sunflower Godfrey identified different people that acted as his brother, father and grandfather. As different people played important roles e.g. the priest when his grandmother died, the physiotherapist helped with his lungs and the dietician helped with his food. Godfrey’s HIV symptoms like chronic diarrhoea. Godfrey, as most HIV positive people, experienced multiple losses in his life. These multiple losses affected all levels of needs according to Maslow’s needs pyramid. Time sharers (volunteers) took him out and exposed him to the life outside the hospice, while the occupational therapist arranged for him to attend school and his teacher and schoolmates supported him. Art played an important part in his life and he expressed his fears and joys in it.

Abstract number: PS 5.8
Abstract type: Parallel Symposium

Decision Making for Children with Cancer When Standard Therapy Has Failed

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When cancer recurs patients are faced with a number of difficult decisions about further care and treatment. Options may include enrolling the child in Phase III trial, trying a second line chemotherapy or even more aggressive therapy, or shifting the focus entirely to symptom directed care. That few parents choose to shift entirely to symptom directed care even within weeks and sometimes days after a child’s death is of concern to some health care professionals. In this paper I present parents’ approaches to care and treatment, consider explanations concerning offered alternative approaches to treating their child and present an alternative approach to interpreting their behaviour; one routed in an analysis of the interactions among parents and decision makers on the course of the treatment, and the implications for clinical practice particularly for developing solutions to what troubles us in practice.

This presentation draws on data collected as part of a comparative ethnographic prospective study of children with cancer when standard treatment had failed and care was not likely conducted at two tertiary centres for children with cancer (Bluebond-Langman M, Belasco J. Goldberg A.) as well as on preparation and preliminary investigations for a prospective, longitudinal qualitative study for the palliative care needs of children with high risk brain tumours scheduled to start later this year (Bluebond-Langman M. Hargrave D. Kelly R. Gibson F. Baysal J.).

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
Neuropsychiatric Symptoms

Abstract number: PS 7.3
Abstract type: Parallel Symposium

Delirium
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Up to 90% of palliative care patients develop delirium in the last days of life. Terminal delirium is one of the greatest stressors for patients, families and health care professionals alike. It is also the most frequent barrier impeding for death at home, and one of the most frequent reasons for palliative sedation. Despite this, it is underdiagnosed and under-treated in 22-50% of the cases. This is due in part to its heterogeneous clinical presentation: hyperactive delirium with agitation (2-21%), hypotensive delirium with apathy and withdrawal (29-43%), as well as mixed forms (43-54%). Pre-existing cognitive deficits or depression can also hamper diagnostic accuracy.

Palliative care patients often exhibit several risk factors for delirium, and 2-3 causes for the disease can on average be identified. Among the most frequent causes are drugs, metabolic disturbances, infections, constipation, hypothermia and associated psychoactive drugs. The most well known causes are anticholinergic drugs and neuroleptics. Small pupils, muscular cramps, hypotension and apnea can cause or worsen a delirium. Delirium is a bad prognosis, but is reversible in 50% of palliative patients. Treatment includes non-pharmacological (calm environment, reorientation aids, individualized care plans, reduction of stressors) as well as pharmacological measures, such as neuroleptics. Haloperidol is the most widely used drug (beoare of extrapyramidal side effects above 4.5 mg/d), atypical neuroleptics such as risperdone, olanzapine and quetiapine are also effective. Benzodiazepines should only be used in combination with neuroleptics. So far, insufficient data are available concerning the effectivness of cholinesterase inhibitors and of psychostimulants such as ritaline for hypotensive delirium.

Resilience
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In the last days of life, increasing restlessness and agitation may occur. This phenomenon is thought to be of multiple origin and does not require any treatment for relief stages. With decrease of organ functions such as liver or renal failure, many natural substances of human metabolism can accumulate with decreasing excretory function. Often, in the end stages of vigilance, respiratory depression may additionally evolve. The management of terminal restlessness has to address a balance between side effects of drugs in use and the continuously decreasing metabolic and excretory liver and renal functions. A frequent problem is the accumulation of morphine-6-glucuronide - the most important morphine metabolite, when morphine is given continuously via intravenous syringe drives in the presence of rapidly developing renal failure. Small pupils, muscular cramps, sedation, hallucinations, and terminal restlessness may develop. This problem can be aggravated in the presence of diaphoresis and hypothermia due to lung failure or reduced ventilation at the end of life or as a side effect of the pharmacological treatment in use. In these rare cases then to reduce or exchange drugs in use for symptom control to account for organ failures. If cognitive homeostasis cannot be established, palliative sedation using benzodiazepines rather than neuroleptics should be considered for refractory cases. Most important, communication with patients and their relatives helps to understand the symptom and to support the patients who have to be treated, but also reflects the last movements or steps of a person that has to make one's way.
Implementing Palliative Care in Nursing Homes

Abstract number: PS 9.1
Abstract type: Parallel Symposium

The EAPC Taskforce on Palliative Care in Long-Term Care Settings for Older People

Background and Aim: Many older people living and dying in long term care facilities (LTCFs) are in need of palliative care during the last phase of their life. A number of ways have been developed to promote palliative care provision for older people living in LTCFs. The EAPC Taskforce on Palliative Care in Long Term Care Settings for Older aimed to identify and map different approaches to the development of palliative care provision.

Methods: Country informants from 13 European countries (Austria, Belgium, France, Germany, Ireland, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, UK) were identified as sources of data within their countries. Two phases of work were undertaken: Phase 1: information about the context of long term care provision in each country; Phase 2: considering the types of LTC settings, the status of LTC providers, funding and phase. Phase 2: examples of initiatives to develop palliative care provision were collected.

Results: The context for LTC provision across Europe is variable. All countries offer care that meets low and high levels of care. Providers of care are located in the public, private, and not for profit sectors. Funding is complex and sources draw on state and personal funds. Regulations are national and local. A typology of interventions has been identified that categorises the initiatives identified. This addresses a number of levels: individual (staff, family, resident), Team, Organisation, Regional / Networks and National. Examples of initiatives at all levels can be seen across Europe. A compendium of current practice and interventions has been compiled. Issues of sustainability for these developments and the important role of LTCF organisations as mediators of change were identified.

Conclusion: A range of initiatives are being undertaken to develop palliative care provision in LTCFs across Europe. Organisational change is key to ensuring the successful implementation of new developments.

Abstract number: PS 9.2
Abstract type: Parallel Symposium

The Gender Issue

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Aims: Questions of integrating palliative care in long term care and nursing settings are embedded with initiatives and effects on different levels: individual, team, organisation and systems environment. Organisational cultures that create space, time and flexibility about living, dying and bereavement are needed. Gender issues as integrated social category have to be considered. The aim of the contribution is to show in which ways gender is important for palliative care in nursing homes.

Methods: A meta-analyses of two projects on gender in nursing homes is presented. Working within a qualitative paradigm of organisational research, in one of the studies a single case study was conducted. Multiperspective interviews, expert opinions and feedback from LTC settings were part of the case study. The other study encompassed a literature review, a transdisciplinary workshop, a book publication and expert interviews.

Results: Nursing homes can be characterised as “female lifeworlds”. Traditional gender roles and gender relations dominate the lifeworld in nursing homes. Women living there have to be acknowledged in their life long balancing of act of bringing, doing family, housework and occupational work together. Men living there have to be acknowledged for their main job-focused biographies. Historically relevant knowledge of gender relations play a central role in palliative care and end of life care.

Conclusion: The traditional gender culture has to be reflected critically to overcome gender stereotypes in the work of palliative care. Professionals and management working within nursing homes are requested to ask themselves in what way gender sensitivity can be integrated into daily routine works. Structural gender inequalities within our societies have to be recognised. Gender sensitivity in palliative care in nursing homes is a multidimensional process that always has to do with the interplay of attentiveness, interaction, reflection and structures.

Teaching Session: Planning and Conducting Clinical and Public Health Research in Palliative Care

Abstract number: PS 10.1
Abstract type: Parallel Symposium

How to Get Started - and How Can the EAPC Research Network Contribute?

Spang 
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In order to optimise palliative care, we need high level scientific evidence implemented into international and national treatment guidelines. The content of these guidelines must be implemented into clinical practice. One mechanism is to develop standardised patient trajectories, assure the implication of these into the health care system and to quality assure the level of effect on each individual patient.

Some key elements need to be considered before clinical research projects are initiated: The aim / research questions must be relevant and have a potential to improve clinical practice. The method/design of the study needs to be sound and contribute to valid answers to the research questions. Intervention studies are per se studies that have a good potential to improve clinical practice. The studies need to be planned and conducted according to international standards and to be sufficiently sized. Multicentre studies will often be needed.

Planning, Conducting and Avoiding Pitfalls in Public Health Research

Deliens L.
End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels, Belgium, VU University Medical Center, EMEG Institute for Health and Care Research, Amsterdam, Netherlands

Planning public health research in palliative care involves a large amount of money and one or more grant preparations and applications. The process of building a consortium or research team, deciding about study settings and procedures to negotiate contracts will take at least a year. When you have mobilised enough resources, researchers have to be recruited and selected, a full protocol written, and all procedures for data collection have to be developed and tested. Finally in the preparatory phase, you have to prepare and get approvals for laws, regulations and sometimes also from other data protection agencies. At that stage, you have still not collected any data for your study, and a second year may have passed. If it is your aim to conduct a full PhD trajectory, this will require three to five more years in general. Hence, planning of public health research in palliative care requires time and patience. Successfully conducting public health research in palliative care is difficult and requires good organisational conditions and personal research knowledge and skills (e.g. creativity, questionnaire development, sampling techniques, statistics, data analyses, scientific writing, multidisciplinary collaboration and feedback) and knowledge and experience in an academic multidisciplinary research environment is helpful and implies supporting services (statistics, IT support, research methods training, PhD training etc.). Furthermore, researchers need a positive attitude towards research in general, but also towards guidance from their supervisors.

In this presentation, a number of issues will be highlighted and discussed: What do we have to know before planning a study? How can we optimise the team and research environment? How do we draft a good research protocol? What kind of specific problems and pitfalls are related to public health research in palliative care, and how can we best deal with these?

Innovations in Learning

Abstract number: PS 11.1
Abstract type: Parallel Symposium

How to Teach Attitudes

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The importance of the ‘right’ attitudes towards patients, colleagues and even ourselves, should not be underestimated. Can we define, teach and assess them? What do they look or feel like? Do students notice the people who are, the field you work in, or the country you live in? Are they fixed or flexible? How might societal and technological changes affect what attitudes are required of healthcare professionals (HCPs)? Attitudinal competence is recognized as vital for doctors. Professionalism, encompassing values, ethical principles and skills, is an important factor for doctors, no matter where they work. Multicentre studies have a good potential to improve clinical practice. The studies need to be planned and conducted according to international standards and to be sufficiently sized. Multicentre studies will often be needed.

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Planning, Conducting and Avoiding Pitfalls in Public Health Research

Deliens L.
End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels, Belgium, VU University Medical Center, EMEG Institute for Health and Care Research, Amsterdam, Netherlands

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Experiences with an Online Master's Program: Education Needs in Central and Eastern Europe

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

Abstract number: PS 11.3
Abstract type: Parallel Symposium

Experiences with an Online Master's Program

Beker C

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In light of the growing need for palliative care, in 2009 the Ministry of Science, Research and Arts of the federal state of Baden-Württemberg, Germany backed the establishment of a part-time, postgraduate, multiprofessional Master’s program, “Master Online - Palliative Care”. The program resides in the Medical Faculty of the University of Freiburg. Upon completion of the four-semester program, students obtain an internationally recognized Master’s degree. This interdisciplinary, practice-oriented and research-based degree qualifies students take on various positions in both inpatient and outpatient palliative care settings, ranging from management to work with patients. One particularly innovative element of this Master’s program is its use of blended learning, which allows students to continue their career alongside their studies. Blended learning combines traditional face-to-face classroom methods with e-learning, utilizing the strengths of both methods to communicate knowledge and skills. In the winter semester 2010/2011, the Master program admitted its first students and succeeded in bringing together students from various professional backgrounds. Two-thirds of the presently enrolled 36 students are physicians, while the other third consists of nurses, theologians and social workers. Among the current students, 19 work in Germany and 17 are employed in Switzerland. In the fall of 2012, the first students successfully completed the Master of Science in Palliative Care. To foster the continued improvement of the program, regular evaluations are conducted. Due to the small sample size, the data provided in this report cannot be generalized and only provides examples of dyspnea, regarding students’ responses to the program offerings. Nevertheless, the data presented here along with the feedback of students show that there is a growing need to improve the course content and format within the program because of the practice-oriented material presented.

IMPACT

Abstract number: PS 12.2
Abstract type: Parallel Symposium

Models for the Organization of Palliative Care in Patients with Cancer and Patients with Dementia

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Aim: To develop a model of palliative care for people with dementia that captures commonalities and differences across Europe.

Background: Palliative care for people with dementia is often sub-optimal. This is partly because of the challenging nature of dementia itself, and partly because of system failings that are particularly salient in primary care and community settings. There is a need to systematize palliative care for people with dementia, to clarify where changes in practice could be made.

Methods: A technology development approach was adopted, using mixed methods including 1) critical synthesis of the research literature and policy documents, 2) interviews with national experts in policy, service organisation, service delivery, patient and carer interests, and research in palliative care, and 3) involvement of researchers tasked with synthesising data and modelling palliative care.

Findings & Outputs: A generic model of palliative care, into which quality indicators can be embedded, was developed. The proposed model divides palliative care into four phases, based on the need for palliative care. Each phase is further divided into different components, the structure and function of care planning, the management of risk and increasing complexity; boundaries between active treatment and end-of-life care, and the process of bereavement. Conclusion: The co-design approach to developing a generic model of palliative care for people with dementia has placed the need for palliative care within a landscape of services and professional disciplines. This model will be described in this presentation, and its future evaluation discussed.

Abstract number: PS 12.3
Abstract type: Parallel Symposium

Barriers and Facilitators to Implementing Quality Improvements in the Organization of Palliative Care

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New knowledge is not necessarily readily applied in palliative care, even when there is evidence of its effectiveness. To overcome these problems, systematic implementation is needed to translate scientific evidence or consensus into everyday clinical routines. Implementation is a complex process of improving care processes, and involves change in knowledge, attitudes and/or changes of proven value; the aim being that these are given a structural place in professional practice, in the functions of care processes or in the care health structure (Goel et al 2005).

An increasing number of older people with progressive, incurable, life-limiting chronic diseases like dementia or cancer need palliative care. Altering well-established patterns of care or organization is difficult. Changing the organisation of palliative care is a major challenge, since this requires collaboration between a range of different professionals and healthcare organisations. For those reasons the aim of this project is to implement quality indicators (QIs) and improvement projects in settings that provide palliative care for patients with dementia or patients with cancer.

QIs can be used to measure the organization of palliative care. Within our EU FP7 IMPACT project with partners from 10 European countries, we developed such a set of QIs, that will be used to measure the organization of palliative care in six general practices, nursing homes, hospices and hospitals in NL, D, UK, IT, and No. With the help of tools and guidance of a consultant, the instruments within the settings will use the feedback on the QIs to improve their organization of care. After 9 months, the QIs will be used again to measure the effect of the interventions, the intervention development phase, the intervention period, and the process analysis, barriers and incentives for improving the organization will be taken into account.

At the end of the IMPACT project (2011-2015) the set of QIs, as well as the tools will be available for broader implementation in Europe.

Neurology

Abstract number: PS 13.1
Abstract type: Parallel Symposium

Palliative Care for ALS Patients

Barson G

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Amyotrophic lateral sclerosis (ALS) is the most common degenerative motor neuron disease in adults. The clinical picture consists of generalized fasciculations, progressive atrophy and weakness of the skeletal muscles, spasticity and pyramidal tract signs, dystarhria, dysphagia and dyspnoea. Pathologic laughing and crying is common, as are cognitive deficits of the fronto-temporal type. Disease-specific treatment options are still unsatisfactory. However, therapeutic nihilism is not justified as a large array of palliative measures is available to enhance the quality of life of patients and their families. Because of its clinical characteristics, ALS represents a paradigm for palliative care in neurologic diseases. Numerous projects are being undertaken worldwide in order to enlarge the evidence base for palliative interventions in ALS. Palliative care in ALS is a multidisciplinary effort requiring careful coordination of care. An open and empathic disclosure of the diagnosis is essential. Nutritional deficiency due to dysphagia can be relieved by a percutaneous endoscopic gastrostomy. Systemic respiratory insufficiency can be effectively treated by non-invasive home mechanical ventilation. The terminal phase of the disease should be discussed at the latest when symptoms of dysphagia occur in order to prevent unwarranted fears of “choking to death”. Psychosocial and spiritual care of patients and families are of paramount importance. Collaboration with hospice institutions and completion of advance directives can be of invaluable help in the terminal phase. Remarkably, ALS patients can reach a high quality of life and satisfaction with their subjectively perceived meaning in life throughout the course of the illness, despite progressive loss of functional.
**Parallel sessions**

- Early advance care planning is recommended
- Recognition of deterioration over the last weeks and months is relevant for appropriate management
- Proactive assessment of physical and psychosocial issues reduces the need for crisis intervention
- The principles of symptom management should be applied uniformly and consistently
- Diagnosis of the dying phase allows appropriate planning and education of the family
- Palliative care should be concerned with the patient and their needs
- The understanding and management of neurological symptoms should be provided for specialist palliative care professionals

**Conclusion:** The development of the guidelines has allowed recommendations on practice for the care of people with neurological disease. The aim is for these to be disseminated to both neurology and palliative care clinicians with the aim of improving the care and quality of life for these patients and their families.

**Abstract number:** PS 13.3

**Abstract type:** Parallel Symposium

**Neuromuscular Electrical Stimulation for Muscle Weakness in Adults with Advanced Disease: A Cochrane Systematic Review**

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**Background:** Patients with advanced disease often experience muscle weakness which impacts adversely on independence and quality of life. In patients unable or unwilling to undertake existing forms of exercise, neuromuscular electrical stimulation (NMES) may provide an alternative approach to maintaining leg muscle strength. Programmes appear well tolerated and have led to improvements in physical function and quality of life. Our primary objective was to determine the effect of NMES on quadriceps strength in adults with advanced disease.

Secondary objectives were to determine effects on maximal quadriceps strength in adults with advanced disease.

**Method:** Randomised controlled trials in adults with advanced COPD, chronic heart failure or cancer comparing a NMES programme to a no treatment, placebo or active control were identified from the Cochrane Library, databases and conference proceedings. Two authors independently extracted data on study design, participants, interventions and outcomes. Mean differences or standardised mean differences (SMD) between NMES and control groups were calculated.

**Results:** Eleven studies involving 218 participants across COPD, chronic heart failure and cancer met the inclusion criteria. NMES significantly improved quadriceps strength by a SMD of 0.9 (95% CI 0.33 to 1.46), equating to 0.34 kg/m². Mean differences across various walking tests, all favouring NMES, were 40m (95% CI 4.1 to 84) for the six-minute walk test, 69m (95% CI 19 to 119) for the 12-minute walk test and 160m (95% CI 34 to 287) for the endurance walk test.**Conclusion:** NMES appears an effective means of improving muscle weakness in adults with advanced COPD, chronic heart failure and cancer. Further research should clarify its place in clinical practice by determining optimal programme parameters, patient most likely to benefit, and impact on mortality and service use.

**Abstract number:** PS 13.4

**Abstract type:** Parallel Symposium

**Palliative Care for Stroke Patients - Experience from the Regional Organization of Care**

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Every year 105 000 people die in the CR: 25% of malignant tumours, 50% of circulatory system diseases (cardiovascular and cerebrovascular disorders) and the remaining 25% of being pulmonary, liver and kidney diseases, poisoning and accidents [1]. Most of these people (70-80%) need palliative care. In the last 5 months of their end-of-life. Patients with the post-stroke tumours, 50 % of circulatory system diseases (cardiovascular and cerebrovascular disorders) and the remaining 25% of being pulmonary, liver and kidney diseases, poisoning and accidents [1]. Most of these people (70-80%) need palliative care. In the last 5 months of their end-of-life. Patients with the post-stroke post-stroke accidents [1]. Most of these people (70-80%) need palliative care. In the last 5 months of their end-of-life. Patients with the post-stroke accidents [1]. Most of these people (70-80%) need palliative care. In the last 5 months of their end-of-life. Patients with the post-stroke accidents [1]. Most of these people (70-80%) need palliative care. In the last 5 months of their end-of-life. Patients with the post-stroke accidents [1]. Most of these people (70-80%) need palliative care. In the last 5 months of their end-of-life. Patients with the post-stroke 13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

**Religious Aspects in Palliative Care**

**Abstract number:** PS 15.1

**Abstract type:** Parallel Symposium

**Palliative Care in Muslim-majority countries: A situation analysis**

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There are currently over 1.6 billion Muslims living in all parts of the world and representing nearly one-quarter of the world’s population (www.perforw.org). About three-quarters of the world’s Muslims live in the 49 Muslim-majority countries (MMC’s), and about one-quarter live in Muslim-majority countries of the developing world.
Implications in Turkey

Islam and Palliative Care - Practical for the illness or responds to the reactions (or expected context of illness and terminal care both these experiences overlap, they can also be distinguished. Guilt is concerned

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

Abstract number: PS 15.2
Abstract type: Parallel Symposium

Islam and Palliative Care - Practical Implications in Turkey

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Turkey lies at the crossroads between Eastern and Western civilisations. Turkey has a history which contains the diverse cultural and religious traditions of both the East and the West. Social life contains a large number of different beliefs, customs, traditions, rites and ceremonies, stereotype attitudes, etc.

Turkey has a unique place among modern Muslim nation states. Turkey is a secular country, trying to find a balance between Islamic and modern. Turkey is trying to live its democratic culture. Today, Turkey emerges a country that supports a moderate, tolerant and inclusive perception of Islam. The widespread perception of Islam in Turkey is not radical, fundamentalist or exclusive.

The majority of the Muslim’s population belongs to the loosely defined Sunni interpretation of Islam. The current perception and practice of Islam varies from mystical and folk Islam to conservative and more moderate understanding of Islam. Several non-Muslim religious groups also exist in Turkey.

In this paper, the current perception and practice of Islam in Turkey will be discussed in the focus of palliative care. The meaning of life and death, perception and social aspects of illness, taking care of the dying, grief and mourning, disclosure of diagnosis and prognosis, etc. will be argued.

Palliative care is an emerging topic in Turkey within recent years. The need of treatment of Turkish Cancer Control Project 2009-2015 is palliative care and a serial palliative care unit implementation with continuous training programs. The current palliative care situation in Turkey and Pakistan-Turk Project will be briefly summarized.

Abstract number: PS 15.3
Abstract type: Parallel Symposium

Issues of Guilt and Shame in Life Threatening Illness and Death: A Challenge for Christian Pastoral Care

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Aim: To explore Christian pastoral responses to the presence of guilt or shame for people who are dying

Background: Research has shown that very early age we can experience guilt or shame and, while these feelings may overlap, they can also be distinguished. Guilt is concerned with the consequences of one’s actions which are believed to be wrong or harmful. Shame links more closely to embarrassment or humiliation and feelings of low esteem - often for not having met the expectations of others. In the context of illness and terminal care both these experiences can result from the way the individual tries to find a cause for the illness or responds to the reactions (or expected reactions) of others to news of the diagnosis and prognosis.

This is often expressed in terms of questions such as: “Why me?”, “What have I done to deserve this etc. In this presentation I shall look at some of the ways in which guilt and shame can shape responses to diagnosis and treatment, assess the contribution they can make to spiritual and psychosocial distress, and suggest palliative responses within the context of Christian care.

Conclusion: Sensitive pastoral exploration can help to reduce the same somatic and spiritual suffering. When appropriate religious liturgy / ritual can also assist transition of the experience and help the dying person achieve a greater sense of inner peace.

Abstract number: PS 16.1
Abstract type: Parallel Symposium

The International Collaborative Project to Evaluate the Availability and Accessibility of Opioids for the Management of Cancer Pain: Final Survey Result

Cherny, N. J.
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Introduction: The International Collaborative Project to Evaluate the Availability and Accessibility of Opioids for the Management of Cancer Pain (ICP) was coordinated by ESMO, EAPC, UICC, PPSG + WHO with collaboration from international PC and oncology societies.

Aim: To develop a tool to assess availability and accessibility of opioid medication for the management of cancer pain in Africa, Asia, Latin America and the Caribbean and Middle East. The adequacy of formulary availability is evaluated relative to the International Association of Hospice and Palliative Care list of Essential Medicines for Palliative Care. Overregulation was evaluated according to descriptors identified by the World Health Organization and the International Narcotics Control Board.

Results: Between 12/2010-7/2012, 156 reports were submitted from identified reporters in 76 countries and 19 Indian states (58% countries, 83% population). Very few countries provide all 7 opioids on the essential drug list of the IAPHC (Codeine, immediate and slow release oral morphine, oral IR oxycodone and transdermal fentanyl) and in many countries less than 3/7 drugs are available. Furthermore, in most of the countries opioids are either not or are weakly subsidised by gov. and availability is often limited. Many countries have highly restrictive regulations that limit entitlement of patients to receive prescriptions, limit prescriber privileges, impose restrictive limits on duration of prescription, restrict dispensing, and increase bureaucratic burden of the prescribing and dispensing process.

Conclusion: In many places across Africa, Asia, ME and L+C America governments are failing cancer patients in delivery of adequate pain relief. There is a need for increased availability of affordable opioids for the management of cancer pain. A priority action is exchange of drug control policies and repeal of excessive restrictions which impede this most fundamental aspect of cancer care.

Abstract number: PS 16.2
Abstract type: Parallel Symposium

Integration of Palliative Care into Oncology

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Palliative care has become more complicated due to the developments of diagnostic technology and follow up of patients. More patients are living longer because of better life-prolonging treatment. However, the benefit for the patients on symptom control, function and quality of life is varying, and there is a need for quantifying the effect. One needs to focus just as much on quality as on quantity of life.

The complexity of cancer care increases needed at various stages of cancer care: Curative, life-prolonging, palliative care and end-of-life care.

The patients are in need of symptom management, psychological and social and existential care independent of treatment intention. Therefore, the traditional organisational structures as a division between mainstream oncology and palliative care do not seem to be the optimal structure.

Developing Collaboration for Palliative Care: Experience and Challenges

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The concept of collaboration features prominently in palliative care. The purpose of this symposium is to share the experiences and challenges of developing research collaboration used by the All-Ireland Institute of Hospice and Palliative Care (AIHPC), which is a large 5 year collaborative initiated in 2011 to improve palliative care on the island of Ireland. There have been a number of challenges as a result of seeking to create an initiative that brings together three Work Packages of Education, Research and Policy and Practice into a single entity, allowing the activities and outcomes of each to add value to the others.

In this symposium, we will present work streams that are aimed at developing collaboration for palliative care in line with the international agenda. Paper 1 will provide the strategic context within Ireland that has supported the development of the All-Ireland Institute of
Hospice and Palliative Care. Paper 2 will describe the activities undertaken in developing a research collaborative community, emphasizing the importance of the spectrum of activity that can contribute to research and knowledge generation. Paper 3 presents models of mentorship and provides an overview of the spectrum of activity that can contribute to research and knowledge generation.

Abstract number: PS 17.4
Abstract type: Parallel Symposium

Developing Collaboration for Palliative Care: Experience and Challenges
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2University of Ulster Jordanstown, Institute of Nursing Research, Newtownbray, United Kingdom.
3Lancaster University, International Observatory on End of Life Care, Faculty of Health and Medicine, Lancaster, United Kingdom.

The concept of collaboration features prominently in palliative care. The purpose of this symposium is to share the experiences and challenges of developing a model of collaboration used by the All Ireland Institute of Hospice and Palliative Care (AIHPC), which is a large 5 year collaborative initiated in 2011 to improve palliative care on the island of Ireland. There have been a number of key areas of challenges as a result of seeking to create an initiative that brings together three Work Packages of Education, Research and Support. The project has evolved into a single entity, allowing the activities and outcomes of each to add value to the others. The key findings from this symposium will present the processes that are ongoing and the lessons that have been learned. Specifically focus will be directed to the United Kingdom’s National Cancer Care Research Institute funded Cancer Experiences Collaborative project which was a five year initiative designed to increase the quality and quantity of supportive and palliative care research, and to increase the capacity of researchers. The project was a European Commission funded ATOME (Access to Opioid Medication in Europe) project which is designed to support 12 countries in Central and Eastern Europe to have better balance in medication policy and access. Analysis of the resources, structures, processes and outcomes of these projects will be discussed. There have been some key challenges in developing the research collaboratives such as: sustainable capacity building, leadership, engagement of service users, track record of key players and mentorship.

Abstract number: PS 17.3
Abstract type: Parallel Symposium

Models of Mentorship and Educational Networks for Palliative Care
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Modern society is changing in terms of social, cultural and economic features. Europe is developing novel forms of political and health care systems. Palliative care is a relatively young health specialty, in rapid growth, with a solid and well established foundation, and with new landscapes to explore. Future palliative care leaders need to be prepared to face the challenges of this new liquid modernity. The aim of this symposium is to share the role of educators and education in this capacity development. Careful succession planning is a critical step, which includes the identification of gaps, a visioning and transparency as key elements. For education mentorship to be effective and tailored it needs international networking and peer support. As such a formal academic setting should be paired with informal settings where students can meet and share experiences. Central to this is the development of a close collaboration between universities, research institutes and management schools, in order to provide the skills and competencies needed to accomplish future leadership roles. Learning methods within Europe as e-learning and new technologies, should be used to enable blended learning together with traditional techniques. The need for expansion of interprofessional learning has been highlighted as something that can enhance both learning and mutual recognition of roles within the multi-disciplinary team. In conclusion stakeholders should recognize, prioritize and respond to emerging educational needs.

Abstract number: PS 17.2
Abstract type: Parallel Symposium

Developing a Research Collaborative Community
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Aims: This presentation draws upon evidence of international and national research collaboratives and international partnering opportunities for promoting and facilitating them.

Methods: Using experience from two different types of research collaboratives, I will describe the strengths and limitations. One type of research collaborative has a specific goal which is to design, implement and deliver a specific piece of research. This is funded through the European Commission. The second type of research collaborative has a wider remit which might include research capacity building and continuing professional development, in addition to high quality research outputs.

Results: The presentation will draw upon lessons learnt via these two types of research collaboratives, to describe the key elements that are present in both. Specific focus will be directed to the United Kingdom’s National Cancer Care Research Institute funded Cancer Experiences Collaborative project which was a five year initiative designed to increase the quality and quantity of supportive and palliative care research, and to increase the capacity of researchers. This project was a European Commission funded ATOME (Access to Opioid Medication in Europe) project which is designed to support 12 countries in Central and Eastern Europe to have better balance in medication policy and access. Analysis of the resources, structures, processes and outcomes of these projects will be discussed. There have been some key challenges in developing the research collaboratives such as: sustainable capacity building, leadership, engagement of service users, track record of key players and mentorship.

Conclusions: This presentation will outline the processes used within the development of research collaboratives and provide evidence of the factors that determine sustainability, and provide further debate on considerations of key criteria that predict positive outcomes.

Abstract number: PS 17.3
Abstract type: Parallel Symposium

EAPC Taskforces in Paediatric Palliative care and European Steering Committee for Palliative Care in Children
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In 2006, an international group of 18 paediatric palliative care experts and representatives from the Maruzza Lefebvre D’Ovidio Foundation (Maruzza Foundation), the Luiss Benini Foundation and the ‘No Pain for Children’ Association, met in Trento, Italy, to examine strategies and best practices for the care of children with incurable conditions. The outcome of the Trento meeting was the publication of a united document, the ‘ImPACT Charter’, which defines and identifies standards of care for children with life-limiting and terminal illness. This document has been developed by the EAPC and, consequently, the EAPC Taskforce - Palliative Care in Children was established. The second publication resulting from the work of this Task Force, ‘Palliative Care for Infants, Children and Young People: The Facts’, translated into several different languages, has become a reference document for professionals working for the improvement and reorganization of palliative care practices for children in many countries all over Europe.

Subsequently, in 2010, the Task Force was broadened to encompass members from a wider geographical, professional and academic base. The European Steering Committee for Palliative Care in Children was created and two key areas of Interest were identified for the formation of two new EAPC Task Forces:
• The EAPC Taskforce for the mapping of palliative care services for children and adolescents in Europe, in collaboration with the International Observatory on End of Life Care, is gathering information regarding the provision of Palliative Care for Children and Young People throughout Europe.
• The EAPC Task Force for the formulation of standardized curricula for medical staff working in Paediatric Palliative Care is working to define core curricula for healthcare professionals working in paediatric palliative care.

The holistic nature of palliative care for children and families involves accepting the family as part of their own culture, and the cultural environment in which they are cared for. With the changing nature of society, the team around the child may consist of many different cultures and cultural beliefs, some of which may conflict with the families own norms and beliefs. Respect for the differences includes knowledge of the different cultures, differences in understanding and differences in approach. Communication can be complex when members of the team do not share a common language. This is even more the case when the first language. Within the cultural complexities, the child may have his or her own “culture”, language and beliefs. There are a variety of types of training programmes available on children’s palliative care, some more accessible than others, and some which impact not just knowledge but also the skills and attitudes necessary for children’s palliative care. Examples will be discussed utilizing work from the Spain children’s palliative care task force along with the programmes developed through the International Children’s Palliative Care Network. Key components of an education programme/ strategy for children’s palliative care will be identified and discussed and the implications of this for us in practice.

In order to improve the quality of palliative care provision for children, it is important that there are educational initiatives that are available and accessible to those who need it, as well as fit for practice, addressing both skills and attitudes as well as knowledge. A comprehensive education programme needs to address education for different cadres working at the different levels of service delivery such that children in need can access palliative care in the place that they need it.

Abstract number: PS 18.3
Abstract type: Parallel Symposium

Managing Differences - the Influence of Culture in Palliative Care for Children
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The holistic nature of palliative care for children and families involves accepting the family as part of their own culture, and the cultural environment in which they are cared for. With the changing nature of society, the team around the child may consist of many different cultures and cultural beliefs, some of which may conflict with the families own norms and beliefs. Respect for the differences includes knowledge of the different cultures, differences in understanding and differences in approach.

Communication can be complex when members of the team do not share a common language. This is even more the case when the first language. Within the cultural complexities, the child may have his or her own “culture”, language and beliefs. There are a variety of types of training programmes available on children’s palliative care, some more accessible than others, and some which impact not just knowledge but also the skills and attitudes necessary for children’s palliative care. Examples will be discussed utilizing work from the Spain children’s palliative care task force along with the programmes developed through the International Children’s Palliative Care Network. Key components of an education programme/ strategy for children’s palliative care will be identified and discussed and the implications of this for us in practice.

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Dementia

Abstract number: PS 19.1
Abstract type: Parallel Symposium

White Paper on Palliative Care in Dementia
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Dementia is an incurable, life-limiting disease. Patients and families may have specific palliative care needs. The European Association for Palliative Care (EAPC) presents a white paper on palliative care in dementia.

Parallel sessions

Parallel Session X

Communication in Dementia
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The population of people with dementia (PWD) is rising throughout the world. It is expected that the average person will live with their disease throughout their entire lives. The disease has a profound impact on family caregivers and healthcare professionals. In each stage of a dementia illness positive communication is paramount to the PWD's quality of life.

Therefore, we must understand how to successfully communicate using appropriate verbal and non-verbal techniques. This includes an awareness of how the environment may impact on these techniques. It is clear that there are too many distractions that disrupt the ability to pay attention. The care partner must insist they have the PWD's attention before they begin to communicate with them and make sure their words match their non-verbal communication. In the early stages, people may still be able to understand simple commands both verbal and written. In the moderate stage, PWD may be in a different reality and the person communicating with them needs to "join" their journey just long enough to try a really basic approach. When the person with dementia enters the severe stage of a dementing illness it is the most effective way of communication. Not only is it important for care partners to successfully communicate to a person with dementia; they must also also take part in the communication from them. A lecture will explore how to learn the "language" of dementia. Assessment of pain and discomfort is vital to helping people with dementia live with quality in their lives during the duration of their life. Many scales have been developed for people in the early stages of dementia and the PARADICE Scale is successful in assessing pain and discomfort in people with severe dementia. Although we do not have a cure for dementia and no way to successfully slow down its progression, we do know how to communicate with PWDs and help them have moments of joy.

Outcome Assessment in Palliative Care

Abstract number: PS 20.1
Abstract type: Parallel Symposium

Electronic Assessment: Pros and Cons
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Reports have emphasised the benefits of replacing the traditional paper based rating in clinical practice and in clinical research. Systems are registration forms with electronic assessment tools in clinical work and research. This presentation focuses on three aspects in relation to electronic assessment tools: patients, caregivers and outcome measurement in low-to-middle income countries.

The EAPC White Paper on Outcome Measurement in Palliative Care is working on a White Paper to provide guidance on standardised methodology and is interested in how to be able to evaluate face-validity, feasibility, and usefulness. The paper offers guidance to all services regardless of the setting it is being provided in (e.g. community, hospice, hospital), the country in which it is being delivered and regardless of the model of care being used. The paper consists of ten recommendations and concludes with guidance on establishing national outcome measurement programmes the EAPC Toolkit on Outcome Measurement in Palliative Care.

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Access Issues / Access to Care

Abstract number: PS 21.1
Abstract type: Parallel Symposium

Disadvantaged Groups in the Access to Palliative Care
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Equity of access means that people of equal need should have the same access to care. The level of care should depend only on patients' level of need and not on factors
irrelevant to that need. This presentation will in particular focus on patients with non-cancer diagnoses, older patients, patients with lower socioeconomic status and ethnic minorities, and those who are disadvantaged in their access to palliative care. It will present evidence that differential access is unlikely to be due to differences in need and considerable alternative factors that may help explain patterns. These include difficulty in establishing prognosis, differences in care given by the hospital, communication with professionals and acknowledgment of dying, existing resource, knowledge of services and expectations. Finally, potential solutions to inequity in access will be considered.

Parallel Symposium

Abstract number: PS 21.2
Abstract type: Parallel Symposium

Rural Perspectives in Palliative Care - How Do We Deliver Care in Sparsely Populated Areas?

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Countries that were under Communist prior to 1998, located in Eastern Europe (EE), have social systems that are considered rudimentary, with economical backgrounds mainly based on agriculture. This rural perspective creates a need to find ways of delivering good Palliative Care (PC) to the underserved population and overcome challenges like: poverty, migration of young generations to urban areas or abroad, low availability of trained medical staff willing to serve these communities, difficult access to medical facilities abroad, low availability of trained medical staff willing to serve these communities, difficult access to medical facilities and under-developed infrastructure, etc. The focus of this presentation is on the existing situation in 4 different EE countries, where there are PC initiatives to serve few rural regions, like Moldova, 66% rural population, Hospice “Carolina de Nord” inpatient unit and home care team in Zăbęstii, Săcăul Teiului, Romania - 45.9% rural population, Hospice “Casă Speranței” in Botoșani, 59% rural population, Hospice “Carolina de Nord” inpatient unit and home care team in Zăbęstii, Săcăul Teiului, Romania - 45.9% rural population, Hospice “Casă Speranței” in Botoșani, 59% rural population, Hospice “Carolina de Nord” inpatient unit and home care team in Zăbęstii, Săcăul Teiului, Romania - 45.9% rural population, Hospice “Casă Speranței” in Botoșani, 59% rural population, Hospice “Carolina de Nord” inpatient unit and home care team in Zăbęstii, Săcăul Teiului, Romania - 45.9% rural population, Hospice “Casă Speranței” in Botoșani, 59% rural population, Hospice “Carolina de Nord” inpatient unit and home care team in Zăbęstii, Săcăul Teiului, Romania - 45.9% rural population, Hospice “Casă Speranței” in Botoșani.

Gomes B
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It has only been recently that palliative care has given attention to the importance of caring for increasingly diverse societies. Many are already multicultural and this is amplified by growing migration. Moreover, social disparities are increasing; the number of smaller families, women in full-employment out of home and older people living alone is rising. This socio-demographic shift widens the diversity in circumstances in the population including people in need of palliative care. This means that although general patterns, preferences, priorities for palliative care persist, there is greater diversity among patient groups with different needs/experiences/preferences. Professionals are required to ensure both equity and quality care for all. There is therefore a need for evidence on social diversity in palliative care and ways of addressing this in the future.

This presentation examines different facets of the issue, drawing on a growing body of evidence in Europe including: 1) discuss variations in access and outcomes of palliative care likely to reflect inequity, 2) identify key social factors potentially impacting palliative care for patients with advanced illness and families, 3) learn from recent initiatives and care models tailored to respect diversity and address needs/preferences of patients in under social conditions. Clinical, policy and research actions needed to more closely reflect the increasing diversity in social circumstance, needs and families in need of palliative care will be discussed.

Reference:
Koffman, M.J.M. Dying in Germany 2011; pp116-31

Gomes et al. Heterogeneity and changes in preferences for dying at home: a systematic review. From Budapest to Prague - From Commitments to Rights

Parallel Symposium

Abstract number: PS 22.1
Abstract type: Parallel Symposium

The ATOME Project: Improving Access to Opioid Medication in Central and Eastern Europe

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The Access to Opioid Medication in Europe (ATOME) project commenced in December 2010 and is supported by the European Commission’s 7th Framework Programme over five years. The objective is to improve access to opioids in 12 European countries (atome.org). The project seeks to ensure accessibility, availability, and affordability for all patients requiring treatment with opioid medicines. To accomplish its objectives, the ATOME project follows two tracks of activities in parallel.

One track is related to the analysis of national policies and circumstances that affect the accessibility and availability of opioids, such as a lack of education for health-care professionals, as well as myths and misconceptions about opioids among the public, other health-care professionals and in the general public. The goals are both to make recommendations to the government and to make health-care professionals aware of the possibilities arising from these professional practice related to the use of opioids.

The other track aims at optimising the relevant legislation in order to allow both the prevention of all these problems and the dependence and the medical need for these medicines. The goal is to identify legal provisions that may impede access to opioid medicine, and to make recommendations for improvement in consultation with the national counterparts.

To raise awareness on a larger scale and increase the likelihood of change, the outcomes of the national policy and legislation analysis are disseminated to a wider audience of relevant policy makers, stakeholders, and health-care professionals during national one-day conferences in each of the 12 countries.

Close collaboration of the project in the European countries shall ensure that recommendations for legislative and policy changes made within the ATOME project will be validated and their applicability to the country-specific situation will be verified. The final recommendations will be handed over to the Ministries of Health of the 12 countries in 2014.

Abstract number: PS 22.2
Abstract type: Parallel Symposium

Regulatory Barriers in Practice

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Background: Many factors contribute to limited access to opioid medicines for medical purposes, including legislation and policies. The Access To Opioid Medicines in Europe (ATOME) is undertaking a situational analysis in European countries. Legislation regulating opioid medicines is reviewed to identify potential barriers to access and make recommendations for improvement.

Aims: To identify potential legal barriers that may impede access to opioid medicine in practice in 11 Southern and Eastern European countries. Legislation regulating opioid medicines is reviewed to identify potential barriers to access and make recommendations for improvement.

Methods: A template was developed as the ATOME legislation review method focusing on 9 different categories of barriers. Relevant data is collected in consultation with national counterparts in the target countries. Selected provisions were independently reviewed by three reviewers. Different views were discussed until consensus was reached.

Results: All countries showed potential barriers in their legislation that could make prescribing, dispensing and language as main potential barriers. Although the identified potential barriers could lead to limited access, additional research is needed to assess the actual impact of these barriers on accessing opioid medicines in practice.

Abstract number: PS 22.3
Abstract type: Parallel Symposium

Differences between Countries and Cultures

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Aims: The objective of this session is to addres gaps in knowledge about the nature of palliative care services provided to adults by hospices, specialist palliative care teams and other health care organizations in Europe. Specifically, the aims include a critical analysis of how health care differences are described in international comparative analyses and the extent to which cultures of care and social norms are assessed and recognised.

Method: Drawing upon data from ‘Country Reports’ prepared by the International Observatory on End of Life Care and experiences gained during the ATOME project, the ATOME project involves senior people working together in ‘Country teams’ which are based in 12 Central and Eastern European countries with the aim of addressing barriers to opioid medication access in their countries. Data were collected using documented analysis, questionnaires, national and international participative workshops.

Results: The majority of respondents were from nine countries. They attributed differences to a number of causes: the legacy of European history, especially communism, the availability of resources, especially recent economic conditions in the euro area, cross-cultural differences in the way end of life care is approached and open disclosure of care, concerns about opioid medication use, especially addiction and tolerance in the public and professionals.

Conclusions: Many of these countries appear to share common features which act as barriers to access to pain medication and the development of palliative care. Moreover, there is a tension between aspirations to promote ‘excellence’ in palliative care based on models developed in Western European countries which will require sustainable, affordable and culturally appropriate care which values cultural aspects inherent in each country.

From Budapest to Prague - From Commitments to Rights

Parallel Symposium

Abstract number: PS 23.1
Abstract type: Parallel Symposium

Charter for the Care of the Critically Ill and the Dying in Germany

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In September 2010, the Charter for the Care of the Critically Ill and the Dying in Germany was officially launched in Berlin. This national project is Germany’s contribution to the Budapest Commitments, an international framework for palliative care development. Since its launch, more than 600 organisations and 1800 individuals have signed up to the charter. Furthermore, in one of so-called ‘Budapest Commitments’ for sustainable, affordable and culturally appropriate care which values cultural aspects inherent in each country.

The charter comprises the following five key principles:

1. Socio-political challenges

- Ethics, the law and public debate
Every human being has a right to a dignified death. It must be ensured that they will be respected in the last phase of life with regard to their preferences, wishes and values.

2. Needs of patients and families / organisation of care
All critically ill and dying people have a right to comprehensive information, support, full respect for diverse social and spiritual care that takes into account their individual situation and palliative/hospice care needs.

3. Training and education of healthcare professionals
All critically ill and dying people have a right to appropriate, qualified and, if required, multi-professional care.

4. Future development and research
All critically ill and dying people have a right to care based...
Palliative Care - Part of the Main or Specialized Discipline?

Abstract number: PS 24.2
Abstract type: Parallel Symposium

Pro General Approach: Palliative Care for All Means by All

Murray S.†
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Around 80% of people die after a progressive illness and thus can benefit from palliative care. However most people in Europe fail to access such care from palliative care specialists as there are not enough of such specialist doctors and nurses to see all the patients in need. The most important challenge facing palliative care in the next decade is to make it equally available to all according to need, and there is only one practical way of delivering this. The only way for palliative care to reach the vast majority of people in need is for it to be delivered by generalist nurses and doctors working in all settings: hospitals, general practice, nursing homes. These generalists need to be trained to identify people for early palliative care, and then provide generic palliative care. In other words, they can assess physical, social, psychological and spiritual needs of patients and then provide pro-active care to the patient and carer. Where they need assistance or in complex cases patients can then be referred to specialist palliative care services. Summarily, if palliative care is integrated into mainstream medicine, especially in care of people with long-term conditions, it can:• Reach patients with all life-threatening illnesses• Start early in the course of life-threatening disease• Meet all dimensions of need: physical, social, psychological and spiritual• Provide care in clinics, care homes and at home thus preventing unnecessary hospital admissions• Support family carers and provide bereavement care

In the case that I will put forward I will indicate how this approach is actually carried out in some countries, and how it can be progressed throughout Europe and internationally.

Nutrition in Palliative Care

Abstract number: PS 25.1
Abstract type: Parallel Symposium

EN and PN: Practical Recommendations in Advanced Cancer

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In addition to supplying energy and nutrients, eating and drinking may alleviate hunger and thirst; they may be associated with joy and pleasure or with nausea and pain. Food intake has emotional and social impact and affects the awareness of self-control. These aspects need to be considered when dealing with nutritional problems in cancer patients. Enabling normal food intake should receive high priority.

If nutritional intake in a patient is insufficient it needs to be considered whether this impacts on his/her quality of life and/or on the course of the disease and possibly the expected overall survival. This impact will be small or irrelevant if nutritional intake is close to normal and if the patients’ expected survival is severely limited; the impact will be large if energy intake is close to zero and the expected disease-associated survival is long. The following problems need to be discussed and assessed with the patients and their families: the effects of not using artificial nutrition; the potential benefits of providing artificial nutrition; the burden of undergoing artificial nutrition; the importance of including physical activity in the treatment plan; the importance of considering and if necessary modulating metabolic derangements which interfere with nutritional benefits.

Parallel sessions
The meaning and importance of flavourful food and a shared meal cannot be underestimated. Through the course of an incurable illness, the fulfilment of these fundamental human rights is repeatedly professed, profoundly affecting both the person and the caregivers. Research has shown that appetite and the ability to eat are both very important physical aspects in a patient’s life. But eating or the inability to do so is loaded with social and existential meaning. Eating signifies being alive and living. On not being able to eat or an inability to enjoy advanced ill care can be seen as giving up the fight, abandonment and failure. Such feelings may lead to existential distress for the person concerned and - often even more so - for their carers. Not uncommonly, it can also lead to inappropriate and futile interventions. In respect of this situation, the social and cultural dimensions of food and eating will be explored. Film sequences and patient stories will highlight the complexity of this topic and point to a variety of holistic interventions which may help the patient and their loved ones to cope with cachexia-related suffering.

End of Life Preparation - Health Literacy in the Community

Abstract number: PS 26.1
Abstract type: Parallel Symposium
End of Life Preparation - A Genuine Task for the Community

Fechmüller S.
University Hospital Bern, Centre for Palliative Care, Bern, Switzerland

During the last two decades considerable progress has been made in communities in the field of professional palliative care in various countries. However, such development has rarely been based on proper general needs assessment of the broad public. Needs of communities may reflect the population’s perspective of end of life problems and challenges, and may differ from a professional view. There has been recent effort to reconnect to the community as a nucleus providing framework and concrete support for those who will die within the next months. Models form India and Australia highlight underused resources - structural, intellectual, emotional and even financial - we can find within communities. Findings from these models provide encouraging guidance how to create attention and concrete structure for community based palliative care and end of life preparation.

End of Life Preparation - A Genuine Task for the Community

Abstract number: PS 26.2
Abstract type: Parallel Symposium
The Hospice Movement as Catalyst for Developing End-Of-Life Literacy - Results from an Oral History Project

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While the development of the hospice idea can be traced back to the 19th century, a famous story from the German history of hospice and palliative care shows multiple roots. The first initiatives date back to the 1980s and it was not until the late 1990s that hospice and palliative care started to spread out nationwide. How can this delay in time be explained? An oral history project was done to better understand the specific development of hospice and palliative care in Germany (IFF, University of Klagenfurt). The sample consisted of 73 oral history interviews with pioneers of the hospice movement, representing broad variety of initiatives and movements in various countries and regions.

Results show that in Germany the hospice movement can be characterized mainly as a “social movement”. Parents of children with cancer engaged themselves because they were fascinated by the idea of dealing with the dying in a human way, giving a voice to the dying and their families following a holistic approach. Christian foundations did play a role for many people, though first initiatives were strongly opposed by the official church. Voluntary hospice services, free standing hospices or various palliative professionals and lay persons were developed within these grass-root initiatives. These had a major impact on the society as a whole. The hospice movement raised the issue of dying, death and bereavement in Germany and offered a language to talk about these sensitive topics as an aftermath of the 2nd world war and the crimes of the Nazis.

The global concept of palliative care as it has developed in Germany under the initiative of the “German Hospices” shows many commonalities with the hospice movement, indeed. In case of Germany a distinction between palliative care and the hospice movement is necessary to preserve the unique achievements of this civil movement for future development.

Abstract number: PS 26.3
Abstract type: Parallel Symposium
Parallel Symposium East of Life Preparation - Health Literacy in the Community

Gómez-Bustos X.
Catalan Institute of Oncology, Barcelona, Spain

Identifying and improving the palliative care approach for persons with advanced ill care situations and limited life prognosis in health at social services with a duration of 28 minutes including time for questions

Describes the experience of the project “Palliative care needs of long term care services in Catalonia (PALLISER)”, the implementation of a methodology to identify patients with advanced chronic conditions in the general population, including:

- Creation of a tool based in the GSF
- Determination of the prevalence in districts and settings
- Implementation of a community approach of improving the quality of care for those patients in the region and in Spain
- Research and ethical debates associated to this project.

Palliative Care as a Human Right

Abstract number: PS 27.1
Abstract type: Parallel Symposium
The Right to Palliative Care as a Human Right

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This presentation will describe the legal, ethical and moral basis for the recognition of the right to palliative care as a human right, the advocacy initiatives by several organizations, the role of UN bodies and member states, and some of the strategies to improve the quality of care for those patients in the region and in Spain.

The concept of the right to palliative care gained momentum in the late 1990s as a result of 4 factors: the interaction of 3 disciplines (palliative care, public health and human rights); the recognition of palliative care as clinical and academic discipline which coincided with the development of a global and community health; the recognition of the care of the dying as a public health issue; and the accumulation of evidence which indicates that patients are inadequately treated.

Several palliative care and human rights organizations developed campaigns to remind member states of their obligations to ensure access to palliative care and to generate awareness among the civil society of the patient’s rights to care, including the Joint Statement of Commitment for the Recognition of Palliative Care and Pain Treatment as Human Rights, and more recently, the Prague Charter.

The role of the World Health Organization, the International Narcotics Control Board and the United Nations Human Rights Council as how they relate to this right will be discussed, particularly with respect to access to opioids for pain treatment.

Strategies for improvement include promoting palliative care as a fundamental human and legal right, framing palliative care as a fundamental human right, incorporating constitutional guarantees and statutory regulations that span negligence law, criminal law, and elder abuse; categorizing failure to provide palliative care as professional misconduct, and issuing guidelines and standards of practice by professional bodies. Failure to treat suffering should be viewed worldwide as poor health care, unethical medical practice, and a denial of a fundamental human right.

Abstract number: PS 27.2
Abstract type: Parallel Symposium
Palliative Care Policies in the National Governments and the European Institutions

Marta Alvarez JA., Lynch T., Gamarra E., Centeno C.
1. Universidad de Valencia, Dep. Medicina Preventiva y Salud Publica & Hospital Clinico Universitarios, Valencia, Spain, 2. Universidad de Navarra, Instituto de Cultura y Sociedad, Programa de investigación ATLANTE, Pamplona, Spain
Contact address: jose.maria.martinojus@unican.es

Aims: Approximately 5 million Europeans need palliative care (PC) every year. The objective of this presentation is to review the main initiatives adopted since 2006, and an examination of which countries currently have a national PC plan. We will also provide a qualitative analysis of the most important political and legal changes affecting PC development, according to professional leaders in each country. Finally, a systematic review of available information, including from scientific literature and EU and WHO bodies. Failure to treat suffering should be viewed as giving up the fight, abandonment and failure. Such problems relate to the recognition of palliative care as a fundamental human and legal right, framing palliative care as a fundamental human right, incorporating constitutional guarantees and statutory regulations that span negligence law, criminal law, and elder abuse; categorizing failure to provide palliative care as professional misconduct, and issuing guidelines and standards of practice by professional bodies.

Results and discussion: Specific laws on PC exist in at least Belgium, France and Germany. Many other countries include the right to PC in their general health legislations; e.g., Spain, the Netherlands, Poland and the UK). In addition, 23 out of 46 countries have developed a national PC plan. However, our problems related to the indications of the distribution of the health system budget, insufficient services, problems with organization and coordination affecting PC provision, quality in the distribution of services, limited access to existing services for patients, and lack of coverage by insurance companies. In November 2012, and within the framework of a noncommunicable disease control, WHO approved an indicator of access to PC: the consumption of strong opioids (as equivalent dose of morphine) and cancer-related death. Conclusion: The rising need for PC requires clear action from EU Member States and European institutions. The study of PC policies should be promoted in order to ensure accountability in an area which constitutes an ethical responsibility as well as a matter of health system efficiency and efficacy.

Abstract number: PS 27.3
Abstract type: Parallel Symposium
Changing the Legislation: An Example from Russia

Vedernikova E.
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Palliative care in Russia has its origins in late 1980s with the emergence of the first palliative care centers in Petersburg and Rostov and the hospice movement led by Andrei Gnezdilov and later Vera Minskovich. During all these years palliative care developed sporadically and mainly by the initiative of enthusiasts. In November 2011 Russia’s president has ratified the New Health Bill “On the Basis of Health Care Provision in the Russian Federation”. As well as making fundamental changes to the country’s health care system in general, the bill in fact opens a new era for palliative care progress. For the first time in history it defines palliative care as a branch of the national Health Care history it provides a definition of palliative care, it says “palliative care is a set of interventions aimed to relieve pain and other severe manifestations of the disease in order to improve the quality of life of incurable people”(Article 36). Palliative care in accordance with the law for the first time has been included in the list of medical care forms guaranteed by the government for the citizens (Article 32). The law says that “palliative care... can be provided by health professionals who have been trained to provide such care” (Article 36). Palliative care will be funded through the Program of the state guarantees of rendering free medical care to the citizens of the Russian Federation. “(Article 80). Palliative care issues have been included in the Health Care Strategy of the Russian Federation to 2020. Recently the National Guidelines for Palliative medical care has been approved. According to the Guidelines palliative medical care should be provided in both inpatient and outpatient units, and various institutions, such as hospices, palliative care departments and clinics. Specialist palliative care centers will be established and physicians will have the opportunity to study specialist palliative care on a regular basis.

Abstract number: PS 27.4
Abstract type: Parallel Symposium
Palliative Care Policies in the National Governments and the European Institutions

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Contact address: jose.maria.martinojus@unican.es

Aims: Approximately 5 million Europeans need palliative care (PC) every year. The objective of this presentation is to review the main initiatives adopted since 2006, and an examination of which countries currently have a national PC plan. We will also provide a qualitative analysis of the most important political and legal changes affecting PC development, according to professional leaders in each country. Finally, a systematic review of available information, including from scientific literature and EU and WHO bodies. Failure to treat suffering should be viewed as giving up the fight, abandonment and failure. Such problems relate to the recognition of palliative care as a fundamental human and legal right, framing palliative care as a fundamental human right, incorporating constitutional guarantees and statutory regulations that span negligence law, criminal law, and elder abuse; categorizing failure to provide palliative care as professional misconduct, and issuing guidelines and standards of practice by professional bodies. Failure to treat suffering should be viewed worldwide as poor health care, unethical medical practice, and a denial of a fundamental human right.
Conclusions:

collection and analysis skills, networking, project and time experience including, writing and presentation skills, data that should be considered to be an integral part of the PhD on how to select and 'manage' your supervisors (promotors). and the high and lows of the journey. Attention will be given with a reflection on the reality of seeking research funding how to prepare a research proposal. The session will end successful at the outset. There will be a discussion about maximise the likelihood of your PhD application being

Methods:

research thesis and/or publications and getting a PhD. It is

The new programme structure as proposed under Horizon 2020 deserves further exploration on how this impacts on the research field of palliative care. An important aspect is the including the role of the agenda through 3-year Strategic Programmes and 2-year Work Programmes in order to ensure calls for research topics at the core of the palliative care field. During the talk, an overview of the new framework will be provided with a strategy on how to become actively involved in influencing the agenda of the strategic agenda as well as an overview on the main evaluation criteria for project selection.

Aims: The new programme strategy will be proposed for the sustainable delivery of EU research projects also address the important performance indicators that are needed to establish a successful career as a postdoctoral researcher.

Abstract number: PS 28.4
Abstract type: Parallel Symposium
Horizon 2020 - Writing Competitive Proposals under a New Framework
Jaspers L
Yellow Research, Amsterdam, Netherlands

The new programme structure as proposed under Horizon 2020 deserves further exploration on how this impacts on the research field of palliative care. An important aspect is the including the role of the agenda through 3-year Strategic Programmes and 2-year Work Programmes in order to ensure calls for research topics at the core of the palliative care field. During the talk, an overview of the new framework will be provided with a strategy on how to become actively involved in influencing the agenda of the strategic agenda as well as an overview on the main evaluation criteria for project selection.

Abstract number: PS 28.5
Abstract type: Parallel Symposium
Future Developments in Electronic Publishing
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The dissemination of scientific research is an integral component of the research process. Publishing and, as a consequence, dissemination of scientific results is changing rapidly.

Aims:

• Gaining insight in future developments in publishing and electronic publishing
• Gaining insight in editorial process
• Dissemination of scientific results through the internet: what to expect
• This presentation will contribute to a better understanding of the dos and don'ts in publishing scientific research.
Breathlessness is a common and distressing symptom in advanced malignant and non-malignant disease, which is still challenging to manage. Reversible treatment options should be considered. For symptomatic management, non-pharmacological and pharmacological treatment options are available which should best be combined. To influence the perception of breathlessness and reduce anxiety, breathing therapy, self-management, relaxation and pacing of daily life can be offered. There is evidence for the beneficial effect of rollators, hand held fans, and neuro-muscular electrical stimulation.

Good evidence exists for oral and parenteral opioids. Titrated against breathlessness, they are safe to use. Average doses are normally lower than for pain management but it is not clear whether any opioid is better than the others. The evidence for benzodiazepines is less clear and they only should be used as second line or in combination with opioids. In non-hypoxic patients, oxygen is not better than room air and the air draft can be produced by easier means such as a hand-held fan.
Meet the expert sessions

- Management of Patients with Difficult Pain. Can the EAPC Opioid Guidelines Help Us ... or Do they Need to Be Improved
- Resilience in Palliative Care
- How to Prevent and Treat Cancer Cachexia
- The Development of Paediatric Palliative Care Services
- The Contribution of Occupational Therapy to Patients with Palliative Care Needs in Europe
- How to Be a Better Reviewer
- Spiritual Care
- Palliative Care Support for Young People and their Families Provided through Schools and Colleges
- Doing Palliative Care Research in Primary Care: Challenges and Opportunities
- Action Research
- Gender Issues in Palliative Care
- Physiotherapy and Palliative Care
Management of Patients with Difficult Pain. Can the EAPC Opioid Guidelines Help Us or Do They Need to Be Improved?

Abstract number: ME 1.1
Abstract type: Meet the Expert

Management of Patients with Difficult Pain. Can the EAPC Opioid Guidelines Help Us or Do They Need to Be Improved?

Siagpen P.
Section of Palliative Medicine, University of Copenhagen, Department of Oncology, Rigshospitalet, Copenhagen, Denmark

Decades ago WHO outlined the use of a stepwise approach or “analgesic ladder” in order to manage cancer pain. The main tenet is to initiate treatment with less potent analgetics and to advance to more potent analgetics with concomitant use of adjuvant drugs and invasive procedures as pain intensifies. The EAPC guidelines and recommendations were published following up the WHO guidelines in addressing the need for an international consensus. The EAPC recommendations published in 1996 and 2001 have been widely cited and used in clinical practice around the world. These recommendations have been criticised for the non-systematic approach in their development and incomplete review of the available evidence. As part of an effort to respond to this criticism the EPCP consortium of research in collaboration with the EAPC Research Network undertook the first effort in Europe to develop a novel set of guidelines for the treatment of cancer pain based on a rigorous evidence based methodology. A comprehensive list of relevant topics on opioid use for cancer pain was derived from a comprehensive list of previous guidelines on cancer pain relief. This list was submitted to an expert consensus process that led to 30 practical clinical questions summarised in 22 topics. The subsequent guidelines development process for each of the 22 topics followed the GRADE system. The EAPC Opioid guidelines has been a major step forward in treating cancer pain however, initiatives have recently been taken in order to address other cancer pain management modalities by a systematic approach in order to include them in more comprehensive guidelines.

Resilience in Palliative Care

Abstract number: ME 2.1
Abstract type: Meet the Expert

Resilience in Palliative Care

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Resilience is a concept that is attracting growing interest (Bluglass, 2003, Huppert, Baylis and Keverne, 2005; Newman, 2005). Varnsetad, (2003) has defined it as ‘the capacity to do well when faced with difficult circumstances’ and the International Resilience Project which collected data from thirty countries described resilience as a ‘universal capacity which allows a person, group or community to prevent, minimise or overcome damaging effects with adversity’ (Neuman and Blackburn, 2002). The concept has considerable relevance to palliative care. The focus of the resilience in palliative care is the ability to continue to exist during time of illness or during time of loss. The focus is on the ability to maintain a healthy life and to continue keeping up the spirits and maintaining the ability to enjoy life. The focus of the resilience in palliative care is the ability to continue to exist during time of illness or during time of loss. The focus is on the ability to maintain a healthy life and to continue keeping up the spirits and maintaining the ability to enjoy life. The focus of the resilience in palliative care is the ability to continue to exist during time of illness or during time of loss. The focus is on the ability to maintain a healthy life and to continue keeping up the spirits and maintaining the ability to enjoy life. The focus of the resilience in palliative care is the ability to continue to exist during time of illness or during time of loss. The focus is on the ability to maintain a healthy life and to continue keeping up the spirits and maintaining the ability to enjoy life. The focus of the resilience in palliative care is the ability to continue to exist during time of illness or during time of loss. The focus is on the ability to maintain a healthy life and to continue keeping up the spirits and maintaining the ability to enjoy life.

The Development of Paediatric Palliative Care Services

Abstract number: ME 6.1
Abstract type: Meet the Expert

Developing Palliative Care Services for Children - Global Trends

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Palliative care services for children began in 1982 with the opening of Helen House in Oxford, UK. The early children’s hospices, both in the UK and countries such as Germany, Canada and Australia followed this model of providing custodial care to the child. As the concept of hospice palliative care for children spread to other countries, some of them with very few resources, new and innovative models developed, most of them providing palliative care for children at community level. Very few free-standing children’s hospice units exist outside of more developed countries. With the development of palliative care for children, the need for education and integration became more apparent. Whilst few countries provide formal qualifications in this field, there exist a few Academic Chairs and specialist qualifications, and there are now a growing number of training courses, including e-learning courses. This presentation will look at the important trends in the development of palliative care for children, with some predictions for future development.

The Contribution of Occupational Therapy to Patients with Palliative Care Needs in Europe

Abstract number: ME 7.1
Abstract type: Meet the Expert

The Contribution of Occupational Therapy to Patients with Palliative Care Needs in Europe

Evgenia E., Ware B.
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Occupational therapy has the potential to provide a valuable service to people with palliative care needs: it supports patients to manage the disabling consequences of life-threatening illness, and it maximises patients’ and their carers’ ability to carry out practical, purposeful and meaningful activities. These include essential day to day tasks such as dressing, cooking, and cleaning, as well as those occupations that make us who we are – jobs, interests, hobbies and relationships. Anecdotal evidence has suggested that the availability and scope of occupational therapy in palliative care varies widely between European countries. In order to investigate this, and to establish connections between occupational therapists in Europe interested in palliative care, an EAPC Occupational Therapy Taskforce was set up at the end of 2010. The main taskforce activity has been to undertake a survey to find out more about the role of occupational therapists working in palliative care in Europe. The survey aimed to identify: 1. the types of activities undertaken by occupational therapists. 2. the variation in activities between European countries. 3. Areas where there are gaps in service provision.

In this session, we will present the results of the survey as a basis for debate and discussion on the actual and potential contribution of occupational therapists working in palliative care in Europe, both from a medical and a rehabilitation perspective. We will identify and seek to address some of the challenges that are encountered.
Palliative Care Support for Young People and their Families Provided through Schools and Colleges

Abstract number: ME 11.1
Abstract type: Meet the Expert

Palliative Care Support for Young People and their Families Provided through Schools and Colleges
Craig F.1,2
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Educational accomplishment should not be considered the only primary purpose of school or college attendance for a young person with palliative care needs. Where we view it as such, we risk isolating the young person and their family from a support system that may supersede that which can be provided by health and social care services. This workshop will explore several key issues:
1. The importance of maintaining school or college attendance
2. Working with young people, families and education services to facilitate access
3. Helping the school or college to develop the skills and knowledge to support the young person with palliative care needs, as well as their family (including siblings) and other students
4. Facilitating continued inclusion and involvement in the school or college community during periods of absence
5. Supporting the school or college to prepare for a death and to support the family, students and staff after a death

Through the development of our program for supporting schools and colleges, young people receiving palliative care can continue to access the social and emotional support of their peers and the adult professionals who work with them. It enables them to maintain a sense of value, purpose and belonging, with opportunities for personal growth and development. Sibling support can also be facilitated, with schools and colleges perhaps better placed to provide this than any other professional group, given that they will often be a constant presence in the young person's life for several years.

The failure of health professionals to recognise schools and colleges as key partners in palliative care provision must be viewed as a critical omission. With appropriate support, school and college staff and other students, can make a meaningful contribution to the health and emotional care of a young person and their family, and can have a valued role in providing support before, during and after death. Much can be done to facilitate this.

Doing Palliative Care Research in Primary Care: Challenges and Opportunities

Abstract number: ME 12.1
Abstract type: Meet the Expert

Doing Palliative Care Research in Primary Care: Challenges and Opportunities
Mitchell G.K.1, Murray S.A.1
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Primary care is where most of the care of people in the final phase of life will take place. Research in and about end of life care in this space is essential to learning how best to do it, and what people coming to the end of their life experience this and the care they receive. There are well known challenges to conducting research in palliative care settings, and these are magnified in the primary care setting. Palliative care research struggles to compete in a very crowded market, because only about one per cent of patients die in a typical general practice per year. Recruitment of both patients and health professionals can thus be very difficult. However, this session will present examples of different types of research in primary palliative care, and how successful primary care research has been achieved in this setting.

Action Research

Abstract number: ME 13.1
Abstract type: Meet the Expert

Action Research and Palliative Care: Principles and Challenges
Froggatt K.1, Hemert A.2
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Action research and palliative care, as research and practice disciplines, are both relatively young and increasing in prominence. These approaches have arisen as a response to identified shortcomings and critique of the more dominant approaches to research and care provision for dying people. Both approaches pay attention to holism either through research that considers the whole person in their whole context or care that addresses all of an individual’s needs in their wider social network of family and friends. An introduction to the principles of action research will be presented and the key features of the participatory research process explained. Drawing upon two recent examples of participatory research in palliative care from Austria and the UK, the current challenges of undertaking action research in palliative care will be considered.

Gender Issues in Palliative Care

Abstract number: ME 14.1
Abstract type: Meet the Expert

Gender Issues in Palliative Care: Tischelman and Twigg
Twigg J.1, Tischelman C.2
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2Karolinska Institute, Stockholm, Sweden
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Carol Tischelman is Professor of Nursing at Karolinska Institute, Department of Learning, Informatics, Management and Ethics/Medical Management Center. She is also affiliated with the Research and Development Unit at Stockholm's Sjukhem Foundation—one of Sweden's major palliative care facilities, and both LaTrobe University and University of Manchester. After initial studies in Women's Health and a later BSN in Nursing from the US, Carol received a PhD from Karolinska Institute and has conducted research in cancer and palliative care for over 20 years in Sweden.

Julia Twigg is Professor of Social Policy and Sociology at the University of Kent, UK. She has written widely on the support of older people, focussing on the front line of care and significance of embodiment for this. In particular she has explored how care work needs to be understood as a species of bodywork. The provision of care, whether by family or workers, is shaped by gendered expectations, both with regard to who does this work and for whom, and how it is understood and valued. In 2012 she was co-editor of Bodywork in Health and Social Care: Critical Themes, New Agendas, Oxford: Wiley-Blackwell.

In this session, Julia and Carol will briefly present their perspectives on gender issues in palliative care, ranging from implications for patients and families, to staff and researchers, before chairing an open discussion.

Physiotherapy and Palliative Care

Abstract number: ME 15.1
Abstract type: Meet the Expert

When to Involve Physiotherapy in Palliative Care?
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1King's College London, Cicely Saunders Institute, London, United Kingdom, 2FH Hetzing, Pneumologische Rehabilitation, Wien, Austria

An increasing emphasis is placed on proactive intervention to reduce or delay the effects of disease and its treatment on physical function, independence and quality of life. In this session we wish to consider the most appropriate starting point for physiotherapy intervention in patients receiving palliative care using examples from thoracic cancer and chronic respiratory disease. Attendees will be asked to discuss the role of physiotherapy at the point of diagnosis, around medical treatments and as physical dependence increases with progressive disease.
Free communication sessions

- Organisation of Services
- End of Life
- Psychology and Communication
- Policy
- Family and Care Givers
- Non-Cancer
- Education
- Ethics
- Palliative Care in the Elderly
- Assessment
- Place of Death
- Children and Young People/ Spirituality
- Pain and other Symptoms
Organisation of Services

Abstract number: FC 1.1
Abstract type: Oral

Research into Practice within Resources: Developing a community based Palliative Care Service for People with Chronic Obstructive Pulmonary Disease

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Background: Chronic obstructive pulmonary disease (COPD) is a common life-limiting illness that can result in significant burden for patient and care. Despite this, access to specialist palliative care is inconsistent, resulting in unmet needs.

Aims: To develop a interdisciplinary team (MDT) meeting for patients with very severe COPD, improve patient identification and symptom management; increase advance care planning; and the numbers of patients dying in their preferred place, increase patient and carer support and satisfaction.

Methods: A four step approach of plan, act, observe and reflect was used. A working group was formed and baseline data collected to identify the needs of people with very severe COPD, the meeting was piloted and evaluated by community matron feedback, patient case studies and an after death analysis (ADA). This service development pilot was conducted over a 12 month period.

Community matrons acted as the key worker as regard to identification of people with severe COPD and complex needs, to support MDT participation.

Results: The community matron feedback, ADA and patient case studies indicated a high level of satisfaction, with improvement in advance care planning, co-ordination of management and support for patients’ preferred place of care at the end of life.

Conclusions: This is the first reported very severe COPD service development established in this way and within current and future resource; preliminary data indicates the development of the MDT model has been positive, with regard to community matron feedback, ADA and patient case studies. The appointment of a co-ordinator will aid this development. Further evaluations particularly seeking patient views and estimations of cost savings will be performed. This service model could readily be implemented into other clinical services wanting to expand into COPD, without the need for extra resources.

Abstract number: FC 1.2
Abstract type: Oral

Reducing Hospital Resource Utilisation in Palliative Care: a Limiting Factor when Working with Community-based Case Conferencing

McCauffey N.1, Cumow D.1, Abembey A.P.1,2
1 Flinders University, Discipline of Palliative & Supportive Services, Adelaide, Australia, 2 Flinders University, Flinders Health Economics Group, Flinders Clinical Effectiveness, Adelaide, Australia

Aims: To describe differences and similarities between social work and spiritual care when working with community-based case conferencing (CMC) - An Electronic Palliative Care Coordination Service for London

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Background: CMC is a clinical service underpinned by an electronic solution. Clinicians are trained in identifying patient in the last 12-24 months of life, suffering from and having difficult conversations. It encourages a change in practice to facilitate coordination of care across multiple healthcare settings. The web-based solution can be accessed by legitimate care provider such as London Ambulance Service, 111 unscheduled telephone service, GP, community nurses, hospital staff and secondary care. All patients prospectively consent to having a CMC record, this can be created in best interest where patients lack capacity. Following a pilot study, we hypothesised that CMC results in fewer hospital deaths and more patients dying in their preferred place (PFD). Pan-London roll out (7.7 million population) will be complete by April 2013 with evaluation the outcomes.

Design and methods:• Stakeholder engagement, agreement of template
• Design of web based, secure, encrypted, scalable electronic solution
• Development of training module including how to: identify & consent patients, have sensitive conversations, create plan care, DNR and use of IT software
• Liasie and contract to become interoperable with other services: 111, London Ambulance service, GP, out of hours GPs, hospices and hospitals
• CMC rolled out Pan-London (population 7.7 million)

Results: Data censored on 24.10.2012. 2,827 CMC records created

Diagnosis: Cancer 45%, non-cancer 55% (15% Dementia).
Deaths: 673 (82% in PPD). Recorded PPD: home 29%, care outside hospital 71%

Conclusions: The Development and Evaluation of an Inpatient Palliative Care Admission Triage Tool

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Abstract number: FC 1.4
Abstract type: Oral

The aim of this study was to evaluate the incremental resource use, cost and consequences of adding case conferences to specialist, community-based palliative care improving the performance status of patients with a life-limiting illness.

Methods: A checklist consisting of 22 items was used from the published cluster-randomised Palliative Care Trial, including: survival time; performance status; quality of life; specialist palliative care service utilisation; acute hospital and palliative care unit stays; outpatient visits; medication usage; general practice visits and other non-hospital services. Participants were adults newly referred to a regional community-based palliative care program, experiencing pain, and expected to live ≤ 6 months.

There was a significant reduction in the number of hospitalisations in participants who had a case conference versus those who did not. The median (interquartile range) of the total case conference length square means, 1.26 hospitalisations per patient (standard error (SE) 0.10) vs usual care 1.70 (SE 0.13; p=0.0006). Further analysis of outpatient services, medication usage and out of hospital resource utilisation will be conducted to evaluate whether reduced hospitalisations offset other cost consequences of case conferences. Participants who had a case conference had maintained performance status longer (GIS: 33%, 95% CI estimated using bootstrap analysis to evaluate the cost effectiveness of potential differences in this context.

The findings suggest case conferences reduce hospital resource utilisation, whilst best maintaining performance status. Further incremental analysis will be presented, defining the net benefit of case conferences from a health system perspective.

Funding: Australian Government, Ian Potter Foundation, Cancer Council Victoria, MEHAC Foundation, RGH, ACH Group Inc & Southern Division of General Practice.

Abstract number: FC 1.3
Abstract type: Oral

Co-ordinate My Care (CMC) - An Electronic Palliative Care Coordination Service for London

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Background: Chronic obstructive pulmonary disease (COPD) is a common life-limiting illness that can result in significant burden for patient and care. Despite this, access to specialist palliative care is inconsistent, resulting in unmet needs.

Aims: To describe differences and similarities between community-based case conferencing (CMC) - An Electronic Palliative Care Coordination Service for London

van Nus-Stad J.1,2, Peet-Vreman A.1,3, Goorjes J.G.K.1, Zuurmond W.G.M.1,4,5,6,7,8
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Purpose of the research: To describe differences and similarities between social work and spiritual care when working with community-based case conferencing.

Method: A checklist consisting of 22 items was used extracted from the "Distress Thermometer" (1), recommended in the practice guidelines for palliative care "Psychosocial Care" as measurement instrument to signal distress in oncological patients. With this checklist, possible conversation topics were registered and categorized into four categories: practical issues, social, factor, mental

Abstract number: FC 1.6
Abstract type: Oral

Palliative Care Models for Mental Illness - A Challenge

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Aims: Mental illnesses remain a huge burden in many parts of the world and services to support those with chronic illmesses living in the community are scarce in many low and middle income countries. MEHAC Foundation has adapted the principles of palliative care specific to mental health care with the community participation.

Design: Models of service delivery were developed in districts in Kerala according to the local needs and in close collaboration with government and other partners. These incorporated outpatients, short admissions and most specifically home care. Holistic care included rehabilitation. Results: 3 distinct models of collaboration across 12 services have emerged involving local governing bodies, non-governmental bodies, institutional/nursing homes. Key outcomes, establishing and sustaining partnerships, organisations, directly offered supervised care in addition to training, and advisory roles; modeling high quality service including rehabilitation and follow up; developing local ownership and empowerment with communities taking direct responsibility for the long term support; integration in service delivery and training, changes in policy for community mental health provision.

Conclusion: Community based services are essential in the long term care of chronic mental illness. In many low and middle income countries models of integrated care are still to develop. Building on communities that are institutional based and do not empower whole communities in the holistic approach to chronic mental illness. Kerala chronic mental health has been seen as part of the palliative care disease spectrum. This approach can be used to develop specific services for those living with mental illness which has resonance for wider settings. The WHO in 2012 announced that mental disorders is included among the non communicable diseases which is a significant step in terms of policy and implementation.
condition and spiritual matters. The number of conversations and the subjects were registered for each patient and their loved ones each week for the duration of 24 months.

Results: 158 conversations with patients and their loved ones were registered. The SW had 91 conversations with 28 patients and 127 with 61 loved ones. The SC had 253 conversations with 75 patients and 16 with 13 loved ones. The SW and SC conversations to indicate most overlap, for talk related to social factors (64%), mental condition (46%) and spiritual matters (33%) but not based on a small sample. Practical issues were more often discussed with the loved ones by the SW (20%) vs. 8%). Concerns for the future were more towards practical issues, whereas spiritual matters tended to be predominately the domain of the SC. These results indicate a degree of complementarity and added value of both disciplines in the palliative care of terminally ill patients.

Discussion:

End of Life

Abstract number: FC 2.1
Abstract type: Oral

Dying with Dementia: Symptoms, Treatment and Quality of Life in the Last Week of Life

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Aims: Burdensome symptoms are frequently present in patients with dementia at the end of life, but little is known about symptom control, such as type and dosages of medication. The aim of this study was to investigate the prevalence of symptoms, prescribed treatment, and explored associations of symptom quality of life in the last week of life and symptom prevalence with causes of death of nursing home residents with dementia.

Methods: Within two weeks after death, physicians completed questionnaires about symptoms and their treatment in the last week of life of 330 nursing home residents with dementia in the Netherlands between 2007 and 2010. Quality of life was assessed with the Quality of Life in Late-Stage Dementia scale and the physicians (direct) cause of death from the death certificate. We used independent t-tests and chi-square tests to compare subgroups, and linear regression to assess associations with quality of life.

Results: Pain was the most common symptom (52%), followed by agitation (34%), and shortness of breath (34%). Opioid analgesics were the most prescribed treatment for residents in pain (75%) and residents with shortness of breath (69%). Agitation was mainly treated with antipsychotics (51%). At the end of life, 10% of all residents received opioids with a median of 90 oral morphine equivalents and 20% received palliative sedation. Pain and agitation were associated with a diminished quality of life. Death from respiratory infection was associated with the largest symptom burden.

Conclusion: Burdensome symptoms are common and some are associated with a diminished quality of life at the end of life, despite the large majority of residents receiving opioids. Decision may be suboptimal with regard to weighing of effects and side effects. Future observational research which employs observation on a day-to-day basis is indicated and may lead to better effectiveness of symptom control and possible side effects.

Abstract number: FC 2.2
Abstract type: Oral

A Qualitative Study of Health Professionals’ Views of Scope and Feasibility of Transferring Patients from Critical Care to Die at Home in the UK

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Background: Increased choice and the concept of preferred place of care is key in current UK Health policy. Research undertaken indicates that the majority of people express a preference to die at home. Whilst progress has been made toward this policy imperative there is limited evidence how long they are able to remain at home during their dying in critical care. The aim of this qualitative study was to determine the scope, experience and feasibility of transferring critical care patients home for their last 6 weeks from UK critical care units.

Methods: Data collection involved six focus groups (FGs), 60 telephone interviews (TIs) and 177 home visits. (HCVs) from critical care units (n=4), primary care (n=1) and patient representatives (n=1) Focus group questions were informed by the results of a scoping review and clinical experience. Questions guided the participants’ views toward TCCPHD, factors that would influence decision making regarding this initiative, and factors needed to facilitate this initiative.

Results: Data analysis generated five overarching themes: views, barriers, facilitators, patient characteristics and guidelines, providing insight into the decision-making and action-oriented processes that inform practice regarding TCCPHD. While transfer home from critical care was positively regarded, identified barriers included: community care, home environment, time and logistics. In addition, concerns (under theme ‘views’) included: relatives’ ability to care for the patient at home, the ethics of prolonging life to facilitate the transfer and the complexities of the decision-making process. Developing the process of transferring patients home to die from critical care in identifying barriers to transfer and HCVs concern for stress on relatives when caring for a patient with dementia at home. The decision-making process is dependent on a multitude of factors and timing making this negotiated process a complex one.

Discussion:

Abstract number: FC 2.3
Abstract type: Oral

Emergency Readmission Rates in Patients Whose Recovery is Uncertain: The Impact of the AMBER Care Bundle

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Aim: To evaluate the impact on 30 day emergency readmission rate of a novel care bundle. The bundle is aimed at acute ill hospital patients with limited clinical reversibility judged to be at risk of dying in the next 1-2 months (uncertain recovery). Around 58% of deaths in England occur in hospital, contrary to surveyed preferences. The National End of Life Care Intelligence Network states that 89% of those who die in hospital do so following an emergency admission. In people in the last year of life with conditions with potential palliative care need, analysis shows that 32.6% of hospital admissions occur in the 30 days before death. There is evidence of delayed recognition of patients who, despite ongoing active medical care, are at risk of dying from their underlying illness.

Methods: The AMBER care bundle was developed to improve treatment planning, escalation decision and communication with patients, carers and the team, prioritising end of life care at each step. In our acute care hospital where the bundle is used on seventeen wards, 55% of patients supported with the AMBER care bundle are discharged with an individualised package of care. Patients discharged from 01/10/10 to 30/09/11, who died within 100 days of discharge, were followed up to identify any emergency readmissions. We compared this group of patients with discharged from the same wards and who also went on to die within 100 days but who had not been supported by the care bundle.

Results: Patients receiving standard care were three times more likely to have an emergency readmission (36%) than those receiving AMBER support (12%) - a difference of 24% (95% CI 18%-29%).

Conclusions: Early findings demonstrate a significant difference in 30-day emergency readmission rate for this vulnerable group of patients. It is possible to implement a care bundle in this complex clinical area which supports discussion of patient preferences, more robust discharge arrangements and contingency planning.

Abstract number: FC 2.4
Abstract type: Oral

Are Relatives’ Preferences Aligned with the Patients’ and Do They Change Their Minds?

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Aim: To determine the congruence between patients and relatives’ preferences for place of death and the percentage of agreement. We use kappa statistics to assess congruence between their preferences, and the McNemar test to compare preferences for home death from patients and relatives. We report the proportion of relatives who changed their preferences and their reasons for changing. We compared our results with two researchers with disagreements resolved by consensus.

Results: As reported by relatives, patients most often chose home (69%) as the place to die (71% hospice, 5% hospital, 2% care home, 2% -1 setting and 5% had no preference). About half (48%) of relatives chose home, 24% hospice, 9% hospital, 4% care home, 2% -1 setting, 1% elsewhere and 13% had no preference. A preference for home death (vs. others) was less common amongst relatives than amongst patients in this study. Further integrating the palliative care approach with relatives may improve agreement.

Discussion:

Elderly Patients with Advanced Frailty in the Community: A Qualitative Study on their Needs and Experiences

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Aim: Frail elderly patients are a major target group in general practice but little is known about the needs of these patients towards the end of life. This study aims to explore the needs and experiences of patients with advanced frailty in the community.

Methods: Qualitative study with patients interviews at home. Participants were purposively recruited to ensure their practices to reflect a range of sex, social background and presence of an informal carer. Main inclusion criteria were moderate/severe frailty, age >70 years, the ability to give informed consent. Interviews took place in the patients’ homes addressing their experiences of being frail, support, concerns and expectations. Interviews were tape-recorded and transcribed verbatim. Narrative and thematic analysis was conducted within and across cases. To identify codes and develop (sub)categories constant comparative analysis was used.

Results: The sample consists of 26 patients (15 female, 11 male, mean age 83 years, range 71-95 years). The patients’ view of ‘being frail’ affects almost all aspects of life: The exhaustion of capabilities due to the loss of physical and cognitive strength, increased vulnerable health and symptom burden, and social losses often interfere with the ‘knowing’ and ‘caring’ family doctor was stressed. Conclusion: Further integration of palliative approach into general practice seems necessary to meet the needs of frail elderly patients in the community. The study will be continued with three follow-up interviews to generat hoped to gain a deeper understanding of the dynamic experience of patients with advanced frailty, and how patients needs vary over time if frailty progresses.*

* The study is funded by the German Federal Ministry of Education and Research (01GI1128), study duration: 02/2012-01/2017.
Maximizing Corporate Support: Useful Strategies to Develop Effective Partnerships

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In an era when many palliative care organizations are facing financial constraints and with the limited number of palliative care funders in existence, it is important for organizations to review their own financial models and aim to diversify resources. Philanthropy or corporate social responsibility is funding stream that can bring new dollars to the palliative care sector and help to keep patients at home longer. Understanding the basic key steps in developing relationships with corporations is vital. The bottom line is that most, if not all palliative care organizations are doing spectacular work and changes the lives of many vulnerable people with great success. Unfortunately, there are many other spectacular organizations globally doing similar work with the same if not more level of success. They too are also looking for potential partners. In view of this, to access corporate partners, it is critical that we have done our homework and we can prove to a prospective corporate partner that we are the best non-profit partner for their support. Standing out from the crowd of qualified organizations in order to attract corporate funders is a task that most nonprofits face time and time again. The presentation will offer useful insights on how to help organizations gain a better understanding of what they should do, and look for, when preparing to engage in a successful philanthropic partnership. Many key steps on how to make your case; by looking at; doing the research; developing relationships and ownership; being responsive and communicating effectively are the measures that one can offer and final, making tangible results that support your organization. In addition to the information above, useful contact details of individual contact persons will be shared with participants giving them an opportunity to explore the contacts in order to develop their own organizational partnerships and funding.

Aims: This study was the first to aim to examine the presence of ACP in the provision of psychosocial support. It reports hospice nurses’ responses to patients’ psychosocial needs. The paper explores the realities of psychosocial support from the perspective of one psychosocial need patients’ rights to make choices.

Methods: In a mixed methods study, participant observation of nurse-patient interactions was supported by data from interviews, nursing documentation, clinical meetings, workload distribution and participant demographics. A maximum variation sampling strategy was used; ensuring observations occurred at different times of the day, involving nurses with different roles and patients with different diagnoses. The aim was to develop an observational instrument to measure nurse-FP relative about the existence and content of ACP.

Results: We identified 205 deceased residents with dementia in 69 nursing homes. Residents expressed their wishes regarding care in the last phase of life in 11.8% according to the FP and 7.0% according to the nurse. The FP and nurse spoke with the resident in 22.0% and 9.7% respectively and with the relative in 70.6% and 59.3%. An AD was present in 10.8% according to the FP and 11.8% to the nurse. A maximum variation sampling strategy was used, ensuring observations occurred at different times of the day, involving nurses with different roles and patients with different diagnoses.

Conclusion: Communication regarding care is rarely patient-driven and more often the extent of professional caregiver- or family-driven. The level of congruence found between professional caregivers and relatives is low. The study was supported by a major grant from Vrije Universiteit Brussel (GOA HVW, YUB) and part of the “Dying Well with Dementia” study.

Development of an Intervention to Improve Physician-patient Communication in Patients with Advanced Cancer. A Focus Group Study

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Research aims: Many patients with recently diagnosed advanced lung cancer who wanted to be informed about prognosis, palliative care and end of life decisions (EoL) did not need. Patients who wanted to share medical decisions with their physician often did not achieve this involvement.

The aim was to:
1) discuss these problems with oncologists/pulmonologists and list their suggestions for improvement;
2) to develop recommendations and a model of intervention to improve communication, and present these to oncologists/pulmonologists for evaluation.

Study design and methods: Focus group sessions were transcribed and analysed through systematic coding and comparing the data. The following research questions served as a guide to developing recommendations and intervention, a questionnaire was developed.

Results: Three focus group discussions with 8 oncologists and 5 pulmonologists took place. Identified barriers to the provision of information about prognosis, palliative care and EoLs were fear of destroying hope in the patient, uncertainty about the disease trajectory and propensity of physicians to care rather than to offer palliative care options. Barriers for shared decision-making were the physician’s belief that shared decision making is not possible, and the perceived inability of the patient to have contributions options. On the basis of the received suggestions for improvement, we proposed:
1) an upfront noble offer of information and deliberation by the physician and
2) recommendations and an intervention to promote patient physician communication.

The proposed intervention consists of a communication skills training program with role play for physicians and a questionnaire list for patients. Recommendations and intervention were evaluated as useful and feasible. Conclusion: In future research, recommendations and intervention have to be adapted to the patient’s perception, confronted with patient’s view, and tested with regard to effect on patient outcomes.

A Literature Review of Patient Recorded Outcome Measures (PROMs) Used for a Trial Evaluating the Effect of Quality-of-life Patient Communication in Randomised Control Trials (RCTs)

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Background: Patients priorise good communication skills in Doctors. Evidence that Communication Skills Training (CST) for Doctors can enhance patient-doctor communication. Patients who are more patient concerned are elicted, is mostly through expert behavioral analysis rather than patients’ perception of the communication. A recent meta-analysis of research relating to CST with cancer patients was restricted because every study used different PROMs.

Aim and methods: The aim of this literature review was to identify what PROMs had been used to measure the quality of doctor patient communication in RCTs. Each were then assessed for their applicability to the specific research question and potential for a trial evaluating the effect of CST in hospital outpatient clinics.

Results: Fourteen PROMs which assessed doctors communication within which the PROMs had been evaluated, were found not applicable for a study regarding the effect of CST for Doctors in a hospital outpatient clinic. Mainly these tools were too specific; the focus being on one aspect of communication (risk or shared decision making) or consultation outcome (treatment decision). The seven remaining PROMs which have previously been used in a RCT to assess doctor patient communication and appeared applicable to a study in hospital outpatient clinics were assessed using seven criteria that investigators should consider when choosing a PROM, appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility.

Conclusions: Few identified PROMs were developed beyond the phalage phase or had extensive psychometric information. Consultation And Relational empathy measure (CARE and PATIENT ENABLE) were judged the most applicable PROMs against the seven criteria. CARE measure assesses the doctor’s communication and empathy with the consultation and PSI gauges how enabled the patient is.

When Your Patient Friends on You Facebook: Social Media’s Growing Promote and Pitfalls for the Palliative Care Practitioners

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Increasing utilization of social media sites such as Facebook and Twitter as well as the ability to interconnect a variety of personal blogs, photographs and “favorites” websites, raise interesting questions for palliative care practitioners. For some, social media sites offer a way to mobilize support for associated professional organizations; the authors recently “re-launched the European Association of Palliative Care Facebook page, joining 456 others in doing so. Twitter has become a way for palliative care practitioners to post recent scientific articles, reports in the lay press pertaining to palliative care and engaging in conversations in real-time at professional conferences.
Lessons Learned for Developing a Supportive Environment for Sharing Bad News: What Is the Role of Family/Friends Present at Bad News Consultations to Support Patients with Lung Cancer? A Mixed Methods Study in the United Kingdom

Abstract number: FC.3.6
Abstract type: Oral

What Is the Role of Family/Friends Present at Bad News Consultations to Support Patients with Lung Cancer? A Mixed Methods Study in the United Kingdom

Abstract number: FC.3.6
Abstract type: Oral

Background: Developing for specialist palliative care influence provision and service development. As palliative care services integrate into mainstream health care provision, opportunities to develop funding mechanisms arise. We compare different funding models and draw critical lessons from international experiences.

Aim: To assess model and methods for funding and commissioning palliative care services.

Methods: Initial literature scoping yielded limited evidence on the subject as international policy documents are difficult to identify, access, and interpret. We therefore undertook country expert consultations within our research network, to identify and appraise international models of palliative care financing. The countries included - Australia, Austria, England, Germany, Hungary, Ireland, Republic of Ireland, New Zealand, Netherlands, Norway, Poland, Spain, Sweden, Switzerland, USA and Wales - represent different levels of service development and a variety of funding mechanisms.

Results: Funding mechanisms for specialist palliative care in different countries vary as much as provision of palliative care itself. We develop a typology for funding models based on the variety of funding flows. Using examples from specific countries, our recommendations are based on these observations:

Provider payment is rarely linked to population need, and mostly based on historic resource allocations.

Although the absolute amount of funding at the provider level in most countries, provider payment is rarely linked to the quality of services.

Conclusion: Funding mechanisms hold the potential to provide powerful policy levers that reward excellence. They need to be used with care to ensure best practice and minimize preventable suffering. Palliative care community needs to be involved in the opportunities to reshape funding and reimbursement mechanisms, to improve patient care access and ensure equity.

Funding: Palliative Care Funding Review, Department of Health

Policy

Abstract number: FC.4.1
Abstract type: Oral

Barriers to Palliative Care Information in Central and Eastern Europe and the Commonwealth of Independent States

Abstract number: FC.4.4
Abstract type: Oral

Policy

Abstract number: FC.4.1
Abstract type: Oral

What Factors Are Associated with National Health Service Spend on Specialist Palliative Care in England? A Nationwide Ecological Study

Abstract number: FC.4.2
Abstract type: Oral

What Factors Are Associated with National Health Service Spend on Specialist Palliative Care in England? A Nationwide Ecological Study

Abstract number: FC.4.2
Abstract type: Oral

Policy

Abstract number: FC.4.1
Abstract type: Oral

Access to Palliative Care Information in Central and Eastern Europe and the Commonwealth of Independent States

Policy

Abstract number: FC.4.1
Abstract type: Oral

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is needed, preferably in the participants’ own language. The availability of one comprehensive source informing about pc would be desirable for health care professionals to keep themselves informed with a reasonable time investment.

Abstract number: FC 4.5
Abstract type: Oral

Exploring Public Awareness of Palliative Care

McInnes S.1, Hasoon F.1, Northern Ireland Palliative Care Research Fund Committee

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Background: International research suggests that the general public are not well informed about what palliative care is and who provides it (Hirai et al. 2011; McCarthy et al. 2011). Evidence suggests that this can lead to negative impressions and consequences for the quality of care provided to the dying and bereaved (Seymour et al. 2010). Given the aging population and the increasing number of patients requiring palliative care it is vital to explore the public’s perception of such services.

Objective: To explore public’s perceptions of palliative care.

Methods: A sequential exploratory mixed methods research design was used. Phase 1 involved a descriptive, self-report survey. The sample for the study included members of the Public Awareness of Palliative Care Survey of 2010). A survey was distributed electronically, on line and post. Data was analysed using SPSS and descriptive and inferential statistics were used to examine the data. Phase 2 comprised semi-structured telephone interviews with those respondents who indicated a willingness to participate from stage 1 (N=68). The interviews were taped recorded, supplemented by field notes and content analysis.

Results: Key themes emerged from the telephone interviews focusing on an overall perception of palliative care and the importance of developing targeted strategies for educating the public. Inadequate palliative care and over optimism were acknowledged. There were significant differences on variables such as age and gender

Conclusions: The general public have differing perceptions and views on palliative care and the findings can inform policy makers on strategies to raise awareness of palliative care.

Abstract number: FC 4.6
Abstract type: Oral

Assessment of Noninvasive Opioids Availability in Russia

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Approximately 300 thousand cancer and HIV/AIDS patients die in Russia every year. According to research from the Global Access to Pain Relief Initiative, Pain and Policy Studies Group, and Human Rights Watch, in 2009 in Russia, only 18.7% of patients who died from cancer and HIV/AIDS received opioid analgesics. As a result, 183,134 patients died with untreated moderate to severe pain. Only injectable morphine, sustained release morphine tablets, and fentanyl patches were available for pain management.

Aim: To assess the availability of noninvasive opioids in adequate doses for cancer patients in Moscow and in the other 82 regions of Russia.

Method: This study was based upon expert opinion (K. Foley et al. 2006), which indicates the average oral morphine consumption for 180 days of terminal care is 15,019 mg in Moscow and 5,365 mg in the other 82 regions of the Russian Federation. Fentanyl consumption was 289.12 morphine-mg equivalent doses in Moscow and 24.94 morphine-mg equivalent doses in the other regions. 2,431 patients received MST-continus and 4,681 patients received fentanyl patches in recommended doses. However, only 868 patients received MST-continus and 4,040 patients received fentanyl patches in recommended doses in the other regions. MST-continus is a noninvasive opioids in Moscow and only 1.9% of patients received noninvasive opioids in the other regions. Therefore, only 12,000 cancer patients (4.2%) in Russia were treated with noninvasive opioids in recommended doses.

Results: In 2008, 286,628 cancer patients died in Russia. Among them, 23,362 cancer patients died in Moscow. MST-continus consumption was 15,019 mg in Moscow and 5,365 mg in the other 82 regions of the Russian Federation. Fentanyl consumption was 289.12 morphine-mg equivalent doses in Moscow and 24.94 morphine-mg equivalent doses in the other regions. 2,431 patients received MST-continus and 4,681 patients received fentanyl patches in recommended doses. However, only 868 patients received MST-continus and 4,040 patients received fentanyl patches in recommended doses in the other regions. MST-continus is a noninvasive opioids in Moscow and only 1.9% of patients received noninvasive opioids in the other regions. Therefore, only 12,000 cancer patients (4.2%) in Russia were treated with noninvasive opioids in recommended doses.

Conclusions: The vast majority of cancer patients did not have access to noninvasive opioids. Sustained release morphine tablets and oral formulations of fast-acting morphine in adequate doses for cancer patients were available for pain management. There is an urgent need for improvement in pain policy in Russia.

Family and Care Givers

Abstract number: FC 5.1
Abstract type: Oral

Psychological Distress in Family Caregivers of Terminally Ill Patients: Do High Caregiver Burden and Lack of Communication in the Family Increase Distress?

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Aims: Family caregivers of terminally ill patients are in a vulnerable position. Previous studies show that they are at an increased risk of psychological distress e.g. depression and anxiety. Caregiver burden and lack of communication between the patient and the caregiver about the illness and the impending death seem to influence psychological distress in the family caregiver. The aim of this study was to perform a nation-wide study investigating the association of both perceived caregiver burden and lack of communication with psychological distress in caregivers of terminal patients.

Methods: During 2010-2011, we interviewed 8,085 patients in Denmark having been granted drug reimbursement in connection with terminal illness was obtained on a weekly basis from The Danish Health and Medicines Authority. All newly registered patients were mailed a letter requesting them to pass on the enclosed questionnaire to their closest relative. The analysis of the questionnaire is ongoing but is exploring influencing factors and significant differences on variables such as age and gender

Conclusions: The general public have differing perceptions and views on palliative care and the findings can inform policy makers on strategies to raise awareness of palliative care.

Abstract number: FC 5.2
Abstract type: Oral

Relationships between Lack of Support during End of Life Care and Carers’ Bereavement Outcomes

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Background: Studies suggest that insufficient support for carers during and following the end of life care has a significant impact on outcomes in bereavement. The Care Support Needs Assessment Tool (CSNAT) has been developed to measure ‘care’s’ support needs during the final 6 months.

Aim: To investigate how perceived lack of support measured through CSNAT related to carers’ outcomes in bereavement.

Sample: Main part of a study of care of six hospice home care services across the UK. 182 carers took part (22% response rate).

Methods: Post bereavement, palliative care, bereavement, qualitative, semistructured interviews were undertaken. Interviews were transcribed verbatim and were fully transcribed and supplemented by field notes and content analysis.

Results: In total, 1,781 carers had been contacted and 2,581 carers had answered the questionnaire (response rate 39.1 %). Results from the total inclusion period, i.e. the year 2012, will be presented describing the scales of depression, anxiety, caregiver burden and communication. Furthermore, the association of caregiver burden and communication with psychological distress will be analyzed using regression models.

Conclusions: This study will provide valuable information on the association of caregiver burden and communication with psychological distress. The perspective is to optimize the intervention for family caregivers in an attempt to prevent depression and anxiety as a reaction to the high caregiver burden or lack of communication encountered.

Abstract number: FC 5.3
Abstract type: Oral

Self-reported Quality of Life and Psychological Well-being in Patients with Primary Brain Tumours and their Caregivers

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Patients with primary brain tumours (PBT) encounter challenging symptoms many of which are unique to malignant brain tumours. Over time, these symptoms also place significant burdens on the patient and their caregivers. The purpose of this study was to determine the unique challenges faced by these patients and a subset of their caregivers.

Objectives:

1. To describe symptom burden and to measure the severity of symptoms among patients with primary brain tumours and their caregivers.

2. To measure these parameters within caregivers and their effects on the relationship with the patient.

3. To screen for anxiety and depression within this caregiver group.

Methods: This is a cross-sectional quantitative survey. All adult patients who have a radiological or histological diagnosis of a PBT, are recruited. The patients will also be sampled from the regional palliative care service over a six month period. Consenting patients complete a validated questionnaire, the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30).
Burden on Family Carers and Difficulty in Covering Costs of Care at the End of Life: A Cross-national Retrospective Study via Representative Networks of General Practitioners


1, 2, 3, 4, 8, 10 University of the Witwatersrand, The Centre for Rehabilitation, London, United Kingdom, 2, 3, 7 Duke University, Community, Valencia, Spain, 8 VU University Medical Center, Community of Castile and Leon, Public Health Directorate, Spain, 2, 5, 6 University of the Witwatersrand, The Centre for Rehabilitation, London, United Kingdom, 30 May – 2 June 2013.

Abstract number: FC 5.5
Abstract type: Oral

Background: Given a growing number of people with long disease trajectories and a preference for home death, need for family care is expected to increase. However, population-based data on the prevalence of burden in family carers of patients at the end of life and of caregivers are scarce.

Objectives: To describe and compare, with respect to participants, the end of life in Belgium, the Netherlands, Italy and Spain, the number and associated factors of family carers feeling overburdened and of families with difficulty in covering costs of care.

Design and methods: Cross-national retrospective study. In 2009 and 2010, representative GP networks weekly registered every non-sudden death among their patients (≥18 years) using a standardised form surveying the patients’ last illness, including care burden. Analysis involved descriptive statistics, x² tests and multiple logistic regression analyses.

Results: Their median life expectancy was 72.7 (IQR: 58-85) years. 28% (Belgium), 30% (Netherlands), 35% (Spain) and 71% (Italy) GPs judged that carers felt overburdened (p<001). For 8% (Spain), 14% (Belgium), 23% (Netherlands) and 43% (Italy) they judged difficulty for families in covering the costs of care (p<001). Carers’ burden and difficulty in covering costs were more likely for younger patients (Belgium, Italy). Cancer (versus non-cancer) death was associated with lower difficulty in covering costs (Italy, Spain). Residing in a nursing home, as opposed to home, predicted lower carers’ burden in all countries except the Netherlands.

Conclusions: In all countries studied, and particularly in Italy, GPs observe overburdened family carers and difficulties in covering end-of-life care. Carers of patients at home and carers of younger patients may be at particular risk of burden. This requires future research, particularly when advocating a shift in end-of-life care from institutions to home.

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The Challenging Landscape of End Stage Kidney Disease - What Palliative Care Is Needed?

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Introduction: The incidence of amyotrophic lateral sclerosis (ALS) is about 3-4/100.000. Most patients experience progressive paralysis, dysphagia, and severe dyspnoea due to the course of the disease. Death occurs after 3-4 years - usually due to respiratory insufficiency. It is difficult for patients as well as for their caregivers to cope with the relentless progression of the disease. The study was aimed to systematically assess psychosocial burdens of ALS patients and their family. Furthermore, a possible need for the involvement of palliative care services was highlighted.

Methods: We conducted detailed interviews with seven ALS-patients and their care-givers. The interview protocols were aimed to systematically assess psychosocial burdens of ALS patients and their family. Furthermore, a possible need for the involvement of palliative care services was highlighted.

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Palliative Medicine and Stroke - When Should We Be Involved?

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Background: Stroke is the third leading cause of death in Ireland and the single largest cause of adult disability. 20% of patients die in the first month and 35% are significantly disabled following a stroke. Outcomes are best within dedicated stroke units. Challenges to provision of palliative care in this subgroup include the unclear illness trajectory impeding an early identification and potential for deterioration in symptoms.

Aims: To identify the experiences of people with ESRD regarding starting dialysis, its impact on quality of life, and their preferences for future and end of life care.

Methods: Semi-structured qualitative interview study of people with ESRD. Participants reflected on starting dialysis, its impact on quality of life, and what their future preferences were. Interviews were transcribed, verbatim and analysed using thematic analysis in the framework approach. Recruitment ceased once data saturation had been achieved.

Results: Themes emerged around the trauma of starting dialysis, denial, fear, grief at losing their health, and the life changing impact of dialysis for patients and families. Experiences at the dialysis unit varied. Challenges included getting used to the environment with staff, and the long conveyor belt dialysis units. Positive included the kindness of some staff, and the equipment quality. Participants also reported a desire to have more information about their disease and treatment.

Discussion: Many patients were at risk of dying in the next 12 months, particularly in non-cancer dying trajectories. This study identified complex challenges limiting access to palliative care for people with advanced organ failure.

Family Carer Perspectives on Palliative Care

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Aims: The palliative care approach involves care of patients with advanced conditions but family doctors and hospital clinicians often report difficulties in recognising when a patient is at risk of dying in the next 12 months, particularly in unpredictable, non-cancer dying trajectories. This study identified complex challenges limiting access to palliative care for people with advanced organ failure.

Methods and design: Ward staff in four units of a large Scottish teaching hospital attended a teaching session which included 'schooling' and discussion. Following the session, staff were asked to complete the SPICT™ (the Supportive and Palliative Care Indicators Tool) which identifies patients likely to benefit from supportive and palliative care. We reviewed the admission and care planning processes of SPICT™ positive patients using a mixed methods approach in line with the initial development phases of MRC Framework for complex interventions.

Results: The SPICT™ identified 130 patients with clinical indicators of advanced conditions. Many had multiple significant co-morbidities, a deteriorating performance status and increased care needs.

Discussion: wards staff in four units of a large Scottish teaching hospital attended a teaching session which included 'schooling' and discussion. Following the session, staff were asked to complete the SPICT™ (the Supportive and Palliative Care Indicators Tool) which identifies patients likely to benefit from supportive and palliative care. We reviewed the admission and care planning processes of SPICT™ positive patients using a mixed methods approach in line with the initial development phases of MRC Framework for complex interventions.

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Background: Managing complex pain is core business for specialist palliative care services and nurses play a key role in this process. Despite guidelines recommending routine pain screening, assessment and reassessment practices, there is often sub-optimal evidence of this occurring, which impacts on pain management. Addressing entrenched clinical practice is challenging, and requires consideration of a range of educational strategies, including multi-faceted educational interventions.

Aim: To test the acceptability, feasibility and impact of a novel on-line learning pain assessment module using a spaced and adaptive learning format (Spaced Education) on specialist palliative care nurses pain assessment knowledge and attitudes and practices.

Methodology:
- Study design: A quasi-experimental pre-post test design.
- Intervention: A pain assessment scenario was developed by an expert panel and delivered to participants via email using a Spaced Education.
- Methods: Survey and chart audit data was collected at four time points: baseline (T1), immediately post intervention (T2), and six weeks (T3). Award the survey changed in pain assessment knowledge and attitudes, while the chart audit appraised the quality of pain assessment documentation.

Results: Descriptive statistics and Multivariate Analysis of Variance comparing the pre-post test mean survey scores.

Conclusion: A significant increase in the quality of pain assessment documentation from T1 to T2 (7.38 vs. 8.74). This improvement was reflected in an increase in the chart audits on pain assessment documentation increased from T1 to T2 (2.48 vs. 4.20 per admission), with the majority (87%) of pain assessments understood. This project was funded by the Curran Foundation and a St Vincent’s Clinic Multidisciplinary Research Grant.

Abstract number: FC 7.4
Abstract type: Oral

Lost for Words? Communication Training for Medical Students as Part of the Palliative Medicine Curriculum

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Background: Communication with patients in a palliative care setting requires a high level of expertise and is a skill that needs to be improved in order to achieve desired patient outcomes and prevent exacerbations of patients’ suffering. This task can be especially challenging for medical students and residents, as they often feel unprepared and inexperienced when confronted with the complexities of end-of-life cases. The aim of this project was to conduct a pilot study testing the feasibility and effectiveness of an on-line communication training for medical students as part of the Palliative Medicine Curriculum at the University of Bonn.

Methods: Fourteen "actor patients" were trained with six role scripts 2011/2012. This mandatory block course combines 28 hours of lectures, workshops, self-experience, and role-plays. The e-learning Palliative Care Program in Latin America is a range of targeted strategies, including multi-faceted learning of education -1 level competencies that belong to level A education -1 to level B education -13. The top 3 barriers in implementing those competencies working in specialized Palliative Care (PC) services, to highlight the barriers in implementing those competencies and the potential positive results once PC is recognized as a specialty for nurses.

Conclusion: The project suggests that Spaced Education offers a useful tool which facilitates access to training of palliative care doctors and nurses.

E-learning Palliative Care Program in Latin America: Improvements in Knowledge and Self Perceived Comfort Level

Buenos Aires, Argentina

Palliative Care (PC) offers effective methods for the control of distressing symptoms in patients with advanced diseases. Courses via internet were delivered in Spanish for nurses and physicians. A total of 170 nurses currently working in the palliative care field, taking part in the internet course.

Method: Learners were asked to complete an online questionnaire pre and post course, it consisted of a knowledge test and a self-assessment tool. In the first approach with asynchronous and synchronous activity, Modular-based ten modules; each lasting one-week long with specific topics, such as communication, pain management, delirium, and therapeutic approaches for each stage of the longitudinal course with specific topics.

Objective: To describe changes in knowledge and self perceived comfort levels of learners after taking the PC online course.

Results: A total of 41 doctors and 19 nurses enrolled in the courses, 73% completed it. The computer science program of the University of Bonn is offering a range of courses; 75% completed it.

Conclusion: The e-learning Palliative Care Program in Latin America is an effective tool which facilitates access to training of palliative care doctors and nurses.

Ethics

Abstract number: FC 8.1
Abstract type: Oral

Medical, Philosophy and Law Students’ Attitudes towards Euthanasia in Flanders, Belgium: Role of Academic Background, Philosophy of Life, Relevant Knowledge and Experience

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Research aims: Professionals with different academic backgrounds are involved in end-of-life decisions (EOL). It can be expected that persons with different academic backgrounds have different perspectives to EOL. With Belgium having a legal euthanasia practice involving physicians, lawyers, and ethicists, differences were investigated between medical, law, and philosophy students in terms of attitudes towards euthanasia and existence of the euthanasia law. Moreover, associations of these attitudes with other characteristics were examined.

Methods: In 2012, all 1,390 students of the faculties of medicine, law and philosophy at Vrije Universiteit Brussel were invited by e-mail to fill in an online anonymous questionnaire. Dependent variables were attitudes towards euthanasia and existence of the law. Independent variables were student’s discipline, philosophy of life, relevant knowledge, and experience.

Results: 391 questionnaires were returned; 84% of the students completely rejected euthanasia and 4% rejected the existence of the euthanasia law. Independent variables did not influence students’ discipline, philosophy of life, relevant knowledge, and experience once euthanasia or palliative sedation in a related paper or friend, and years of education. Logistic regression analysis was performed.

Conclusion: Existence of the euthanasia law was equally supported by students with different academic backgrounds. More medical training on euthanasia increased acceptance of euthanasia only under certain conditions instead of always. A positive attitude towards the existence of the euthanasia law was more likely among catholic (OR=16.76) and humanist students (OR=8.44) compared to the survey on euthanasia including Muslim.

Palliative Sedation from the Perspective of Professionals with Different Academic Backgrounds: A Pilot Study

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Research aims: Palliative sedation until death (PS) is associated with highly debated ethical issues and often provokes serious concerns in health care professionals and relatives. This paper investigates the subjective ideas and wishes of palliative care patients regarding the option of PS.

Methods: In a semi-structured interview study on terminally ill cancer patients’ wishes to die (N=30; 116 interviews) we also asked patients and relatives about their views on PS. Data analysis: Grounded Theory and Interpretive Phenomenological Analysis.

Results: Two topical levels emerged:
(1) Informed level: Many patients reported that they knew little about PS if anything at all. Only few patients felt well informed. Generally, patients understood that in PS they will depend continuously until they die, and they will find redemption from suffering. Most patients who received information reported that already the knowledge about the availability of this option gave them reassurance and reduced fear.

(2) Level of moral significance: Patients were careful about the moral implications of PS, asking how and why PS can be feasibly distinguished from (assisted) suicide. Others were concerned about the burden for their loved ones having to assist them without the possibility to communicate. Several patients who desired to die, but for whom hastening death was not a moral option, saw PS as a morally acceptable alternative.

Relatives struggled with the prospect to lose contact
Palliative Care in the Elderly

Abstract number: FC 9.1
Abstract type: Oral

Implementation and Audit of the ‘Proactive Elderly Persons’ Advisory Care’ Planning Project on modiﬁed ‘PEACE Project’: A Collaboration between Geriatric and Specialist Palliative Care Services to Improve End of Life Care for Elderly Patients Using a Future Care Planning Tool

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The Proactive Elderly persons’ Advisory Care planning project, or modiﬁed PEACE Project, was undertaken in an acute hospital between February and March 2011. The project aimed to introduce a future care planning document for elderly patients approaching the end of their lives which would prevent inappropriate and potentially harmful hospital readmissions. The project focused on elderly patients from nursing homes, where evidence suggests that hospital admissions are unplanned, inappropriate and potentially harmful. Readmission rates for elderly patients are high, with up to 40% of all hospital readmissions involving patients aged 75 years or older. Most often, the readmission related to a primary care admission decision. The original PEACE project was developed at Kings College Hospital, London. Locally, a number of modiﬁcations to this document were made through consultation with the Palliative Care team including compliance with the Mental Capacity Act 2005, reference to ‘Just in Case’ medications and the Liverpool Care pathway in the last few days of life, and inclusion of a DNACPR decision. In contrast to the King’s project, local hospice services supported the introduction of the PEACE tool into nursing homes. An audit of patient outcomes was completed in October 2012. Of the 42 patients eligible for the study, 35 patients were readmitted to hospital, half for treatment of acute infection in accordance with their PEACE plan. The remaining 17 patients died at home, 17 died in hospital. Both groups had had some life-shortening effect in 77% of cases, and estimated median survival times of one week or more in 21%. Readmission rates were 58.4%, 58.4% and 58.4% for the three groups, respectively. The majority of the 42 patients had had some life-shortening effect in 77% of cases, and estimated median survival times of one week or more in 21%. For those with a life-shortening effect, the median survival time was 10.5 months. Readmission rates for elderly patients approaching the end of their lives are high and that patients are dissatisﬁed with care received. The PEACE project showed that future care planning for complex, elderly patients approaching the end of life is possible, and may prevent inappropriate hospital readmission and promote better palliative care.

Abstract number: FC 9.2
Abstract type: Oral

Hospitalizations of Nursing Home Residents with Dementia in the Last Month of Life: Results from a Nationwide Study

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The introduction of standardized care plans for nursing homes in Belgium to improve the quality of care for patients with dementia in the last months of life has increased. This study aimed to assess the changes in hospitalization rates over time for residents in nursing homes in Belgium aged 65 and older with a diagnosis of dementia. The study included all individuals with a diagnosis of dementia who died in nursing homes in Belgium between 2006 and 2011. The hospitalization rates were calculated for three time periods: 2006, 2008, and 2010. The results showed a decrease in hospitalization rates for nursing home residents with dementia in the last month of life from 2006 to 2010. This indicates an improvement in the quality of care for residents in nursing homes with dementia in the last month of life. However, the rates remained high, highlighting the need for further improvements in care and support for these residents.

Abstract number: FC 8.6
Abstract type: Oral

The Association between Past Grief Reactions, Quality of Hospice Care Assessments and Bereaved Caregivers’ Sensations of Parenteral Hydration during the Last Weeks of Life

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Context: Barriers to the conduct of clinical trials with palliative care patients and caregivers are numerous, yet evidence based end of life clinical practice is vital. Aims: To identify the demographic, clinical, psychosocial and health system related factors associated with the overall benefits of parenteral hydration (PH) for hospice cancer patients during last weeks of life as reported by bereaved caregivers. Methods: Bereaved caregivers previously enrolled in a randomized, double-blind controlled trial investigating the efficacy of PH for hospice cancer patients were interviewed 3-23 months after their loved one’s death to identify their attitudes and beliefs regarding PH using a 16-item, Likert-type scale, their frequency of PH use, and the PH perceptions (Cronbach’s Alpha = 0.81). Secondary data analyses were used to identify characteristics of caregivers PH perceptions using linear regression analysis. Results: Seventy-six interviews with bereaved caregivers were completed (78% response rate). Most caregivers agreed/strongly agreed (76%) that PH was beneficial for their loved one. The majority (84%) reported that the quality of hospice care received was “very good” or “excellent” and 46% classed as having an absence of grief following their loved one’s death. Bereaved caregivers in receipt of PH had more favorable PH perceptions: “excellent” ratings of hospice care (P = 0.003), absence of past grief (P = 0.035) and female caregivers (P = 0.014). Conclusion: Findings suggest that clinical research in hospice populations is feasible and can be conducted with improved levels of satisfaction with standard care and initial adjustments to death. Longitudinal studies with diverse groups of caregivers are needed to establish direction of these associations and examine how PH in the hospice context may influence satisfaction with care and the bereavement process.

Abstract number: FC 8.5
Abstract type: Oral

Forging Artificial Nutrition or Hydration (ANH) at the End of Life in Belgium

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Objectives: The purpose of this study is to examine the frequency of decisions to forgo withhold or withdraw artificial nutrition or hydration (ANH) at the end of life in Belgium and to describe background characteristics of the patients and the decision making process. Methods: Postal questionnaires regarding end of life decisions (including ANH) were mailed to physicians certifying a large representative sample (n=6927) of Belgian death certificates in 2007. Results: Response rate was 58.4%. A decision to forgo ANH occurred in 6.6% of all deaths (4.2% withheld, 3.9% withdrawn). Reasons to forgo ANH were care of home or hospital, and suffering from nervous system diseases (including dementia) or malignancies were the most important patient related reasons and conflicts associated with a decision to forgo ANH. Physicians indicated that the decision to forgo ANH had had some life-shortening effect in 77% of cases, and estimated median survival times of one week or more in 21%. Forgiving ANH was requested by the patient in 10%. Not consulting with the patient was mostly due to incompetence (26%). The family and other caregivers were mostly involved in the decision making. Conclusion: An important proportion of deaths in Belgium are preceded by withholding or withdrawing life support. These are ethically challenging decisions for all involved as nourishment epitomizes the basic care for a person in need and ANH decisions imply loss of longevity. The finding that only 10% of patients themselves requested ANH to be forgone shows that the family and care team are mostly burdened with these decisions. In Belgium patients are legally entitled to withhold or withdraw any clinically ‘pointless’ treatment on their own accord, the gravity of ANH decisions calls for a model of shared decision making, preferably with the patient. Developing a protocol for timely discussion (particularly in institutional end-of-life care settings) may help to ensure such a decision model.

Abstract number: FC 8.4
Abstract type: Oral

The Belgian Model of End-of-Life Care: Hereby, Experience, Prototype?

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Methodology: Physicians-assisted dying (PAD) is legal only in the Benelux countries. Elsewhere palliative care (PC) and PAD are often considered incompatible for fundamental reasons and antagonistic because PAD might stum the development of PC, endanger vulnerable patients and compromise public confidence in health care.

Results: The Flemish Federation of Palliative Care has endorsed ‘compassionate care’ projects and including the possibility of PAD in order to prioritise the patient’s values and to promote ‘total care’ also in the practice of PAD. However, individual cancer patients are not necessarily refused PAD if they request it. The latter palliative care approach seems to be even more needful.

Conclusion: PAD and individualized PAD care are best combined.

Abstract number: FC 8.3
Abstract type: Oral

Ethical Aspects in Palliative Care for Patients with Cardiovascular Disease - Case Series Observations

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Background: Epidemiology, prognosis, symptom burden and other reasons favour palliative care support also for patients with underlying cardiac disease. It is unclear, though, to what extent a disease specific palliative care approach for patients with cardiac disease is required. Here, we focus on disease specific and distinguishing ethical questions in the care for patients with cardiac disease that have to be taken into consideration when expanding palliative care on the particular group of patients.

Method: We therefore retrospectively analysed institutional data (palliative care unit, outpatient clinic, consultation services, home care to patients with cardiac disease and describe a case series of ten index patients suffering from congestive heart failure that illustrate disease specific ethical conflicts.

Results: The ethical issues discussed comprise: redefining palliative treatment goals, role of symptom control for individual patient needs and symptom control for the institution, cardiac care and emergency procedure planning, the role of disabling internal devices (ICD) as part of a palliative care concept, palliative care approach for patients with cardiac disease and describe a case series of ten index patients suffering from congestive heart failure that illustrate disease specific ethical conflicts.

Conclusion: Discussions on the appropriate treatment goals of palliative care have rather decreased, “practical slippery slope” effects did not occur. Palliative care for patients with cardiac disease is required. Here, we focus on disease specific and distinguishing ethical questions in the care for patients with cardiac disease that have to be taken into consideration when expanding palliative care on the particular group of patients.

Conclusion: Discussions on the appropriate treatment goals of palliative care have rather decreased, “practical slippery slope” effects did not occur. Palliative care for patients with cardiac disease is required.


**Meeting the Prime Ministers’ Challenge – Integrating and Improving End of Life Care for People with Dementia Following the Gold Standards Framework Dementia Care Training Programme**

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**Abstract number:** FC 9.4

**Abstract type:** Oral

**Aims:** To evaluate the NASMATE CARE programme in 6 nursing homes in the Netherlands for the purpose of: 1. improving quality of life for residents with advanced dementia; 2. facilitating ‘best available evidence’; 3. improving care, aid decision-making and quality of care for patients with non-cancer.

Methods: 1. A survey with the objective of documenting which clinical tools are currently used in the palliative care sector in Victoria, Australia.

Clinical Tools to Assist with Specialist Palliative Care Provision

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Aims: The aim of this project was to recommend key clinical tools that may assist with the admission and coordination of care provision for patients and family caregivers across specialist palliative care settings.

Methods: The process of developing the list of recommended tools involved four phases:

1. A survey with the objective of documenting which clinical tools are currently used in the palliative care sector in Victoria, Australia.

2. A literature review, with the objective of identifying further clinical tools specific to palliative care.

3. An appraisal process, in order to establish a checklist of clinical tools that meet designated criteria.

4. A multi-disciplinary expert specialist focus group meeting, with the objective of endorsing a suite of clinical tools that meet the aims of the project for the specialist palliative care provision in Victoria, Australia.

The analysis was guided by nine domains of palliative care, care provision in Victoria, Australia.

**Abstract number:** FC 10.1

**Abstract type:** Oral

**Better Dying in Residential Care-homes with the Liverpool Care Pathway - An Intervention Study**

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Aims: To investigate the effects of an intervention on end of life care in residential care-homes.

Methods: A longitudinal, retrospective pre-test, post-test study with a control group design, in which the intervention group was provided with the Liverpool Care Pathway (LCP) for dying residents, and the control group was provided with usual care. A total of 10 Swedish residential care homes, 423 residents and their family members participated.

Results: The study showed that the intervention group had a significantly higher quality of end of life care, as measured by the End of Life Quality Assessment, compared to the control group.

Conclusion: The Liverpool Care Pathway is an effective tool for improving end of life care in residential care-homes.

**Abstract number:** FC 9.6

**Abstract type:** Oral
Abstract number: FC 10.4
Abstract type: Oral

Assessing Decision-making Capacity at the End of Life: Concordance between Clinician-rated Capacity and Performance on the MacCAT-T
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+Calvary Hospital, Palliative Care Institute, Bron, NY, United States
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Despite the clinical, ethical and legal magnitude of end-of-life decision-making, little is known about the decision-making capacity of patients with advanced cancer. Clinicians are largely responsible for determining when these patients are no longer competent to make treatment decisions. The purpose of this study is to assess decision-making capacity in terminally ill cancer patients, specifically concordance between clinician-rated capacity and performance on a validated measure of capacity. Patients with advanced cancer receiving inpatient palliative care (n=58) completed the MacCAT-T, a semi-structured interview that evaluates decision-making capacity with regard to four commonly-used legal standards of competence: ability to express a choice, understand information relevant to treatment decisions, appreciate the significance of the treatment decision and rationally manipulate relevant information. Impairment on one or more of these tasks was calculated using a group of common age-hapieatched adults (n=50). Participants physicians independently rated decision-making capacity. Participants were largely female (56.9%), Caucasian (65.5%), and mean age was 69.5. Most participants were able to express a treatment choice (62.7%). However, patients evidenced more problems with understanding the treatment options (17.2%, 39.7%), understanding (37.9%, 27.6%), and reasoning (39.3%, 37.9%) subscales respectively. Cohen’s Kappa coefficient was calculated to assess inter-rater reliability between physician-rated capacity and performance on the MacCAT-T. Agreement between ratings was slight, kappa ranged from 0.29-0.73. High clinical assessments are considered the gold standard in capacity assessment, agreement between clinician assessment and performance on the MacCAT-T is poor. These findings should inform the development of instruments to measure key functional abilities relevant to specific domains of capacity as they pertain to the different legal standards.

study the level of satisfaction with palliative care in a nationally representative sample. The results indicate dissatisfaction with key aspects of palliative care.

Abstract number: FC 10.6
Abstract type: Oral

Clinical Signs of Impending Death in Cancer Patients
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Aims: The fundamental process of dying has not been well characterized in cancer patients. We determined the prevalence, onset and likelihood ratios (LRs) for clinical signs associated with the dying process in advanced cancer patients. Methods: We systematically documented 80 physical signs on consecutive advanced cancer patients admitted to palliative care units at two tertiary cancer centers every 12 hours from admission to death or discharge. We examined the frequency and median time of onset of each sign from death backwards, and calculated their LRs associated with death within 3, 5 and 7 days.

Results: 203/357 patients died. 20/80 signs had very high positive LRs (>10 for impending death. Multivariable logistic regression analysis indicated that inability to close eye lids, non-reactive pupils, grunting of vocal cords, and respiration with mandibular movement were associated with imminent death within 3 days (Table 1). Death rattle, drooping of nasolabial fold, and decreased response to verbal stimuli were associated with death in 5 days and 7 days (Table 2). The positive LRs for doublet combinations of these signs were between 20 and 30. These signs occurred in 90-70% of patients and mostly in the last 3 days of life.

Conclusion: We identified highly specific physical signs associated with impending death among advanced cancer patients.

Table 1. Signs of Impending Death in 3 Days
<table>
<thead>
<tr>
<th>Sign</th>
<th>Prevalence (%)</th>
<th>Median Time</th>
<th>Sensitivity (95% CI)</th>
<th>Specificity (95% CI)</th>
<th>Negative Predictive Value (95% CI)</th>
<th>Positive Predictive Value (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death rattle</td>
<td>19 (9)</td>
<td>1.5 (1.0-2.0)</td>
<td>91 (87-95)</td>
<td>58 (54-62)</td>
<td>97 (95-99)</td>
<td>0.85 (0.70-0.94)</td>
</tr>
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<td>Drooping of nasolabial fold</td>
<td>96 (51)</td>
<td>1.5 (1.0-2.0)</td>
<td>65 (60-70)</td>
<td>97 (96-98)</td>
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</tr>
<tr>
<td>Decreased response to verbal stimuli</td>
<td>100 (54)</td>
<td>1.5 (1.0-2.0)</td>
<td>76 (71-82)</td>
<td>97 (96-98)</td>
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<td>0.95 (0.93-0.97)</td>
</tr>
</tbody>
</table>

Table 2. Signs of Impending Death in 5 and 7 Days
<table>
<thead>
<tr>
<th>Sign</th>
<th>Prevalence (%)</th>
<th>Median Time</th>
<th>Sensitivity (95% CI)</th>
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Abstract number: FC 11.1
Abstract type: Oral

The Hospital as a Place of Death
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Place of Death

Free communication sessions

Health in Scotland: A case study in implementing a Whole Systems Approach to Palliative Care
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Abstract number: FC 10.3
Abstract type: Oral

Validation of an Inflammatory Based Biomarker Prognostic Score (mGPS) in Combination with Performance Status in a National Cohort of Advanced Cancer Patients
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Background: Performance status in combination with the inflammation based Glasgow Prognostic Score (mGPS) has been proposed as an approach to prognosis in advanced cancer. We investigated the hypothesis that by adding this single variable we could calculate a score that would lead to an independent dataset.

Methods: Analysis was conducted on an international biobank of patients with cancer. Prognostic markers previously identified as being of potential value were assessed: EORTC QLQ-C30 patient reported outcomes, performance status and mGPS (using C-reactive protein and albumin). The relationship between these variables and survival was assessed using Kaplan-Meier and Cox regression methods.

Results: Data available on 631 patients from 6 countries. The majority of patients (85%) had good performance status (ECOG 0-1) and were under the care of an oncology department (78%). The median survival was 7.03 months (95% CI 2.5-7.33). On multivariate survival analysis, mGPS was superior to performance status in terms of survival. Positive predictive value was 0.85 (95% CI 0.78-0.92) and negative predictive value was 0.83 (0.79-0.86). The relationship between these variables and survival was assessed using Kaplan-Meier and Cox regression methods.

Conclusion: The findings support mGPS in combination with performance status and externally validate this approach for the validation of a new biomarker dataset of advanced cancer patients. The findings also demonstrate the mGPS may be a stronger prognostic factor than performance status in advanced cancer patients.
Aim: To explore bereaved family caregivers' experience of care of older patients (with and without dementia) dying on acute hospital wards.

Background: Hospital care is considered an undesirable place to die. Current UK policy aims to avoid unscheduled admissions and increase the number of patients who die at home. Nevertheless, the majority of deaths occur in hospital, and this number is set to rise as the proportion of the population dying at an advanced age increases in combination with complex comorbidity and associated intensive care needs continues to increase. There is a pressing need for greater understanding of the experience of death in acute hospital settings and how this may be improved.

Setting: 4 acute wards in a UK general hospital.

Method: Qualitative study involving triangulated data from ward observation (245 hours), interviews with 38 (38 bereaved family carers (13), and patient medical records review (42). Thematic analysis using constant comparative method.

Results: The experience of dying varied across wards and family responses were strongly determined by prior expectations of outcome and the circumstances of each case. However, the hospital was not generally viewed as an undesirable or inapplicable place to die. Some families wanted their relative to remain on the ward. Others altered their initial preference as they came to doubt their capacity to cope with the care required.

Conclusion: Rather than being vilified, the hospital needs to be improved to help in case management to improve the care of dying patients and their families.

Abstract number: FC 11.2

Type of abstract: Oral

Trends and Projections for Place of Death in One of the Most Aged Populations in Europe (Portugal, 1988 - 2030)

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Background: With a population of 10 million and more than 100,000 deaths per year, Portugal has the 5th most ageing population in the European Union (EUROFAC 2010). Evidence on projections for place of death in Portugal to inform service development is lacking.

Aim: To forecast the last part of life for elderly people by age and sex, and to project future trends until 2030, to inform palliative care services development in Portugal.

Methods: Data were obtained from death certificates of a study of adult (18+ years) deaths in Portugal (2002-2011) and applied life table projections.

Results: Annual numbers of deaths increased 11.1%, from 95,154 in 1988 to 105,091 in 2010, and are projected to rise further by 5.6% in 2030 (111,584 deaths). Proportions of hospital deaths increased steadily by a mean of 0.8% to 10.30% deaths per year, from 64.4% to 65.3/171 deaths) in 2010 to 68.1% (65.221 deaths) in 2030, in all age groups (except the youngest, 18-34 yrs), with a rise of >20% in the older age group (65+ yrs). This is the most pronounced change in the last five years (2006-2010) to EUROSTAT mortality projections.

Conclusions: Annual numbers of deaths increased 11.1%, from 95,154 in 1988 to 205,091 in 2010, and are projected to rise further by 5.6% in 2030 (111,584 deaths). Proportions of hospital deaths increased steadily by a mean of 0.8% to 10.30% deaths per year, from 64.4% to 65.3/171 deaths) in 2010 to 68.1% (65.221 deaths) in 2030, in all age groups (except the youngest, 18-34 yrs), with a rise of >20% in the older age group (65+ yrs). This is the most pronounced change in the last five years (2006-2010) to EUROSTAT mortality projections.

Methods: We used death certificate data of all deaths in Belgium in 2008 (N=101685) to examine characteristics of deaths caused by both dementia and pneumonia.

Introduction: Only few people suffering from dementia would want to die in hospital. In particular for people with dementia with pneumonia a hospitalisation at the end of life may be of little benefit and result in unfavourable outcomes. The aim of this study is to estimate the incidence and risk factors of hospital death in people dying from or with dementia and pneumonia.

Methods: We used death certificate data of all deaths in Belgium in 2008 (N=101685) to examine characteristics of deaths caused by both dementia and pneumonia. Information about the urbanization level of the place of residence, available hospital beds, residential (without current skilled nursing) and skilled nursing home beds in the proximity of the deceased was linked through the ZIP-code of the place of residence.

Overall, 59% of the deceased died in hospital with dementia and pneumonia (N=11420), 47.2% died in hospital. Of those living in nursing homes at the time of death, 25.6% died in hospital. Risk factors for hospital death were being single (AOR=2.83, 95%CI:1.30-6.16) and living in urbanized areas (AOR=4.48, 95%CI:4.74-8.18) for those living in their private home at the time of death and the availability of residential nursing home beds (AOR per unit: 1.02, 95%CI:1.01-1.03) for those living in nursing homes. Those who died from or with Alzheimer disease and pneumonia were less likely to be hospital as compared to unspecified dementia and pneumonia, both in those living at home (AOR=0.36, 95%CI:0.20-0.62) and in residential care (AOR=0.47, 95%CI:0.31-0.70).

Conclusion: Half of the people dying from or with dementia and pneumonia died in hospitals, a quarter of those living in care homes. The results suggest shortcomings in the Belgium healthcare system in avoiding unnecessary hospitalization of vulnerable populations.

Abstract number: FC 11.5

Type of abstract: Oral

Perceived Quality of Home Care at the End of Life: Which Factors are Associated with Bereaved Relatives Being Highly Satisfied with the Care Provided by GPs?

Poediek L., Harding R., Monteiro Calanzani N., M. C. P., Hall C.S., Deliens L.J.H., Högström I.J., Gomes B., on behalf of EUFAMP.

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Contact address: liana.poediek@vub.ac.be

Background: Studying relatives’ satisfaction with home care at the end of life is important when examining quality of care. It is particularly crucial to determine the factors related to high satisfaction with GP home care as this is known to facilitate home death. Aims: To examine bereaved relatives’ satisfaction with end of life care received by care-givers of deceased patients. To examine the associations between satisfaction with GP care and service and non-service factors.

Methods: Multicentre family genogram survey. From death registrations in four health regions in London (UK, one year period 2009-2010) we identified the persons who received care from a GP. They completed a postal questionnaire on the care that patients had received in the last three months of life by GPs, palliative care specialists, and other nurses (district/sharing/community/private). Analysis involved descriptive statistics and multivariate logistic regression of being highly satisfied with GP care (excellent/very good vs. good/fair/poor/very poor).

Results: Questionnaires were completed for 596 decedents (59% response rate) of whom 548 stayed at home at least one day in the last three months of life. Home care was reported by 49% of respondents for GP care, 78% for specialist palliative care and 66% for care by other nurses. High satisfaction with GP care was associated with good GP-family communication (OR=8.1 [3.1, 19.8], perceived GP competence (OR=9.1 [3.1, 24.9]) and symptom relief (OR=16.7 [4.9, 65.0]) and was more likely in cases of home as opposed to hospital death (OR=3.8 [1.6, 8.6]). No effect of age and socioeconomic deprivation was found.

Conclusions: Although bereaved relatives’ satisfaction with end of life home care is generally high, it is less so for GPs. Satisfaction with GP care of dying patients and home death potentially facilitated, by helping GPs to improve pain and symptom control and communication.

Funding: Cicely Saunders International, EU FP7

Abstract number: FC 11.6

Type of abstract: Oral

Pain in People with Dementia: Deployment of Pain Assessment in a Long Term Care Institution

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Situation in Long term care institutions specialized on care of older adults with dementia in the Czech Republic will be discussed, regarding to communication, pain and suffering with clients and within the interprofessional team.

The grant NT 11325 of the Ministry of Health of the Czech Republic, “Long term care for seniors: quality of care in institutions” is focused on indicators of quality of care. Pain may be considered one of the most important indicators, data mapping prevalence of pain in LTC institutions are being collected. The project “Geriatric and Organisational Supervision“ is seeking possible ways of intervention.

Methods: Use of the CES-D scale and MOBID scale are instruments for pain assessment in people with advanced dementia, using observation. For both of these scales Czech version was published. PAIND and MOBID were offered as tools for education of interprofessional team of Czech LTC institutions and eventually one or both were accepted for regular use for assessment of pain in people with advanced dementia. The
experience with Czech version of PAINAD and MOBID in practice will be discussed. Methods used for intervention: education, train the trainers, consultation and organizational self-assessment. Results: Pain was present in more than 70% of residents with dementia at baseline. Preliminary results on the effect of Pain Management in a Czech long-term care institution for people with dementia will be presented. Conclusions: Advanced stages of dementia with communication deficits, challenging behaviour may be the most noticeable sign of pain. It is vital that professional carers are able to understand this possible interrelationship between cognition and pain, being trained to recognize non-verbal signs of pain.

Supporting Information: NT-1253 and NT-1705 of the Ministry of Health of the Czech Republic.

**Children and Young People/ Spirituality**

**Abstract number:** FC 12.1

**Abstract type:** Oral

**Educating Adult Palliative Care Teams about the Needs of Transition Age Young People: What Do They Need to Know?**

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**Aims:** The prognosis of life-limiting conditions of childhood has improved and an increasing number of young people are accessing adult Palliative Care (PC) services. Adult PC teams are inexperienced in caring for the complex needs of these young people and have some concerns regarding skills, knowledge and service capabilities. We aimed to identify the current needs of PC teams regarding the care of young adults.

**Methods:** Delphi: An online Delphi process collated expert opinion on format, delivery and content of the package. Round 1 participants (n=44) answered free text questions, generating items which were then collated to form a round 2, 46 participants rated the extent to which they agreed/disagreed with the items on 5-point Likert type scales. Median and mean scores assessed the importance of each item. Interquartile range scores assessed level of consensus for each item; items lacking consensus were re-rated by 35 participants in Round 3. Focus Groups: Focus groups were held with young people pre-transition, post-transition, parents/carers of young people post-transition and staff from a local adult hospice. Discussions explored the care and support needs of young people and their families, and the training needs of PC teams. Free text data were analysed using thematic analysis.

**Results:** Delphi: Consensus was reached on a range of suggested format, delivery, content of the training, as well as several clinical, psychosocial and practical topics. Training should be delivered as a continuous/rolling programme and not as ‘a one-off’. Focus Groups: Discussions centred on: challenges of caring for young people; barriers to transition; staff education and training; facilitating transition.

**Conclusions:** Recommendations include a continuous/rolling programme of education, tailored for content and mode of delivery, and incorporated into working practice. A template to guide handover and a single point of contact would facilitate the transition process.

**Understanding Posttraumatic Growth in Children with Life-limiting Illnesses**

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**Research aims:** Caring for a child with a life-limiting illness (LLI) is a stressful and unenjoyable circumstance. While there is growing evidence that posttraumatic growth can co-occur with stressful events and activities, less is known about how this growth occurs or how growth can be nurtured. The goal of this study is to explore the process of growth among parents who are or have been caring for a child with a LLI.

**Methods:** This was a mixed methods study using quantitative data gathered from 273 parent caregivers of children with LLI from Canada and the U.S.A. and qualitative data from interviews with a sub-set (n=25) of parents. Survey packages included demographic information and previously verified scales measuring meaning in caregiving, optimism, self-efficacy, spirituality, depression, caregiver burden, and posttraumatic growth. Structural equation modeling identified models of possible factors that allow these parent caregivers to experience posttraumatic growth. Semi-structured interviews were transcribed and analyzed using thematic analysis to explore parents’ lived experiences of growth.

**Results:** The most promising structural equation model shows that particular personal resources reflected in personal wellbeing are prerequisites to the process of positive meaning making which in turn contributes to growth. Interviews with parents clarify the ways in which growth occurs and how personal resources play a role. Mean age 49, 65% female, 65% spiritual but not religious. 52% reported their work as mainly clinical; including 283 palliative care physicians, 112 nurses and 113 chaplains. A high level of agreement in the priorities identified in the quantitative and qualitative data. Highest priority areas were:

1. Responding to spiritual needs - evaluating interventions, determining effectiveness.
2. Helping staff talk about spiritual issues – conversations models, overcoming barriers in attitudes and knowledge.
3. Identifying those with spiritual needs - screening.
4. Assessing patients’ spiritual needs and preferences in multi-faith, multi-cultural populations was a cross-cutting theme. <2.5% said no further research was needed in spiritual care.

**Conclusion:** There is unanimous international support for research focusing on spiritual care interventions, conversation models and screening assessment. Knowledge of priority areas can guide patient-centred, inclusive and culturally sensitive research.

**Abstract number:** FC 12.5

**Abstract type:** Oral

**Psychosocial Support to Seriously Ill Cancer Patients with Under-aged Children in Palliative Care**

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**Aim of project:**
1. identify parent's need for child-oriented support.
2. barriers to involve children in the terminal process.
3. determine an effective framework for support.

**Design:** Patients with children < 18yrs in specialist palliative care, were offered semi-structured conversations at referral till 6 months post-death of patient. Conversations, with a psychologist and a social counsellor, took place in the home and covered topics and concerns brought up by patients supplemented by therapists drawing upon an earlier pilot study and family-focused grief theory. At each session patients completed MYCAW questionnaires stating main concerns and topics of discussion. At end of conversation, completion of therapy the surviving parent provided a content and structure-oriented evaluation.

**Results:** Of 12 families participated with a median number of conversations of 3 pre- and 3 post-death. Mean time of participation before death was 58 days. The majority of parents had many worries about their child and was ill-equipped to inform and prepare the child for the forthcoming death. Barriers inhibiting dialogue between parents and child were due to fear of disturbing the child, lack of recognition of the severity of the illness situation and uncertainty of how to handle the child's reactions. Structural aspects of importance to parents were home visits, conversations with parents alone, the possibility of including the child in conversations and flexibility in providing conversations according to parental need.

**Conclusion:** There is an unmet need among terminal cancer patients and their spouses to engage with palliation professionals about child-related concerns. Patients exhibited improved confidence in providing care and supporting to their child. Child-focused support and therapy interventions for parents should be developed according to parental need and focus on provision of information to the child, preparing the child for the death of a parent and on the child's coping.

**Abstract number:** FC 12.6

**Abstract type:** Oral

**Assessing Spiritual Distress in Residents of Care Homes for Older People Using the FACT-Spirit: A Cognitive Interviewing Study**

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**Method:** FACT-Spirit was evaluated with cognitive interviewing in 17 care homes for older adults in the United Kingdom. Interviewers were trained in conducting cognitive interviews and reliability of interviews was monitored. Patients were approached by interviewers who explained the study and asked if they were interested in participating in two-stage cognitive interviews of 20 minutes each. Interviews were audio-recorded and transcribed for analysis.

**Results:** Of 41 eligible patients, 32 (78%) consented to participate. The majority (65%) of the sample were women, aged 80 years and above, and the mean duration of stay was 3 years. Participants were asked to rate the distress subscales as ‘very distressing’, ‘moderately distressing’, ‘slightly distressing’ or ‘no distress’. The subscales of ‘transient’ and ‘persistent and existential’ had the highest endorsement at ‘very distressing’ in 20 and 16 respondents respectively. Descriptive statistics were collected and compared with scores from the FACT-Spirit. Interviews showed participants did not distinguish between ‘transient’ and ‘persistent and existential’ subscales.

**Conclusion:** FACT-Spirit was evaluated with cognitive interviewing in 17 care homes for older adults in the United Kingdom. Interviewers were trained in conducting cognitive interviews and reliability of interviews was monitored. Participants were approached by interviewers who explained the study and asked if they were interested in participating in two-stage cognitive interviews of 20 minutes each. Interviews were audio-recorded and transcribed for analysis. Participants were asked to rate the distress subscales as ‘very distressing’, ‘moderately distressing’, ‘slightly distressing’ or ‘no distress’. The subscales of ‘transient’ and ‘persistent and existential’ had the highest endorsement at ‘very distressing’ in 20 and 16 respondents respectively.
Background: An increasing number of older people live and die in care homes, but relatively little is known of their spiritual needs or how to assess them. Although many residents demonstrate signs of spiritual distress, long-term care homes may lack sufficient knowledge of spiritual care. The aim of this study was to assess the needs and to explore the spiritual care of residents.

Methods: A mixed-methods study was conducted. The first phase involved a facility-wide survey, and the second phase involved spiritual interviewing at the 17 facilities identified as having a higher prevalence of spiritual distress. The first phase included assessments of prevalence of spiritual distress (on a 4-point scale) and a report of the prevalence of spiritual care at each facility. The second phase involved spiritual interviewing of residents from the top 17 facilities identified in the first phase. The interviews were conducted by nurse practitioners and spiritual care providers on a 13-item Likert scale of importance and impact. The data were analyzed using descriptive statistics.

Results: Of the 17 facilities identified in the first phase, 10 were selected for the second phase of the study. The prevalence of spiritual distress at the 17 facilities was 66.7% (n = 667). The prevalence of spiritual care at these facilities was 11.7% (n = 82). The scores for the spiritual care providers were 11.6 (± 1.2), and the scores for the residents were 11.7 (± 1.2). The scores for the spirituality of the residents were 11.6 (± 1.3), and the scores for the spirituality of the care providers were 11.7 (± 1.3). The scores for the spirituality of the care providers were 11.6 (± 1.3), and the scores for the spirituality of the residents were 11.7 (± 1.3).

Conclusion: The findings from this study showed that implementing an NP-led Pain Team can significantly improve clinical practice behaviors of LTC staff and improve resident pain management outcomes. The implementation of a pain management intervention in care homes should be performed with a low threshold for initiating pain management. Use of the intervention in care homes should be encouraged, especially in facilities where there is a high prevalence of spiritual distress.

using the Patient Health Questionnaire (PHQ-9), based on the DSM-IV criteria, and on a 0-10 NRS.

Results: Out of 1051 patient registrations, 969 patients completed the PHQ-9 depression measure. Of these, 48% were females, mean age of 62 years (SD 12.4), mean KPS of 71 (SD16.3) and 84% had metastatic disease. Mean pain intensity score for the last 24 hours was 2.1 (SD 2.3). 131 (13.5%) patients used ADs for symptoms other than pain. 133 (13.7%) patients met the PHQ-9 criteria for major depressive disorder (MDD), of whom 33 (24.8%) were receiving ADs for symptoms other than pain. Mean NRS-score for depression was 1.9 (SD 2.3) for the entire sample, 1.6 (SD 2.1) for all patients categorized as depressed, 2.8 (SD 2.7) for those receiving ADs, and 4.7 (SD 2.6) for those depressed and receiving ADs.

Conclusion and discussion: Low numbers of patients with MDD are receiving AD. There is a need to increase the awareness of depression in patients with advanced cancer. It is reason to believe that more patients may benefit from ADs.

Acknowledgment: EURO IMPACT, European Intersectorial and Multidisciplinary Palliative Care Research Training, is funded by the European Union Seventh Framework Programme (FP7/2007-2013, under grant agreement n° 264697).

Abstract number: FC 13.6

Abstract type: Oral

Definition, Categorisation Framework and Terminology of Episodic Breathlessness: Consensus by an International Delphi Panel

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Aims: Episodic breathlessness is a common and distressing symptom in patients with advanced disease. Still, it is not yet clearly defined. The aim of this study was to agree on a definition, categorisation framework and terminology of episodic breathlessness.

Methods: A web-based Delphi survey (three rounds) was conducted with international experts in the field of breathlessness. A structured questionnaire was used to identify specific aspects and to reach agreement on statements on definition, categorisation and terminology on a 5-point Likert scale. Responses were analysed anonymously. Descriptive analysis was used and consensus was defined in advance as ≥70% agreement. Comments were analysed using framework analysis.

Results: 31/ 68 (45.6%), 29/67 (43.3%) and 33/ 67 (49.3%) experts responded in the 1st/2nd/3rd round, respectively. Participants were from USA, Canada, Europe and Australia, between 20-79 years, about 60% male, and >75% rated their own expertise regarding breathlessness as moderate to high. After the 3rd round, consensus was reached on a definition (84.4% agreement), categorisation (96.3%) and terminology (episodic breathlessness) (92.9%). The final definition includes general aspects on the symptom occurrence, e.g. its intermittent, time-limited character and independence of underlying continuous breathlessness, as well as qualitative aspects of the symptom, e.g. a severe worsening of intensity or unpleasantness of breathlessness in the patient’s perception. Episodes may be predictable or unpredictable, depending on whether any triggers can be identified.

Conclusion: Based on this Delphi survey, there is high agreement on clinical and operational aspects of episodic breathlessness among international experts. The consented definition and categorisation may serve as a catalyst for clinical and basic research on episodic breathlessness in order to improve symptom control and quality of life.
Poster discussion sessions

Assessment and Symptom Management
End of Life and Services
Abstract number: PD 1.1

Assessment and Symptom Management

Delirium in Patients Admitted to an Inpatient Palliative Care Unit

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Introduction: Palliative patients have a high risk of delirium. The diagnosis is mainly clinical. Terminal sedation may be required.

Objectives: To determine the frequency of delirium in a palliative care unit, the factors that influence its occurrence, and its impacts on physical condition and survival.

Methodology: Observational, retrospective, longitudinal of all patients admitted to a palliative UCP for a period of 6 months, excluding those who died in the first 24 hours. Delirium is considered if described in the clinical chart and/or was reflected in the medical criteria of DSM-IV delirium.

Results: N=175 patients, 1 patient was dismissed by death in < 24 hours, 64% were male, mean age 76 years (range: 43-109), 93% cancer, 5% Alzheimer disease. The drug most commonly used for sedation was midazolam (18% divided by 50mg/día), 67% was associated with other drugs. Delirium episodes were more common in patients who used midazolam (mean dose 50-100mg/day). Delirium was more common in patients with cancer (71% vs 43%), 31% of the patients had delirium in the first 24 hours, 42% (SD=87.1) versus 39% (SD=79.9). There was no significant differences between groups in the other neuropsychological test and both had good performance consistency.

Conclusions: Similar cognitive performance was observed between both groups; however, patients had worse cognitive performance in one test which requires interaction among attention, psychomotor speed, and mental flexibility.

Abstract number: PD 1.3

An Experimental Model in Cancer Pain to Investigate the Effects of Pain and Opioids on Cognitive Function

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Aims: To study the effects of pain and opioids on sustained attention.

Methods: Randomized, double-blind, placebo controlled, cross-over study with 23 healthy Caucasian male volunteers (age 20-28 y). Volunteers were randomized, the ability to read and respond to stimuli was tested under the influence of experimental pain of mild and moderate intensities induced by a pneumatic tourniquet cuff with a computer-controlled air compressor.

Results: 2nd session: CRT was tested under the influence of placebo (saline) or remifentanil 0.1 μg kg⁻¹ min⁻¹; 3rd session: a model of pain relief as well as breathlessness was induced by adjusting the tourniquet cuff on the calf to increase pain sensation after pain relief with remifentanil or placebo. Assessments occurred when the volunteers reported stable pain or 10 minutes after steady-state inhalation.

Conclusions: The Ethics Committee has approved the study.

Abstract number: PD 1.2

Cognitive Performance in Cancer Patients Receiving Palliative Chemotherapy

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Objective: To compare the cognitive function in patients with cancer that had with that of healthy volunteers.

Methods: Cross-sectional study, in which 180 patients with cancer in palliative chemotherapy and 191 healthy volunteers were assessed. Data were collected between 2011 and 2012. Trail Making Test A and B (TTMT), Digit Span Test (DST), Continuous Reaction Time (CRT), Finger Tapping Test (FTT) and the Montreal Cognitive Assessment (MoCA) were used to evaluate different domains of cognitive function.

Results: Participants mean age 58.0 (SD=10.6), schooling mean 11.3y (SD=3.4), IPS mean 88% (SD=9.7). Pain intensity mean 1.1 (SD=2.2), variance 0-10, depression mean 5.7 (SD=3.8), variance 0-18. Anxiety mean 6.6 (SD=4.2), variance 0-20. Colorectal (38.7%) and breast (21%) cancers were the most frequent diagnoses, 53% had metastasis. Both groups were similar regarding schooling and income and limited fatigue. Groups were homogeneous, however, differed in age (volunteers mean 40.9 y, SD=13.4). Participants had slower performance compared to controls in TMT B (113 sec. (SD=79.9) vs 109 sec. (SD=64.8)) and the DI and pharmacological and infectious in the DDI. Hyperactive and mixed 31%.

Abstract number: PD 1.5

The Use of Pain Assessment Tools in the Acute Setting

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Aims: People with severe dementia admitted to acute hospitals often receive poor care, many die in this setting and are at risk of under detection and under treatment of pain. An aim of the BElPain study (Behaviour and Pain in Dementia Study) was to assess the detection of pain in this population.

Design and methods: A longitudinal cohort study in 2 UK acute hospitals. Each participant was assessed every 3-5 days during admission, using the following tools: PAINAD (Pain Assessment in Advanced Dementia) at rest and during movement, the FACES Pain Scale and the question ‘Do you have any pain?’ (Self-report is considered to be the ‘gold standard’). Results: 230 participants were recruited. 14% of our sample had language with no verbal expression. On the PAINAD, 28% of participants were assessed as in pain at rest but 65% had pain on movement. In total, pain was observed at nearly 50% of all visits during the study. On the PAINAD scale, 28% were rated as mild pain (score 1-3), 11% as moderate (score 4-6) and 5% severe (score 7-10). The PAINAD had good inter-rater reliability (Kappa = 0.76). The FACES pain scale was less effective; 49% were unable to complete this scale for themselves. Our self-report measure was of limited utility; 28% assessed on the PAINAD as being in pain answered that they were not in pain.

Conclusions: The PAINAD scale was a usable and reliable tool for measuring pain in the acute setting. The data highlights the importance of observing for pain at rest and during movement. People with severe dementia are at risk of under-detection and under-treatment of pain. It may suggest impairment for complex tasks and it can be used in the more unwell palliative and comorbid renal patients.

Abstract number: PD 1.4

Retinal Ith - Systematic Evidence on New Tools in the Fight

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Background: Pruritus is a common problem in end-stage kidney disease, with up to 77% of dialyzed and 74% of conservatively managed patients reporting itching. It impacts on mental and physical function, sleep, and is associated with depression and worse survival. Despite this, it remains poorly managed.

Aim: To identify, assess and synthesize the evidence on management of renal itch, to better inform patient care.

Method: Systematic search using PubMed and Embase was performed using the keywords ‘itch’, ‘pruritus’, ‘renal failure’ and ‘management’, and supplemented by reference list and website searches.

Results: 31 papers from Medline and 20 from PubMed were included with 30 further papers from reference lists. Systemic and topical treatments were reported as being effective in renal itch with most evidence from haemodialysis patients and little in conservatively managed patients.

Good evidence supports multiple systemic treatments including cholestyramine (2 RCT), opioid receptor agonists and no 2 randomised control trials (RCT)), thalidomide (1 RCT), gabapentine (2 RCT) and sodium crowlyin (1 RCT). There is limited evidence to support the use of androstanolone (case report), ginsenet (open label trial (OLT) and ketotifen (case report).

Topical therapies include simple emollients and oils (2 OLT), RCT), oils containing policosanol (1 OLT), pramoxine lotion (1 OLT) tazarokimus ointments (2 OLT) and capsaicin creams (2 OLT; 1 OLT).

Non-pharmaceutical therapies have shown efficacy in itch but with less robust evidence. UVB light showed usefulness in OLT. Homeopathy has been studied in a RCT with good reduction in itch. Acupuncture and acupressure have limited evidence compared to sham procedures (2 review papers). Conclusion: This work elucidates the management options when managing renal itch. These treatments can be used in the more stable haemodialysis patient troubled by itch but can also be used in the more unwell palliative and comorbid renal patients.

Abstract number: PD 1.6

A Systematic Review of Prognostic Tools in Advanced Cancer

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Introduction: Accurate prognostication is necessary in cancer patients to ensure effective end-of-life care. Numerous prognostic tools have been developed but few meet the required standards of outcome measurement and validation.

Aim: Examine the prognostic tools for use in advanced incurable cancer and assess their accuracy of survival prediction.

Methods: A systematic review was undertaken. Databases

Poster discussion sessions
Results: Initial search yielded 616 articles. 52 articles met the selection criteria. The prognostic tools identified were the Palliative Prognostic Index (9 studies), D-CAF (12 studies), OECD (2 studies), DCAF-PaP (2 studies), BCI (12/B/39 Index) (2 studies), PPI (Palliative Performance Score) (6 studies), PPS (Palliative Performance Scale) (18 studies), mgPS (modified Glasgow Prognostic Score) (7 studies), and the GPS (Glasgow Prognostic Score) (3 studies). Summary of statistical results for each tool: mgPS HR 1.346 - 2.712; GPS HR range 1.51 - 2.33; D-CAF PaP log range 25.65 - 32.66 and HR 0.214 - 0.56; OECD PaP log range 10.982 - 20.919, HR 0.051 - 0.427; PPI PaP log range 0.73 - 0.814; OECD PaP log range 0.126 - HR 1.12 and log (B12) HR 1.23 on Cox model findings. All 7 tools predicted survival in advanced incurable cancer. The evaluation of the tools within mgPS/GPS tools was also demonstrated in single cancer types, emphasizing versatility and applicability.

Conclusion: The PaP (D-CAF; BCI, PPS, GPS, and mgPS) have been extensively validated in patients with advanced incurable cancer. The heterogeneity of the statistical analysis and study populations means that direct comparison is challenging.

Abstract number: PD 1.7
Abstract type: Poster Discussion

Identification of a Tool to Measure Quality of Life in Paediatric Palliative Care Patients

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Aims: Quality of life (QOL) represents a central evaluation criterion in the care of children. Therefore methods for a reliable and valid measurement of QOL are needed. Multiple-item measurements have the advantage of covering different dimensions, providing a complete profile of QOL. Single-item tools were thought to be a cost effective, easy and less exhaustive alternative to measure QOL. Aim of this study was to identify a useful tool for measuring QOL in children with life-limiting conditions.

Design: This study included 102 children (age range: 9-18 years) suffering from life-terminating diseases and their caregivers. The participants were identified using IMPACT enrol (Craig et al. 2008). The interviews contained multiple item questionnaires (Kindr-R, Kidscreen-27) and two single items.

Results: The correlation coefficient after Pearson was found to be 0.646 between the summed scores of Kindr-R and Kidscreen-27 of the child versions. The scores of the proxy versions of Kindr-R and Kidscreen-27 showed a correlation coefficient after Pearson of 0.67. Dividing the results of the scores into two groups by building one group of low QOL coefficient after Pearson of 0.67. Dividing the results of the versions of Kindl-R and Kidscreen-27 showed a correlation between the child versions. The scores of the proxy version of Kindl-R were divided in two groups by building the correlation coefficient after Pearson of 0.73; BCI (graphic and tabular results) log(B12)b HR 1.23 on Cox model findings. All 7 tools predicted survival in advanced incurable cancer. The evaluation of the tools within mgPS/GPS tools was also demonstrated in single cancer types, emphasizing versatility and applicability.

Conclusion: The PaP (D-CAF; BCI, PPS, GPS, and mgPS) have been extensively validated in patients with advanced incurable cancer. The heterogeneity of the statistical analysis and study populations means that direct comparison is challenging.

Abstract number: PD 1.9
Abstract type: Poster Discussion

Building Research Capacity in a Sub-Saharan Academic Setting: Lessons to Share

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Aims: Few academic services for integrated palliative care team exist in sub-Saharan Africa with minimal evidence of their effectiveness. A key aim of our unit is the establishment of a context-appropriate palliative care team that can develop new and existing researchers and thus increase research activity, publication and enhance the evidence base to provide optimal palliative care for people with CI. Design: Local stakeholders (hospital practitioners, volunteers, NGOs, charity workers) with national and international partners (Ministry of Health, NGOs, Universities) developed a 5 year research capacity building strategy. These included research skills masterclasses and research modules within the Uganda based bSc in palliative care, research dissertations, a national research workshop and a pioneering Advanced Research School. Regular academic supervision is offered and research roles built in to all unit personnel. Grant funding was sought to support these activities.

Results: To date 46 volunteers completed masterclasses, 32 studied the bSc modules, 130 attended the workshop and 25 the Advanced Course, and one PhD is underway. 20 research projects are complete, 21 by new researchers, 12 of whose work has been presented at conferences. The strategy has resulted in a measurable increase in African based research activity.

Conclusion: Building research capacity and integrating an evidenced based approach requires multiple approaches, with medium level capacity building to support the translation of knowledge into further publications, rich collaboration and improved practice. Collaborating nationally, regionally and internationally, research capacity can be supported and result in early increases in research activity. This paper will discuss the development, challenges faced and lessons to share to ensure an effective strategy.

Abstract number: PD 2.2
Abstract type: Poster Discussion

Teenagers’ Advice to the Health Care Staff Caring for Dying Parents of Teenage Children

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Aims: The teenagers describe a variety of advice for the care and support of parents with CI. The AGREE quality score varied from 62%-94%. Higher quality guidelines with more stakeholder involvement in development were more likely to consider people with CI.

Conclusion: Only 2 of 10 European palliative care guidelines were assessed as supportive of stakeholder involvement in people dying with CI. In Europe 7.3 million people have dementia and 1/3rd of people over the age of 65 will die with this disease, national palliative care guidelines should consider this population.

Background: To lose a parent is a traumatic event a child can experience. Little is known about what kind of support teenage children losing a parent to cancer would have wanted from the health care staff. Aim: To investigate cancer patients’ teenage advice to the health care staff caring for dying parents of teenage children.

Method: The study is a part of a nationwide population-based epidemiological study of 622 out of 851 (participation rate 73%) cancer-bereaved youth who lost a parent between the ages of 13 and 16, in 2000 to 2003. Data was collected with study-specific questionnaire 6 to 9 year post-loss. In this paper we investigated the answers to the last question in the survey: Which advice would you like to give the health care staff that encounters teenage family members of parents with cancer? Manifest content analysis was used for the analysis. Results: The teenagers described 21 different advice to the care staff. However, the majority of advice concerns the teenagers’ own need for open, honest and clear information. Some state that the parents are not always able to provide their children with this information and that responsibility should shift to professionals. Answers also touch on how staff should act and that they should do whatever a teenage child who has lost or is about to lose a parent to cancer.

Conclusion: Swedish youths having lost a parent to cancer have given us advice, including clear cut communication about the prognosis in different disease stages and pointing
Factors Associated with Dying at the Place of Wish: A Cross-country Comparison of Cancer Patients with the EURO SENT-MELC Study 2009- 2010

Abstract number: PD 2.3
Abstract type: Poster Discussion

Objective: This study aimed to assess the impact of palliative care on patients’ satisfaction with end of life care from the patients’ point of view. The study was based on a cross-country comparison of cancer patient data from the EURO SENT-MELC study (2009-2010). A total of 1920 deceased patients were identified. Association between 7 factors (age, gender, number of GP contacts, communication about palliative care, GP provision of palliative care, patient’s treatment wishes, patients’ decision making capability) and preference met on place of death separately (excluding hospices) was assessed. All-cause death in a hospital setting during the last week of life was the outcome.

Methods: A mortality follow-back study was undertaken in 2009-2010 via representative nationwide networks of general practitioners (GPs) in Italy (IT, 1,313,868 deaths), the Netherlands (NL, 1,378,171 deaths) and Spain (ES), 33,344 deaths). GPs reported aspects of end of life care of deceased patients weekly on a standardized questionnaire. All-cause death in a hospital setting during the last week of life was the outcome. GPs were recruited from general practice networks in the three countries.

Results: A total of 301 studies were identified. 31 palliative care services were surveyed, from 15 regions across Brazil. On average, 23% of patients were aged 85 or older and 46% of patients were unable to walk, pressure ulcers from immobilization, unable to express verbally; Karnofsky score < 30-40%; age > 75 years (yi).

Conclusions: Therapeutic approach seems not different from younger dementia pts. Knowledge must be implemented to find strategies aiming at reducing hospitalization, modifying approach and increasing quality of life in palliative pts also in acute settings.

Disclosure: There is striking evidence that oldest old dementia pts are still treated in acute wards where therapeutical approach seems different from younger non-sick patients. Further research is needed to evaluate the effectiveness of music therapy interventions for patients with advanced cancer admitted to a palliative care unit (PCU). Study design: Prospective randomized controlled trial. The inclusion criteria: patients with advanced cancer, older than 18 years; Karnofsky performance status of 0 or more.

Introduction: The aim of this review is to synthesise current information and evidence on the use of music interventions to accomplish task-oriented and goal directed use of music interventions to accomplish task-oriented and goal directed.
Background: Most articles on spiritual care in pediatric palliative care focus on single aspects such as the spirituality of the parents or the spiritual quality of life. Other articles show the usefulness of spiritual care in this context. Our aim was to explain the complexity of spiritual care in pediatric palliative care practice.

Method: We analyzed the records of 143 patients from a German specialized outpatient pediatric palliative care unit (SOPPC) between 2004 and 2009. All members of the multidisciplinary team use those records for documentation. Sections are: sociodemographic data, medical report, nursing, social work, and additional information. Although there is no separate section on spiritual care, spiritual, religious, and cultural aspects could be identified throughout the records. The methodology was developed following an IT-based ontology. We collected and structured all data on spiritual, religious and cultural aspects in order to develop a comprehensive concept of spirituality within SOPPC.

Results:
Main topics concern implicit spiritual needs (beyond faith) in relation to culture, concepts of family, understanding of death and nursing problems.
2. The spirituality and spiritual needs of the child may differ from those of the family. Spiritual care interventions address the child, the family or both.

Analyzing cases based on this ontology may help in realizing spiritual care interventions that meet the specific needs of the children and their families: ritual, pastoral counseling, meaningful silence, spiritual guidance.

Discussion: The ontology provides a model to describe the complexity of spiritual care in pediatric palliative care and allows for the integration of spiritual care into current practice.

Abstract number: PD 2.9
Abstract type: Poster Discussion

A Strategic Development Using ‘High’ Facilitation to Implement and Sustain the Gold Standards Framework for Care Homes in 71 NHs across 5 PCTs

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In 2008, St Christopher’s Hospice, UK set up the Care Home Project Team to implement the Gold Standards Framework for Care Homes (GSFCH). The team covered a population of 1.4 million with 71 NHs and consisted of 5.5 FTE clinical nurse specialists (CNSs) funded through local charities. A ‘high’ facilitation model was adopted to counteract the ‘low’ context of care homes.

Aim: To implement the GSFCH and set up a sustainability initiative to: reduce inappropriate hospital deaths; empower NH staff/general practitioners in advance care planning (ACP), Liverpool Care Pathway or equivalent (LCP), and do not attempt resuscitation (DNACPR) orders to improve quality of end of life care.

Methods: CNSs worked across specific areas to build relationships with local NH managers, their general practitioners and local commissioners. Over a 5-year period, all NHs completed the programme. Audit details were undertaken prior to NHs commenced the GSFCH. NH managers were encouraged to join a local sustainability cluster group (7-8 NHs). The groups met regularly and consisted of:
• a palliative care (PC) Induction Day/6 monthly - all new staff (didactic)
• 4-day PC training - nurses/carers (experiential)
• Action learning/6 monthly - NH managers (critical thinking)

Results: Inappropriate deaths in hospital were reduced by 21% across the five PCTs. In 2007/8 prior to commencing GSFCH, 57% residents (n=324) died in 19 NHs undertaking the programme. In 2011/12, across 71 NHs, 78% residents (n=1,351) died in the NH. Similar data is represented in increased use of LCP, DNACPR, and ACP. The team is now fully funded by local PCTs.

Conclusion: Specialist palliative care is in a position to work strategically with NHs to develop high quality EoLC. It requires CNSs, who understand the ‘low’ context of care homes, to develop relationships in order to empower NH staff. Although results are encouraging, it is now important to measure the quality of care during the last month of life.
Poster discussion sessions
Poster sessions – set 1

Pain
Other Symptoms
Assessment & measurement tools
Audit & quality control
Basic & translational research
Bereavement
Education
End of Life Care
Epidemiology
Ethics
Family & Care Givers
Medical Sociology
Organisation of Services
Policy
Psychology & communication
Research Methodology
Non-Cancer
Palliative Care in the Elderly
Palliative Care in Children and Adolescents
Advocacy & Media
Spirituality
Pain

Abstract number: P1-001
Abstract type: Poster

CRPS-I with Neoplastic Origins Treated with Perineural Catheter Placement

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Introduction: Complex Regional Pain Syndrome I (CRPS-I) clinically appears with para-neoplastic manifestations. The clinical case we present, shows results of a female patient affected by CRPS-I associated with recent continuous pain (NRS=8–9), paresthesia, hyperalgesia, perspiration anomaly in the painful area, dyschromia and tremor of the affected limbs. What also makes her story unique is the association with hypothermia of the arm, tremor and dystonia. A neoplastic component became more evident clinically with the patient showing pieling, pin and needles, hyponoalgia, allodynia.

After a therapy with opioids failed, we judged adequate to use PGB 100 mg (pharmacological analgesic technique) for the manifestation of a neurovegetative syndrome, with a severe neuropathic characteristic. An intradermal catheter has been placed in the arm, through the subcutaneous technique. The analgesia obtained with ropivacaine 0,2% after the initial bolus of 3ml has generated the total anesthesia of the harm areas involving both CRPS-I compromised arms and the right hand. The patient reported pain located on the left hand and showed signs and symptoms of CRPS-I associated with recent continuous pain (NRS=8–9), paresthesia, hyperalgesia, perspiration anomaly in the painful area, dyschromia and tremor of the affected limbs. What also makes her story unique is the association with hypothermia of the arm, tremor and dystonia. A neoplastic component became more evident clinically with the patient showing pieling, pin and needles, hyponoalgia, allodynia.

The use of this one drug has increased by more than 21 fold in both early and late opioid switching. Discussion: Opioid switching improved clinical outcome in both early and late groups. Failure of opioid response may be driven by different mechanisms. Use of a randomised controlled trial to examine controlled trials to evaluate the efficacy and tolerability of different opioids for cancer pain. Aims: To explore the circumstances around and results of opioid switching.

A randomised controlled trial of morphine versus oxycodone for cancer-related pain was conducted (n=200). Doses were titrated according to response using the immediate release preparations. Where inadequate analgesia or intolerable side effects persisted, patients were switched to the alternate opioid. Pain Free Response was defined as the proportion of morphine: oxycodone: 2:1 was used in both directions. Pain and adverse reaction scores were recorded at each point of clinical response and non-response.

Results: There were 2 distinct opioid switching types: early switching when pain was uncontrolled and/or intolerable side effects occurred despite dose titration and late switching when an initial good response was subsequently lost. Per protocol analysis showed 50/165 patients required second line opioid switching. Pain Free Response at the point of switching were similar for both early and late opioid switches. Response to second line opioid was similar in both groups. Aims: To determine the prevalence of patients with pain, the development of pharmacological opioid tolerance and the accumulation of metabolites.

Abstract number: P1-006
Abstract type: Poster

The Rise of Oxycodone

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Introduction: Ireland’s opioid consumption is the 8th highest in Europe. However our morphine consumption was 20% lower and our oxycodone consumption was 60% higher in 2010 compared to 2006.

Aim: To report the changes in oral WHO Step III opioid usage from 2000-2011 in a 560 bed Irish teaching hospital.

Methods: Inpatient pharmacy dispensing reports for oral all Step III opioids were reviewed for 2000 and 2011. Results were analysed and compared in terms of percentage change and by conversion to morphine equivalent doses. Results: There has been a 444% rise in Step III opioid usage in Ireland in the past 11 years. The first line sustained release oxycodone peaked at the end of 2000 and 2011 flexed to the oxycodone equivalent of morphine.

Discussion: We review 2 cases of patients who discontinued their opioid medications. There are other studies that have reviewed the patterns of opioid usage in cancer and non-cancer pain patients. There is no difference between morphine and PGB in the first line sustained release oxycodone, including disease progression, change in type of pain, the development of pharmacological opioid tolerance and the accumulation of metabolites.

Abstract number: P1-004
Abstract type: Poster

Hungarian Students’ Fears of Opioids: Results of a Word Association Study and Implications for Interventions

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Aims: Cancer patients and their relatives often fear of opioids which is a major obstacle to the efficient pain control. The direct aim of the study is to gather information on the preconceptions on pain medication by investigating the specific meanings of the word ‘morphine’ among Hungarian students by a specific word association method. The study is one of the pilots of a broader study among cancer patients. The occurrence of cancer in the family was also collected additional information on demographic data, health status, and fears with pain control of the subjects. The occurrence of cancer in the family was also detected.

Results: The answers show mainly negative attitudes towards morphine. The most frequent association was “illegal drug” 81.6% of the subject gave negative associations like addiction, lack of control, lack of relief, harm, death. Only 24.6% of them mentioned more positive associations like ‘pain control’ or ‘relief’. These results were independent from the occurrence of cancer or cancer in the family (Pearson Chi-square=141,25 and 253,25 respectively, n.s.) The presentation gives more detailed analysis of the results. Discussion: We conclude that the institution the author often experience reluctance on the patients’ side to accept adequate pain medication, which is interfere with the professional efforts to alleviate suffering. In order to handle these patients’ and family members’ barriers to pain control, we have to recognize and understand the preconceptions and fears, which - as this study proves - are being formulated long before and independently from the occurrence of cancer in the family. The well established educational programs are needed in this field in Hungary.

Abstract number: P1-005
Abstract type: Poster

Early and Late Opioid Switching Work to Improve Clinical Outcomes

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Background: There is no difference between morphine and oxycodone on a population level, however there is wide individual variation in response within and between these two drugs. Opioid switching is common clinical practice when patients fail to respond to the first line strong opioid. Aims: To explore the circumstances around and results of opioid switching.

Methods: A randomised controlled trial of morphine versus oxycodone for cancer-related pain was conducted (n=200). Doses were titrated according to response using the immediate release preparations. Where inadequate analgesia or intolerable side effects persisted, patients were switched to the alternate opioid. Pain Free Response was defined as the proportion of oxycodone: morphine: 2:1 was used in both directions. Pain and adverse reaction scores were recorded at each point of clinical response and non-response.

Results: There were 2 distinct opioid switching types: early switching when pain was uncontrolled and/or intolerable side effects occurred despite dose titration and late switching when an initial good response was subsequently lost. Per protocol analysis showed 50/165 patients required second line opioid switching. Pain Free Response at the point of switching were similar for both early and late opioid switches. Response to second line opioid was similar in both groups.

Discussion: Opioid switching improved clinical outcome in both early and late groups. Failure of opioid response may be driven by different mechanisms. Use of a randomised controlled trial to examine controlled trials to evaluate the efficacy and tolerability of different opioids for cancer pain.

Abstract number: P1-003
Abstract type: Poster

Pregabalin Withdrawal Symptoms

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Aims: Pregabalin (PGB) is an antiepileptic drug indicated for neuropathic disorders. Given orally in Japan, PGB is approved only for treating neuropathic pain. PGB has been labeled a Schedule V drug with the lowest potential for dependence/abuse. Nonetheless, episodes of breakthrough pain (BTp) in patients treated with PGB have been reported in Japan. Objectives: To evaluate the pharmacodynamic and pharmacokinetic profiles of PGB on healthy volunteers. Methods: We review 2 cases of patients who discontinued PGB and showed unexpected extreme symptoms. Results: Case 1: A 49-year-old man with malignant myeloma was taking 75 mg of PGB once daily with 20 mg oxycodone for neuropathic pain caused by fracture of the 10th vertebra. Because of nausea, he could not take PGB without tapering. Thirty hours later, he developed hyperpyrexia delirium. After administration of PGB (75 mg), the delirium rating scale (DRS) score decreased from 24 to 3. Case 2: A 50-year-old man with renal cell carcinoma and bone metastasis was being treated with sunlinitinib. For leg neuralgia, he received 100 mg of PGB once daily for 28 days with 40 mg oxycodone and acetylaminophen. He discontinued PGB and acetaminophen by himself. Thirty hours later, he felt disoriented and called an ambulance. He developed delirium with fatigue and appetite loss. Restarting of PGB ameliorated most symptoms, and DRS score decreased from 24 to 3. Conclusion: These results indicate that switching from PGB to PGB has generated the total anesthesia of the harm areas involving both CRPS-I compromised arms and the right hand. The patient reported pain located on the left hand and showed signs and symptoms of CRPS-I associated with recent continuous pain (NRS=8–9), paresthesia, hyperalgesia, perspiration anomaly in the painful area, dyschromia and tremor of the affected limbs. What also makes her story unique is the association with hypothermia of the arm, tremor and dystonia. A neoplastic component became more evident clinically with the patient showing pieling, pin and needles, hyponoalgia, allodynia.

The use of this one drug has increased by more than 21 fold in both early and late opioid switching. Discussion: Opioid switching improved clinical outcome in both early and late groups. Failure of opioid response may be driven by different mechanisms. Use of a randomised controlled trial to examine controlled trials to evaluate the efficacy and tolerability of different opioids for cancer pain.
Education of patients regarding pain management can improve pain perception and, consequently, reduce pain intensity. To investigate the effect of education on pain intensity, a multicentre phase 3 study is currently ongoing that randomizes a total of 450 patients between radiotherapy with or without nurse-led education regarding pain management in patients with painful bone metastases (involving one of the 9 most commonly used analgesics: [1-10] a 0-10 numeric rating scale (NRS)). The primary endpoint is pain intensity. Here we report on lack of pain knowledge in patients randomized in the education group.

Patient characteristics, pain intensity (NRS) and patients’ understanding of BTCP and a better knowledge of specific individualized management should be based on a better appropriate pain intensity evaluation. One optimal breakthrough cancer pain depends on frequent and many different BTCP episodes. The successful diagnosis of these episodes was < 30 min for 54.1% of patients, 30 to 60 min for 42.2% and > 60 min for only 3.7% of patients. The mean amplitude of uses of ketamine.

Introduction: Postchemotherapy neuropathy is a common and serious complication of cancer treatment. Chemotherapy-induced peripheral neuropathy (CIPN) is one of the complications of cancer treatment. Neuropathy is a condition that has many causes, because of different mechanisms of action chemotherapeutics agents on nervous system. The symptoms are: numbness, irritation and pain, usually in the extremities. This describes pain as burning, shooting pain with disturbing feeling of touch, warmth and the cold and motor abnormalities. There is no one effective pain relief treatment. The symptoms of this condition are due to altered sense of touch, interpretation, pain perception. CIPN has been classified into three phases: preclinical, clinical and post clinical. The preclinical phase includes patients with a history of chemotherapy treatment but no symptoms of neuropathy. The clinical phase is characterized by the onset of sensory, motor or autonomic symptoms. The post clinical phase refers to the resolution of symptoms or improvement in function. There is a lack of effective treatments for CIPN, and a need for new therapeutic options. In addition, the optimal timing and duration of treatment are not well established. In many cases, the symptoms of CIPN are persistent, leading to significant morbidity and reduced quality of life. The current standard of care for CIPN is based on symptomatic treatment with analgesics, anticonvulsants, and antidepressants. However, these treatments often have limited efficacy and may produce significant side effects. Therefore, there is a need for effective and well-tolerated interventions for the management of CIPN.

Methods: Method of pain management is a major task in palliative care. Patients often experience cancer related pain. Nevertheless, approximately 80% of patients with non-malignant pain such as musculoskeletal and visceral pain. Low-level laser therapy (LLT) is used in physiotherapy for management of non-malignant musculoskeletal pain and visceral pain. LLT has shown promising results in the treatment of pain by reducing pain intensity. However, studies regarding management of non-malignant pain with LLT in a palliative care setting are scarce. The aim of the study was to investigate if LLT can help palliative care patients to reduce non-malignant pain and improve physical functions.

Methods: A single subject experimental design with an ABAB-design was applied.

The first phase (A1): Baseline, no treatment, data collection at 3 times. The second phase (B): Treatment phase, the participants were treated 2-3 times weekly for a total of 5-11 treatments. Data was collected after all treatments. The third phase (A2): Follow-up, no treatment, data collection at 1, 3, 4, 5, weeks and 3 months after the last treatment. Four participants were included in the study and received LLT for different origin of pain, such as fibromyalgia, vertebral compression fracture, arthrosis, neck pain and shoulder pain. Patient Specific Functional Scale and Visual Analogue Scale were used for evaluation. A cluster laser probe, (4 super pulsed 904 nm) was used for all participants. Data was plotted graphically for visual inspection.

Results: Decreases of pain intensity were found in all four participants with a clear change during the phase in which the LLT treatment was applied. Improvements in physical functions were also found indicating that findings affect body function and activity.

Conclusion: The LLT treatment may be a beneficial treatment for managing pain of non-malignant origin in a palliative care setting, but more studies are warranted.
Aims: Methadone is used as an analgesic in palliative care. The evidence base for its use is limited. The complex pharmacology of methadone means that individual responses to it vary, and it can therefore be difficult to titrate. When patients are transferred from another source, there is a lack of consensus over approaches to dose conversion. A supportive audit of regional guidelines on the use of methadone was conducted. An additional survey of healthcare professionals working in palliative care was also conducted to evaluate their perceptions of and confidence in using methadone.

Methods: Healthcare professionals, including doctors, nurses, and pharmacists, completed an internet survey on their attitudes towards the use of methadone. Alongside this, data on the use of methadone was collected prospectively for 7 months. All patients were followed in the initiation of methadone in the previous 12 months. All professional groups recorded an average confidence level of less than 50%.

Results: Of 267 professionals who responded, 42% had experience of using methadone. The fear of addiction and respiratory depression and opioid addiction. Especially the opioid use was hindered by the fear of opioid use due to the addiction and respiratory depression. The questionnaires were returned and evaluated by SPSS 18.0 (Chicago, IL).

Results: One hundred and thirty questionnaires were distributed and 86 were completed and returned back 86 (61%) were male with an average age of 78.7 ± 7.9 years, 74% were experienced with more than 5 years in their profession. The frequency of opioid prescribed was distributed as never in 19.4%, seldom in 25.6%, frequently in 14.5%, always in 24.2% and never in 14.2% (14.2%). For the management of adverse events, laxative use was the only difference, cost was highest in constipation followed by the use of opioids, worry and vomiting. Multiple regression analyses indicate that cancer type and stage, ECOG, pain intensity, and opioid dose were associated with adverse events. In particular, opioid use duration > 6 days was associated with constipation with the odds ratio of 1.67 (1.24-2.6).

Conclusion: This nationwide study evaluated the prevalence of opioid-related adverse events for the first time in cancer pain patients in Korea. As evidenced by the negative impact of adverse events on patients’ daily activities, proper management is critical. Constipation in particular may need a systematic treatment approach where the cause of constipation may be addressed by opioid antagonist since laxatives were ineffective. This study was funded by Mundipharma Korea Ltd.

Abstract number: P-A 01-06
Abstract type: Poster
Meaning of Pain for Patients Living with Advanced Cancer and how it Influences Functional Behaviour: A Qualitative Research Study

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Background: Health related quality of life incorporates physical, psychological, social and existential well-being and is a dynamic, transient process influenced by the following emergent themes:

(i) nature of cancer-related pain,
(ii) multidimensional impact of pain on patients’ function and behaviour

Conclusion: The data suggests meaning of pain has an indirect influence on behaviour, mediated by coping strategies patients adopt, with potential to both constructive and maladaptive responses in functional behaviour. The further exploration of enabling factors and preventing factors of the experience of cancer pain and informing bio-behavioural approaches to pain management. Recommendations include:

(i) tailoring care to address the existential nature of cancer pain with attention to the presence of preparatory grief and (ii) promoting constructive coping strategies to support patients to make sense of their pain and maintain functional independence with the limitations of advancing disease.

Abstract number: P-A 01-17
Abstract type: Poster
Cancer Pain Management in a Northern City of Turkey: Physicians’ Attitudes and Prescribing Practices

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Aim: Although majority of cancer patients experiencing pain can be treated successfully using common interventions, yet many patients complained about the pain. The inadequate management of pain partly lies in the attitude and knowledge of physicians towards pain control. This study aimed to evaluate the opinions, knowledge, and the constraining of physicians dealing with cancer patients towards the pain management especially on opioid use in a Northern city of Turkey.

Materials and methods: The study sample was selected for physicians dealing with outpatients in a second line healthcare facility (the only county hospital). A questionnaire of 9 items were prepared and handed to the physicians. Some of the items included in the questionnaire were the demographic and professional information about the physician, the frequency of opioid use in cancer patients, the fear of opioid use due the addiction and respiratory depression. The questionnaires were returned and evaluated by SPSS 18.0 (Chicago, IL).

Results: One hundred and thirty questionnaires were distributed and 86 were completed and returned back 86 (61%) were male with an average age of 78.7 ± 7.9 years, 74% were experienced with more than 5 years in their profession. The frequency of opioid prescribed was distributed as never in 19.4%, seldom in 25.6%, frequently in 14.5%, always in 24.2% and never in 14.2% (14.2%). For the management of adverse events, laxative use was the only difference, cost was highest in constipation followed by the use of opioids, worry and vomiting. Multiple regression analyses indicate that cancer type and stage, ECOG, pain intensity, and opioid dose were associated with adverse events. In particular, opioid use duration > 6 days was associated with constipation with the odds ratio of 1.67 (1.24-2.6).

Conclusion: This nationwide study evaluated the prevalence of opioid-related adverse events for the first time in cancer pain patients in Korea. As evidenced by the negative impact of adverse events on patients’ daily activities, proper management is critical. Constipation in particular may need a systematic treatment approach where the cause of constipation may be addressed by opioid antagonist since laxatives were ineffective. This study was funded by Mundipharma Korea Ltd.
Family Caregivers’ Beliefs and Barriers to Effective Pain Management of Cancer Patients in Greece

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Introduction: Pain is a common symptom in cancer patients. Nowadays, there is a shift of care from hospital to home that increases the extent to which family caregivers (FC) are involved in pain management (PM). Identifying their beliefs and barriers to PM can improve quality of PM at homecare setting and the cancer patient’s quality of life.

Aims: Perform a reliability and validity study of the Barriers Questionnaire (BQ-II) Greek and describe FC beliefs and barriers to effective PM of cancer patients.

Methods: The study planned as a descriptive and cross-sectional survey of a chart of FC entering PM criteria. They recruited from two regional hospitals and completed BQ-II. Descriptive statistics and frequency distribution were used for responses for all items and Cronbach-a value for the total scale and subscales (Physiological Effects, Familial Caregiver’s Expectation, and Effective T C) tests were conducted to assess relationships between demographic data, previous use of analgesics or patients health status and FC regarding PM. Results: 82 questionnaires were included in the study. Cronbach-a for BQ-II is >0.9.Most of the participants reported that FC provided education on pain and its treatment. They did not report the communication of pain as a factor that distracts doctors from the treatment of the cancer.

Conclusions: BQ-II is a valid and reliable scale for defining FC attitudes and barriers to clinical PM in Greece. Most of their beliefs can act as potential barriers in effective PM in homecare settings. Further education and training of health professionals, interventions targeted to caregivers, establishment of pain centres, recruitment of hospitals with pain management specialists, development of home care teams and a national palliative care plan can change current practices and improve quality of cancer care.

Usefulness of Neurolytic Saddle Block with Intrathecal Dexamethasone for Intractable Sacral Pain due to Bone Metastasis of Rectal Cancer

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Clinical cases: We experienced two cases in which saddle block with combined 0.2mL of phenol and 2mg of dexamethasone intrathecally. After the second approach, his pain was reduced and controlled well with oxycodone 40mg/day without supplemental analgesics.

Conclusions: We can conclude that saddle block with intrathecal combined phenol and dexamethasone might be effective for severe sacral pain due to bone metastasis of rectal cancer.

The Systemic Inflammatory Response and its Relationship to Pain Intensity in Advanced Cancer Patients

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Background: Inflammation has been identified as the 7th hallmark of cancer and is necessary for tumorigenesis and maintenance of the cancer state. Symptoms are also common in cancer patients however little is known about the relationship between symptoms and inflammation in cancer. The aim of the present study was to examine symptoms and their relationship to the inflammation in a large multinational cohort of patients with advanced cancer.

Patients and Methods: A cross-sectional study of multinational cohorts of advanced cancer patients were analysed. Symptoms and patient related outcomes were recorded using the EORTC QLQ-C30. Systemic inflammatory status was assessed using C reactive protein (CRP). The relationship between these symptoms and systemic inflammation were examined using Spearman’s rho (p) correlations and the Moore-Whitney U test. Results: Data were available on 1466 patients across eight European countries, 1215 patients (85%) had metastatic disease at study entry. The median survival was 3.83 months (IQR 1.33–12.17). The following were associated with increasing levels of inflammation: performance status (p=0.179), survival (p=0.347), pain (p=0.154), appetite loss (p=0.026) poorer cognitive function (p=0.137), increasing dyspnoea (p=0.019), increasing fatigue (p=0.019), worsening physical function (p=0.027), worsening role function (p=0.0176), worsening social function (p=0.0132), increasing nausea/vomiting (p=0.019), and increasing abdominal pain (p=0.001). CRP was dichotomised (below/above 11) we obtained almost identical number of highly significant associations. Conclusions: The results show the majority of cancer symptoms are associated with inflammation. Further studies examining the relationship of systemic inflammatory response and the effect on symptoms would be of interest.
Poster sessions

Aim: To assess the clinical benefit of rotation (ROP) to methadone (MTD) as second-line opioid in patients (pts) with advanced cancer and to identify factors of early failure to MTD. Results: 87 pts (< = 28 days post ROP). Material and methods: Prospective study assessing pain on days 3,7,9,14,21 & 28 post ROP to MTD. Pts on MTD & average pain > 4 - < 6 days post ROP. Results: Until now it has included 117 pts (80.7% sample size). Mean age 58 y-old, men 69%. The most frequent co-morbidities were lung 25% & pancreas 14%. Using ECOI-CP98% of pts had a Metastasis with Tramadol SR up to 400 mg. Before MTD ROP pts were on Fentanyl 56%, Oxycodone 18%. Morphine 18%. The mean daily dose of oral morphine before ROP was 200 mg, and the mean after ROP daily dose of oral morphine was 25 mg. The cause of ROP were: poor pain control 81%, opioid toxicity 3%, and both 16%. After ROP pts on the study day 3, 7, 9, 14, 21 & 28 were 96%, 83%, 72%, 61% & 48% respectively. Drop-outs for pain relief assessment (not from MTD) before day 28 happen in 17 pts, 42% clinical worsening or death, 25% for analgesic radiotherapy or invasive analgesia & 33% other causes. MTD Responders to MTD the analysis.

Abstract number: P1-025
Abstract type: Poster

“Is the Whole Thing, it’s Not Just the Pain”. Understanding Pain Control in the Outpatient Head and Neck Cancer Population: A Qualitative Study to Explore the Views of Patients Enrolled in a Proactive Pain Management Programme

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Background: A proactive pain management programme for head and neck cancer patients in the outpatient setting is being evaluated in a large RCT. This qualitative study complements the RCT and aims to explore patients’ views of the programme. Facilitators and barriers to pain control have been explicitly sought.

Methods: Patients’ views of the pain management programme and barriers to pain control were explored using semi-structured in-depth interviews. Patients randomised to the intervention arm of the RCT were sequentially interviewed over a 3-month period. Interviews were audio-recorded, field notes taken and transcribed verbatim. A thematic analysis of the data was conducted.

Results: 6 participants (4 female), from an intervention group of 13 over 3 months were interviewed. Key themes were views on the “screen and treat” system; physical pain was only one component of the cancer experience; significant of head and neck cancer as a visible cancer; societal values prescribed the “total patient” model; specific pain syndromes and barriers to pain control have been explicitly sought.

Conclusions: Patients’ views of the pain management programme and barriers to pain control were explored using semi-structured in-depth interviews. Patients randomised to the intervention arm of the RCT were sequentially interviewed over a 3-month period. Interviews were audio-recorded, field notes taken and transcribed verbatim. A thematic analysis of the data was conducted.

Abstract number: P1-026
Abstract type: Poster

Intravenous Opiate and Ketamine Administration for Rapid Pain Relief in Outpatient Practice

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Background: Detailed case history and physical examination provide a good opportunity to establish the main components of cancer pain generally. However, in a complex situation or in the case of collaboration problems, it may be very difficult to quantify the role of certain components. Tricyclic antidepressants and anticonvulsant drugs have delayed start of action and have many adverse effects, so in the case of diagnostic uncertainty, their ex juvantibus administration is unavoidable. The aim of the current study was to evaluate a method of rapid titration with intravenous morphine, fentanyl and ketamine to achieve rapid pain relief in outpatient settings.

Methods: During a one-year period rapid intravenous titration was performed in 35 cases in a prospective manner. Pain was evaluated on a numeric scale of 0-10. In severe pain situations 0,5 mg/ml morphine or 5 ug/ml fentanyl solution was titrated slowly at 1 mg/min or 10ug/min, respectively. Over 10 mg morphine, there was a waiting period up to 5 minutes (80%). After diminishing the prominent, dull pain, an intravenous ketamine titration was performed with 0,5 mg/ml solution at 1 mg/min, if it was necessary.

Results: The rapid titration was performed on 28 cancer patients in 35 cases. Pain was totally stopped in 19, and was significantly diminished (< VAS3) in 16 cases. In 5 cases results were insufficient or uncertain, because of inadequate communication. Adverse effects were observed in 9 cases (severe pruritus, which were of short and short lasting. The intravenous tests helped to determine the ratio of nociceptive/neuropathic components and the measure of opioid dose escalation.

Conclusions: Intravenous opiate-ketamine test is a safe and effective method to relieve severe, complex cancer pain rapidly in outpatient settings. It may also help to pain analysis and the measuring of opioid dose escalation.

Abstract number: P1-027
Abstract type: Poster

Unsolved Problems of Pharmacotherapy of Chronic Pain in Cancer Patients in Kazakhstan

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Every year more than 30,000 people are taken to the dispensary registration with newly diagnosed malignancies in Kazakhstan. It affects 0.7% of the population of the country. The purpose of the study - to realize the right of incurable cancer patients anesthetist.

Methods: Analysis in pain therapy, the development of optimal tactics treatment of chronic pain in cancer patients with the WHO recommendations.

Results: Kazakhstan has not yet a regulatory framework for effective treatment of cancer patients with chronic pain. Code of the Republic of Kazakhstan on the people’s health and the health care system Article 91 “Patient’s rights” states that patients have the right to “alleviate the suffering to the extent which is allowed with the current level of medical technology”. The list of required narcotic analgesics and adequate standards for their distribution were developed and approved by the Ministry of the Republic of Kazakhstan. But the Republican drugs formulary has only 5 kinds of 30 drugs used in Europe and North America. Of the most powerful analgesics, short-only injectable drugs are available in Europe and North America. Introduction of non-injectable drugs appeared tramadol drops and tablets. Among sustained release formulations fentanyl transdermal therapeutic system and fentanyl dermal patch.

Kazakhstan has free provision of narcotic analgesics for cancer patients. But there is a very complex multi-system diseases and general condition. Ketamine's highly lipophilic nature and multi-step metabolism allows it to be administered by parenteral, oral, topical and buccal routes. Ketamine has shown clinical efficacy in a number of pain syndromes including acute pain, malignant bone pain, topicaly in severe mucositis and painful vascular ulcers, as well as an adjuvant to context of pain control and cancer settings. High-quality randomized studies have been lacking. However, a research group recently reported on a placebo-controlled randomized trial that concluded that ketamine did not have a net clinical benefit, specifically in the treatment of cancer pain.

Concluding evidence, the use of ketamine in specific pain syndromes has been lacking. Ketamine is a dissociative anesthetic with unique pharmacological properties. It has an activity as NMDA-receptor antagonist and associated effects on a variety of other receptors. Ketamine’s effects at the NMDA receptor have generated intense interest as a way to reduce opioid tolerance and central sensitization. Thiourea features are commonly seen in patients with a variety of difficult to control pain syndromes, including neuropathic pain syndromes. Ketamine’s high in the 3-4 min and in 2% of cases mild side-effects were observed such as palpitation, slight fever, nausea, skin rash, fatigue.

Ketamine and its metabolites should be titrated (adjusted) in pts with chronic cancer pain. SLF had rapid onset and was highly effective in BTcP SLF were immediately titrated to MTD started. In 2% of cases mild side-effects were observed such as palpitation, slight fever, nausea, skin rash, fatigue.

Results: ATC in BTcP was highly effective (up to 80%) was observed (80%). Before taking SLF pts always rinsed their mouth with water.

The most common dosage of SLF was 200 mcg (41.2%). In 91% of cases SL-Fab was used. In 2% of cases mild side-effects were observed not influencing considerably the quality of life (QoL) and more linked with the concurrent diseases and general condition.

Abstract number: P1-028
Abstract type: Poster

Ketamine’s Role in the Palliative Care Armamentarium: New Questions and Directions

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Objectives: 1. A new current evidence for the use of ketamine as an analgesic agent in a variety of pain syndromes. 2. Discuss the practice implications of recent data casting doubt on the role of ketamine in the treatment of cancer pain 3. Identify future research directions regarding the use of ketamine in specific pain syndromes.

Ketamine is a dissociative anesthetic with unique pharmacological properties. It has an activity as NMDA-receptor antagonist with associated effects on a variety of other receptors. Ketamine’s effects at the NMDA receptor have generated intense interest as a way to reduce opioid tolerance and central sensitization. Thiourea features are commonly seen in patients with a variety of difficult to control pain syndromes, including neuropathic pain syndromes. Ketamine’s high toxicity and in the 3-4 min and in 2% of cases mild side-effects were observed not influencing considerably the quality of life (QoL) and more linked with the concurrent diseases and general condition.
Ketamine and Uncontrolled Cancer Pain: Experience of a Palliative Care Unit

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Introduction: Almost 80% of patients with cancer experience moderate to severe pain and 80 to 90% of these have controlled pain with standard analgesic therapy following the analgesic ladder of the World Health Organization. Ketamine seems to have a significant impact as an analgesic adjuvant in this context especially with neuropathic pain syndromes that are poorly controlled by opioids.

Objective: To assess the effectiveness of ketamine use in this palliative care unit and discuss its limitations.

Design: Retrospective study including inpatients treated with ketamine for severe pain, over a 32-month period at a tertiary palliative care unit.

Results: We included 13 patients, 3 of them treated with ketamine more than once, corresponding to a total of 16 evaluations. All patients had uncontrolled severe pain, 75% had both nociceptive and neuropathic pain and 25% presented with opioid toxicity. Before starting treatment with ketamine, the medium dose of oral morphine equivalent dose of ketamine was 150 mg/kg and median age was 70 years. Pain scores were reduced in all patients, the MCOED was reduced in 13% of them and the number of readmissions in 3%. The median time to loss of consciousness was 24 hours after the ketamine was introduced. Mean time of survival after ketamine introduction was 38 days. Conclusions: Uncontrolled severe pain was considered as an analgesic adjuvant for patients with severe pain, although with little impact on opioid dose reduction and a significant rate of side effects. It may be considered as an option when opioid dose is limited or over time with other standard analgesics options have failed.

Other Symptoms

Abstract number: P1-032
Abstract type: Poster

Providing an Ultrason Guided Paracentesis Service in the Community Setting

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Background: A significant number of patients with advanced cancer develop ascites. If drainage is needed (necessarily to palliate distressing symptoms) then admission to hospital is usually required. We have developed a community paracentesis service to avoid unnecessary hospital admission and support choice in place of care. This is especially important to our patients due to the rural area in which we work. To ensure patient safety we use ultrasonography to identify the paracietic fluid before proceeding comprehensive guidelines and a care plan.

Method: Electronic notes were examined for patients who had a complication or a significant event over a 12-month period since the service started.

Results: 8 patients (6 female) had at least 1 complication. 5 had an anaesthetic complication, 2 had a complication related to the site of the needle insertion, 1 had an infection and 1 patient died in acute respiratory distress.

Conclusion: Providing an effective community paracentesis service is possible. In total 15 hospital admissions were avoided. This has significant implications for patient choice as well as potentially reducing costs. We would suggest that this also facilitated patients dying in their place of choice. There is increasing emphasis on palliative care services in the community and this is supported by national policy. In addition we give IV bisphosphonates and blood transfusions in the community setting and we aim to continue to develop these services in the future.

Abstract number: P1-033
Abstract type: Poster

Palliative Management and Survival of Advanced Hepatocellular Carcinoma (HCC)

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Background: HCC is the fifth most common cancer worldwide, and its incidence will further increase. There is little information in the literature on the final stage of this neoplasia and its control by palliative care teams.

Objective: Our aim was to evaluate the clinical profile of terminal HCC and its survival.

Methods: Retrospective and descriptive study of patients referred to our Palliative Care Service between January 2010 and April 2012 based on demographic, clinical and survival data registered in the medical record.

Results: A total of 45 patients were analyzed. 82.2% were men. Mean age was 70 years. All patients had liver cirrhosis. The most frequent antecedent of hospitalization was decompensation of the disease achieving an adequate relief of symptoms.

Conclusion: It is important to take into account this metabolic complication with regard to the proper management of the relief of symptoms and the significance of the hypocalcemia and its relationship in the use of bisphosphonates in patients with advanced prostate cancer.

Abstract number: P1-034
Abstract type: Poster

Hungry Bone Syndrome Related to Prostate Cancer: A Case Report

Alfaro H.1, Fanjul C.2, Obledias L.3, Forgás D.1, Planas J.1, 1Pathology & Laboratory, Hospital de Espejuel, Parc de Salut Mar, University of Barcelona, Genitourinary Department, Barcelona, Spain, 2Pathology & Laboratory, Hospital de Espejuel, Parc de Salut Mar, Department of Medical Oncology, Barcelona, Spain

Introduction: Hungry bone syndrome is clinically characterized by the persistent occurrence of bone uptake that produces hypocalcemia. It is a rare metabolic complication that can occur in osteoblastic metastases in prostate cancer, and can make it difficult the symptom management at the end of life.

Aim: The aim of presenting this case report is to reinforce the importance of treatment of hypocalcemia in patients with osteoblastic metastases of prostate cancer in order to improve their quality of life and to allow the control of symptoms.

Method: We report a patient who was admitted to the palliative care unit diagnosed with prostate cancer and osteoblastic metastasis. He was treated after 24 hours with recombinant human parathyroid hormone and zoledronic acid treatment. The patient presented hungry bone syndrome due to disseminated osteoblastic metastasis. Zoledronic acid treatment was removed. He was initially treated orally with calcium carbonate (1500mg per day) and calcitrol (1 mcg a day). As it was not effective, the patient was treated later with venous infusion of calcium gluconate (0.5mg/kg/h), during about one month.

Results: Hypocalcemia symptoms were prevented and calcium levels were improved, although it was unable to obtain normal serum calcium levels although treatment was continued. The patient died due to progressive complications of the disease achieving an adequate relief of symptoms.

Conclusion: It is important to take into account this metabolic complication with regard to the proper management of the relief of symptoms and the significance of the hypocalcemia and its relationship in the use of bisphosphonates in patients with advanced prostate cancer.

Abstract number: P1-035
Abstract type: Poster

Hungry Bone Syndrome Related to Prostate Cancer: A Case Report

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Conclusion: It is important to take into account this metabolic complication with regard to the proper management of the relief of symptoms and the significance of the hypocalcemia and its relationship in the use of bisphosphonates in patients with advanced prostate cancer.
Abstract number: P1-036
Abstract type: Poster

Effectiveness of Anticonvulsant Prophylaxis in People with Brain Neoplasms: A Limited Systematic Review

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Aims: Seizures occur in at least 30% of people with brain neoplasms, according to tumor type, location and size. Antiepileptic drug (AED) prophylaxis has been proposed to prevent these events. However, little is known on its actual effectiveness in people with primary or metastatic brain neoplasms.

In 2000 the American Academy of Neurology (AAN) evidenced that prophylactic AEDs are commonly used in patients with brain neoplasms. The aims of the study are to identify and appraise evidence of AED prophylaxis effectiveness on seizure occurrence in previously seizure-free adults with brain neoplasms.

Methods: Databases MEDLINE, EMBASE, PUBMED, CENTRAL, were searched on March 2012 for randomized and non-randomized controlled trials and cohort studies comparing two AEDs or an AED versus placebo or nothing. Citing papers were searched by Google Scholar.

Papers were screened and data extracted to a predetermined form. Risk of bias was assessed. Level I (randomized controlled trials) and level II (from observational cohort studies) evidence were to be defined.

Results: 1759 records were identified, 18 underwent data extraction. Our search excluded two papers. The postoperative time no evidence of prophylactic AED effectiveness was found.

Conclusions: The role of AED prophylaxis in brain tumor patients is still unclear. AAN guidelines and Cochrane review found no significant evidence of their effectiveness.

In the last five years no randomized controlled trials addressed this issue. Further research is needed to assess who, when and how can benefit of AEDs for preventing seizure occurrence.

Abstract number: P1-037
Abstract type: Poster

A Feasibility Trial to Assess the Use of Physical Activity to Mitigate Cancer Related Fatigue and Improve the Quality of Life in Terminally Ill Advanced Cancer Patients in Brazil: A Preliminary Report

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Objectives: To pilot study to test feasibility and efficacy of physical activity for reducing fatigue and quality of life in patients with advanced cancer at the end of 4 weeks and evaluate patient satisfaction with the physical activity intervention.

Methods: This ongoing clinical trial, all advanced cancer patients presenting with fatigue ≥ 4/10 in a 0-10 scale Edmonton Symptom Assessment Scale (ESAS) were eligible. As per protocol, all patients performed a 10-minute walk and exercises for the upper limbs with 1-lb dumbbells, five sessions a week, during 4 weeks. The quality of life questions ESAS, EVA, ECOG and ESAs are filled out at the beginning, in the end of the 2 weeks and in the end of 4 weeks, the satisfaction scale PGIC (Patients’ Global Impression of Change scale) was assessed at the end of the study.

Results: To date, 14/10 eligible patients were enrolled in the study. 6 completed the 4-week intervention. Of those who completed, 3 patients were below 60 years, 2 had a head and neck cancer and 80% performance status. There was a 1

point improvement in the average ESAS fatigue items scores at D1 and D20 time points. The average EORTC QLQ C-30 showed an improvement of 12.5 points compared to the baseline. In terms of the quality of life, all the 6 patients, 3 patients pointed the item “Better, and a definite improvement that has a real effect and worthwhile”, in the PGIC questionnaire.

Conclusion: According to the preliminary results of the study, physical activity intervention resulted in improvement of fatigue and quality of life in patients who completed the study. Further feasibility studies of various types of exercise interventions are needed.
thoracentesis is recommended as the first drainage procedure for symptom relief. In patients that recur after thoracentesis, chest tube drainage and pleurodesis are recommended. In patients with symptomatic SVC obstruction due to SCLC, chemotherapy is recommended and in patients NSCLC, stent insertion and/or radiation therapy. Mediastinal masses are also recommended for symptomatic patients obstruction who fail to respond to treatment. Non cancer patients with a malignant transesophageal fistula and bronchoesophageal fistula, stenting of esophagus, airway, or both should be considered for symptomatic relief.

Abstract number: P1-042
Abstract type: Poster

Palliative Endobronchial Treatment in Patients with Endobronchial Growth of Malignancies and Respiratory Symptoms

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Aim: Patients with endobronchial growth of malignancies are more likely to have significant dyspnea, hemoptysis, K/R, cough and require urgent therapy. Palliative bronchoscopy plays a major role in the patient's therapy.

Methods: 165 patients underwent 281 endobronchial therapeutic procedures. All procedures were performed under local anesthesia. We wedged videobronchoscope through rigid bronchoscope. According The American Society of Anesthesiologists (ASA) physical classification was 55% patients ASA III and 45% ASA IV. The therapeutic endobronchial procedure was done in 137 patients with endobronchial NSCLC, in 12 patients with endobronchial SCLC, in 6 patients with endobronchial metastases of melanoma, in 3 patients with endobronchial metastasis of renal cancer, in 7 patients we started with endobronchial treatment before the morphological diagnosis. We started with the endobronchial treatment because dyspnea in 100% patients in 55% patients was described as very severe, in 45% patients as severe, in 12% hemoptysis, in 2% pneumonia. During and after procedure we controlled oxymetry, electrocardiography, blood pressure.

Results: During and after procedures we observed in 28% patients hypoxemia, in 23% hemoptoeza > 250 cm³, in 10% arhythmias, in 9% patients we observed hypertension and in 2% patients developed after procedure respiratory failure and both patients were 24 hours on invasive ventilation. Two patients died due complications after procedure. Any complications we observed in 40% of all procedures. The procedure localization was in 95% patients, the difference in the number of complications in patients with ASA III and with ASA IV was not statistically significant (p=0.0007).

Conclusions: Endobronchial treatment (electrosurgery and laser bronchoscopy) is palliative therapeutic procedure with adequate and significant improvement in patients with endobronchial growth of malignancies and in patients with ASA classification III and IV.

Abstract number: P1-043
Abstract type: Poster

Symptom Profile in the Last 7 Days of Life among Cancer Patients Admitted to Acute Palliative Care Units

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Aim: The symptom burden in the last week of life of cancer patients has not been well characterized. We documented the frequency, intensity, and predictors for 25 symptoms in the last 7 days of life among patients admitted to acute palliative care units (APCU).

Methods: We systematically documented the Edmonton Symptom Assessment Scale (ESAS) daily and 15 other symptoms daily on consecutive advanced cancer patients admitted to APCU at 2 Tertiary Care Cancer Centers from admission to death in 2010/2011. Data were only obtained when patients were able to provide patient-reported outcome measures. We determined the frequency and intensity of the symptoms from death backwards, and determined the predictors of ESAS scores <4 using a multivariate generalized estimating equation model.

Results: A total of 203 of 357 patients died. The proportion of patients able to provide patient reported outcomes decreased from 80% to 40% over the last 7 days of life. ESAS anorexia (P=0.001 for longitudinal analysis), drowsiness (P=0.001), fatigue (P=0.001), dyspnea (P=0.001), vomiting (P=0.001), fatigue (P=0.001), dyspnea (P=0.001) increased in intensity closer to death. In contrast, depression (P=0.006) decreased over time. Dysphagia to solids (P=0.01) and liquids (P=0.005) and urinary incontinence (P=0.002) were also present in an increasing percentage of patients in the last few days of life. In multivariate analysis, female sex was associated with more nausea (odds ratio [OR], 95% confidence interval [CI] 2.9, 1.7 7.7), drowsiness (2.8, 1.4 5.4) and anorexia (2.1, 1.43-3.3), vomiting (2.7, 1.2 6.1), dizziness (6.3, 2.7 16.7), poor well being (2.4, 1.2 4.5), dyspnea (2.5, 1.3 4.7) and insomnia (5.9, 2.9 12.5), and lung cancer was associated with higher expression of dyspnea (7.7, 2.5-25).

Conclusions: Depression and fatigue among APCU patients, cancer patients frequently experience high symptom burden as they approached death.

Abstract number: P1-044
Abstract type: Poster

How Is Depression Classified, Assessed, and Reported in Terminal Cancer Care Patients? A Systematic Literature Review

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Methods: The American Society of Anesthesiologists'(ASA) physical classification was 55% patients ASA III and 45% ASA IV. The therapeutic endobronchial procedure was done in 137 patients with endobronchial NSCLC, in 12 patients with endobronchial SCLC, in 6 patients with endobronchial metastases of melanoma, in 3 patients with endobronchial metastasis of renal cancer, in 7 patients we started with endobronchial treatment before the morphological diagnosis. We started with the endobronchial treatment because dyspnea in 100% patients in 55% patients was described as very severe, in 45% patients as severe, in 12% hemoptysis, in 2% pneumonia. During and after procedure we controlled oxymetry, electrocardiography, blood pressure.

Results: During and after procedures we observed in 28% patients hypoxemia, in 23% hemoptoeza > 250 cm³, in 10% arhythmias, in 9% patients we observed hypertension and in 2% patients developed after procedure respiratory failure and both patients were 24 hours on invasive ventilation. Two patients died due complications after procedure. Any complications we observed in 40% of all procedures. The procedure localization was in 95% patients, the difference in the number of complications in patients with ASA III and with ASA IV was not statistically significant (p=0.0007).

Conclusions: Endobronchial treatment (electrosurgery and laser bronchoscopy) is palliative therapeutic procedure with adequate and significant improvement in patients with endobronchial growth of malignancies and in patients with ASA classification III and IV.

Abstract number: P1-045
Abstract type: Poster

Efficacy of Aromatherapy on the Sleep Disturbance of Terminally Ill Cancer Patients

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Background: Reported prevalence rates of depression in palliative care (PC) patients vary from 3-58%. This may be due to selection of patients to the study, study design, and lack of using standardized tools to assess and assessment of depression. To understand the population, key variables need to be presented.

Aim: To examine how depression is classified and assessed, and which clinically relevant variables are reported in order to perform the patient population in clinical studies of depression in PC cancer patients.

Methods: A systematic search using the Mesh terms “depression” and “cancer” and terms covering “palliative care” was performed in Medline, PsychINFO, EMBASE, and CINAHL, covering 2007-2011. Clinical studies in PC cancer patients with depression as the primary outcome were included. Titles and abstracts were screened, and relevant full text papers were evaluated for inclusion by two readers independently.

Results: After deletion of duplicates, 916 citations were screened and 65 papers included for further investigation. The term ‘depression’ and ‘cancer’ was used interchangeably as a diagnosis and to describe depressive symptoms. Depression was diagnosed according to a classification system in 17 papers (26%), the DSM-IV in 15 studies, and ICD-10 in two. Clinical interviews were used for assessment in 15 of these 17 studies, while two provided no information on assessment method. Self-report questionnaires on depression were used in 62 studies. Use of antidepressants was reported in 11 studies (17%). Duration of the present depressive episode was assessed in three studies (4%), while information about prior depressive episodes was reported in 13 (20%).

Conclusion: Standardised classification systems for diagnosing depression in clinical studies were rarely used. Assessment methods varied considerably, and specific clinical infirmities related to depressed well-beings was seldom reported. This calls for a standardisation when investigating depression in PC.

Abstract number: P1-046
Abstract type: Poster

Doctor Does your Patient Rattle? Respiratory Tract Secretion Prevalence and the Use of Clinically Assisted Hydration in Palliative Patients in an Acute Hospital Setting

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Background: Respiratory tract secretions (RTS), or the ‘death rattle’, are one of the most common symptoms in terminal care, affecting a mean of 44% of patients in studies of predominantly cancer patients in hospitals. Despite control with anti-mucus is a goal in the Liverpool Care Pathway for the Dying Patient (LCP), the latest version of which put renewed focus on the role of clinically assisted hydration (CAH). Although the majority of patients die in hospital there is limited evidence on the prevalence of RTS and current practice regarding CAH in palliative patients in a hospital setting compared to cancer patients in hospices. Aim: To identify in a palliative setting in an acute hospital setting the prevalence of RTS and current practice regarding CAH in palliative patients in a hospital setting compared to cancer patients in hospices.

Methods: A retrospective case note review of 100 patients who died in hospital or in palliative care wards (PC). Patients were recruited from 3 main sources – set 1

Poster sessions
Quality of Life and Symptoms in Patients Admitted to a Comprehensive Cancer Centre

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Introduction: Quality of life (QoL) and symptomatology in patients with malignancies admitted to comprehensive cancer centres are rarely investigated. Thus, this study aimed to investigate QoL and symptoms of inpatients at the admission day of haematology and oncology.

Methods: Cross-sectional study, in which 124 cancer inpatients were assessed in May/June 2011. Collecting data was conducted in eight wards in two rounds of five days. No patient was included twice. Inclusion criteria: Age ≥ 18 years. Exclusion criteria: absence at assessments, not to complete the questionnaires, or not to give informed consent. Descriptive data, demographic data and health-related quality of life (EORTC QLQ-C30) were assessed. EORTC QLQ C30 consists of 35 items evaluating health-related quality and symptoms in physical, role, emotional, cognitive, social, global health status/quality of life, fatigue, nausea and vomiting, and pain. Scores were calculated according to the EORTC QLQ C30 scoring manual. Comparisons were analyzed using Wilcoxon two-sample, rank tests, and Fisher’s Exact test.

Results: 124 patients were analysed, mean age = 59 (SD =13.7), 42% admitted to haematological department (14% had algogenic stem cell transplantation), lung cancer was the most frequent diagnosis (15%). Role functioning scale was the most severely impaired (mean score=35), whereas cognitive function showed the best score (mean=70). The median EuroQoL global health score was 43 (IQR=25.6). The symptom burden of the inpatients was strikingly severe and especially fatigue and appetite loss were pronounced. In addition, social functions appeared to be more impaired in haematology patients than in those admitted to oncology (P=0.0372 and 0.0167, respectively).

Conclusions: Inpatients of a comprehensive cancer centre had low quality of life and a severe symptom burden. Fatigue and appetite loss were the most severe symptoms reported.

Abstract number: P-1-050

Abstract type: Poster

The Influence of Distressing Symptoms to Levels of Depression in Cancer Patients

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Research aims: To identify the frequency of reported depression by severe distressing symptoms in younger cancer and geriatric outpatients. Moreover, to assess the associated symptoms of cancer using the MDASI and to evaluate the screening performance of depression between MDASI and IDQ for younger patients and GDS for the elderly.

Study design and methods: 162 advanced cancer patients (group A: patients <65, group B: patients ≥65) attending a palliative care unit, took part in this open-label prospective trial with two parallel groups. The instruments that have been used were the Geriatric Depression Scale (GDS) for geriatric patients and the Greek M. D. Anderson Symptom Inventory (MDASI) for the severity and impact of cancer-related symptoms.

Results: A significant correlation was found between the GDS and MDASI total score (p=0.038). For increased sadness (p=0.001), increased constipation (p=0.021), interference of symptoms in mood (p=0.032) and in relationship with people (p=0.007) while interference of symptoms in mood was the most important risk factor for younger patients, many statistically significant associations were found between distressing symptoms and depression, however, interference of symptoms in mood (p=0.045) was the only significant risk factor.

Conclusions: With aging, functional status is affected and especially in patients with cancer the effects of the disease and its treatment may develop multiple symptoms and an assessment and management of these symptoms is required and more research will be beneficial for the best care of the geriatric patients in advanced stages of cancer. Health-care professionals should take into consideration the risk factors for depressive symptoms suggesting a holistic care in advanced cancer patients.

Abstract number: P-1-051

Abstract type: Poster

The Effect of Artificial Hydration Therapy in Terminally Ill Cancer Patients with Overhydration Symptoms Based on the Guideline for the Use of Artificial Hydration Therapy in Terminally Ill Cancer Patients (Published by the Japanese Society for Palliative Medicine, JSPM)

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Aim: Recently, there has been a growing interest in the use of artificial hydration therapy (AHT) for terminally ill cancer patients who are bedridden. The guideline for the use of artificial hydration therapy (GL) was published by JSPM in 2007. However, there still remains some discrepancy over the use of AHT in this stage depending on the physicians’ personal opinion and experience. Our aim was to define the effects of artificial hydration therapy for the alleviation of various symptoms and QOL.

Methods: Our hospital is certified as a specialized cancer center that has a 30-year history of providing palliative care. Of the terminally ill cancer patients who were transferred from other hospitals to undergo palliative care over the last 18 months, 74 patients were admitted. Moreover, to assess the associated symptoms of overhydration we used MDASI and EORTC-Q30 to compare values measured before and after the treatment.

Results: Symptoms of overhydration except for dyspnea and general QOL scores significantly improved after performing AHT based on the GL (p=0.05). Concerning dyspnea, no significant difference was observed by the single use of AHT; however, the concomitant use of drugs, such as antibiotics and anticholinergic agents, was effective in alleviating symptoms.

Conclusion: The provision of appropriate AHT based on the GL contribute to alleviate overhydration symptoms and improving QOL in terminally ill cancer patients.

Abstract number: P-1-052

Abstract type: Poster

Lessons Learned from Recruiting Palliative Care Patients to a Clinical Trial

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Aim: To describe recruitment patterns to a palliative care randomised controlled trial (RCT), as this area of recruitment can be challenging.

Methods: A Phase III pragmatic single-blind fast track RCT, of a new breathlessness support service (BSS) joint between palliative care and respiratory teams to support breathless people with advanced disease, who were often not referred to palliative care. Analysis of recruitment: patient identification, response rates and reasons for refusal. Results: 212 patients were referred, of which 193 met the inclusion criteria, of these 101 consented (59 men). Diagnoses: COPD 124 referred (55 consented), Cancer 37 (18), Interstitial lung disease 33 (20), chronic heart failure 12 (6), Asthma 3 (1), other 3 (1). Attrition rate for the primary endpoint (6 weeks) is approximately 20%, less than 10% as anticipated. Of the 92 patients that were not consented 45
were uncontactable, 29 refused to participate, 18 were too
old, and 13 did not wish to participate. In total, 96 persons
came to the study or caring for patients who experienced the service and
were unable to complete the validations data.
Background: Careful symptom assessment is paramount
to guarantee effective symptom control for palliative care
patients. The German version of the ESAS, MIDOS, has been
designed to provide a new self-assessment instrument for the
evaluation of the symptom burden of patients. In this study patients
not receiving palliative care as well as healthy probands were
asked to answer the MIDOS questionnaire, allowing
differentiation between these groups and palliative care
patients and in order to complete the validations data.
Methods: Data was collected from December 2011 until June 2012. Four groups were recruited: chronic pain
patients, oncological patients, patients treated by a general
practitioner and medical students of University Bonn. These
persons completed the MIDOS- and the quality of life
questionnaire SF-12.
Results: Until June 105 medical students (35 women,
39 men; age 22-40 years), 45 general practitioners
(56% women, 43% men; age 19-28 years), 60 oncological
patients (37% women,63% men; age 22-86 years)
and 59 chronic pain patients (52.5% women,47.5 men;
age 27-74 years) took part in the survey. The highest
symptom score was 30.
Mean symptom scores differed significantly between
groups, with higher scores for chronic pain patients=7.94 (range
0-17) compared to oncological patients=6.60 (range
0-17) and G.-P. patients=4.19 (range 0-19).
Students scored lower with mean symptom score of 1,7
(range 0-9).
Conclusion: Comparing the mean symptom scores of our
probands to the palliative patients of the MIDOS’ study 2010
(range 0-19) all groups showed - as expected - a lower symptom burden. This confirms the
ability of MIDOS as a self-assessment instrument to describe
the specific burdens of palliative patients.

Palliative Treatment of Patients with Dysphagia and Malignant Stenosis of the Esophagus
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Introduction: Larynx cancer is the second most frequent
cause of malignant esophageal stenosis, which is caused
by either direct invasion of, or by extramural pressure
against, the esophageal wall. Esophageal stenosis reflects an
advanced stage of the single-coil disease of the esophagus.
It is associated with high weight loss, a decrease in
performance status and poor prognosis. Nadgostchai, probe,
percutaneous endoscopic gastrostomy and stent placement
are palliative procedures improving patients’ performance
status, quality of life and food intake during palliative
treatment of advanced malignant disease.
Background: We present case reports of two patients with
esophageal stenosis and dysphagia due to the expansion of a
lung tumour. The patient No.1 developed swallowing
disorder during chemotherapy. Esophageal stenting was

intervention. Main organisational problems relate to
transport to the BSS and patients being unwilling to attend the
second clinic visit.

Nutritive Support - The Inexorable Part of Complex Oncological Treatment
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A cachexia and an unlimited need of weight are mainly
the result of metabolic changes in an oncological patient’s body.
The weight loss is used as an independent survival indicator.
It is known that 5% loss of weight can already decrease the
response to oncological treatment. There are 16 patients
with metastatic and 15 patients with locoregionally
advanced stomach tumours. Their weights when they were
admitted were 77 kg (56-95) and their food intake was 60
70%. The loss of weight before oncological treatment was 8
%(3-24%). Patients already have digestion problems before
being admitted to our hospital, the time period from
making the diagnosis to being admitted to our department
was 3 months. The set of 5 patients has been treated
systematically. Only 4 patients in the entire set were
graded by full planned oncological treatment, 22 patients had
to reduce chemotherapy doses, postpone or stop the
advice and nutritive support before they start the planned
oncological treatment, preferably right after the diagnosis
of their tumour disease is made. It is undesirable to focus on
an individual patient’s treatment when the present nutritive
and functional state, possibly slow down an irreversible
worsening of this state, improve or maintain the quality of
life and respect patient’s wishes simultaneously. The
assessment of presumptive oncological patient’s prognosis
does not only depend on the natural progress of tumour
disease. The quality of complex supporting care and
especially the way how nutrition is ensured influences the
assessment strongly.

Pleuradosis as a Palliative Treatment for Malignant Pleural Effusion
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Background: Malignant pleural effusion is characterized by
the presence of malignant cells in the pleural fluid or by
the evidence of tumour tissue obtained directly from the pleura.
It is mostly associated with malignant tumours of lung and
breast. About 15% of patients are asymptomatic at the time
of diagnosis of malignant pleural effusion. Patients with
a massive pleural effusion tend to suffer from dyspnea, chest
pain, dry cough or nausea.
Pleuradosis is a palliative therapeutic procedure whose aim is
to preclude the formation of fluid between parietal and
visceral pleura in symptomatic patients where
chemotherapy is not an option or has failed.
Aim and methods: A retrospective analysis was performed of
the patients hospitalized with pleural effusion to the
Department of Pulmonary Dis. and TB between
October 2011 and October 2012. Malignant lung tumour
was diagnosed in 27 of them (38%). The malignant origin
of pleural effusion was proved only in 13 patients (42%).
Results: Pleuradosis was performed in 4 patients; in the
remaining patients it was not indicated due to poor clinical
status, short life expectancy, air trapping lung, or presumed
chemosensitivity of the tumour. Case reports are presented
doors for all patients with malignant pleural effusion managed
(with different outcomes) by pleuradosis.
Conclusion: Pleuradosis is an option among palliative
therapeutic modalities which can help to alleviate symptoms
of malignant pleural effusion, particularly.

Poster sessions
Effect of Gorin-san (TJ-17) for Malignant Lymphedema in Advanced Cancer Patient

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Background: Advanced cancer patients often experience uncontrolled pain by malignant lymphedema. Diuretics, corticosteroids sometimes relieve malignant lymphedema but most cases are resistant. Gorin-san (TJ-17), Japanese traditional herbal medicine with Alismatis rhizoma, Atractylodis lanceae rhizoma, Polygonum, Hoelen, and Cinnamomi cortex, is used to treat edema, gastrointestinal symptom (nausea, dry mouth), headache, and dizziness in general practice.

Aim and methods: To examine lymphedema treated by Gorin-san of palliative care cancer patients. Retrospective reviews of cancer patients with consulted by palliative care support teams in Osaka National Hospital from 2011 to 2012.

Results: We treated successfully five lymphedema patients with Gorin-san (TJ-17). Male/female ratio is 4:1; 52-81 y/o. Primary cancer is colorectal, breast, kidney, stomach, and all are severe advanced disease clinically. All patients have lower extremities lymphedema with pain, mild lymph leakage, itching, and swelling. All like diuretics before Gorin-san administration. Average period to relief开发区is 0.14 week. Conclusions: Gorin-san (TJ-17) may manage symptoms of malignant lymphedema in palliative care cancer patients. Further prospective study is required.

Poster sessions

Abstract number: P-060
Abstract type: Poster
A Qualitative Study to Explore the Experience of Patients Attending a Nurse Led Breathing Group

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Aim: To explore patient’s experience of attending a nurse led breathing group and the effects of non pharmaceutical interventions.

Methods: A single group was developed within a UK day hospice, using an multi-disciplinary team (MDT) approach, based on intervention strategies by Corrigan et al (1996). Ethical approval was granted. Semi structured, audio taped interviews were conducted with a purposeful sample of 6 patients who had attended a 4 week breathing group. Collected data was transcribed and analysis and interpretation were for analysis of the data.

Results: The participants had a mix of malignant and non malignant suffering. Breathing connected to spiritual beliefs were central component of the findings was “the breathlessness group” itself, participants spoke about the benefit of knowing that others experienced similar difficulties. This sub divided into benefit gained from the group setting and each other, the sharing with others, the comradeship and the importance of peer and carer support. Participants were aware of the distress their breathlessness caused their families and appreciated the opportunity of support for them.

5 further subthemes emerged, key interventions, psychological gain, MDT input, learning aids and the future. Beneficial interventions included, “the calming hand”, breathing and pacing techniques, relaxation, and the “huff”. Participants described feelings relating to lessening of isolation, sense of dignity and independence.

The MDT approach was beneficial for participants and they described important relationships between themselves and others. Learning strategies improved their management of breathlessness, increased understanding, and reduced anxiety. Increased confidence in managing their breathlessness enabled participants to “face” the future more readily.

Conclusion: This study demonstrates the physical and psychological benefit to patients attending a nurse led MDT breathing group.

Abstract number: P-061
Abstract type: Poster
The Changes of Drug Therapy and Laboratory Data of Cancer Patients toward the End of Life

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Research aims: It is known that a various symptoms appear in terminal patients toward the End of Life. However, it has not been clearly studied the changes of drug therapy and laboratory data of cancer patients toward the End of Life. We tried to get clinical prediction of survival from a retrospective study of 105 patients.

Methods: The medical electric records of 121 cancer patients who died between January 1 and December 31 at 2008 at an acute care hospital were reviewed, and the medical history and laboratory data (LAD) were analyzed. The results were summarized by descriptive statistics and analyzed for the level of association.

Results: N=6801; Age: 61 ± 12, 58% males. 77% were Caucasians and 13% African Americans. The cancer types were prostate 17%, lung 13%, breast 12%, colorectal 5%, bladder 4%. 18% had metastatic disease. 43% received radiotherapy and 38% chemotherapy as antitumor treatment. Median (25th, 75th percentile) weight in kg V1: 81, 68 (85); V2: 79 (66, 94). Weight Difference V1-V2= 0.2 (-1.6, 2.4); V2-V3: 3 (1.2, 4.2); V1-V3 = 1 (2, 5). Median (25%, 75% percentile) Body Mass Index (BMI) V2: 28 (24, 32); V3: 27 (24, 31). The median resting energy expenditure (REE) V1 and V3: 1555 (1345, 1792). The mean systolic/diastolic blood pressure (B.P) on V2 and V3 were 135 ± 19/76 ± 11 and 132 ± 20/75 ± 11 respectively.

Conclusions: 1. 25% lost >5% of their weight from V1 to V2. 2. Preference of care and symptom burden decreased from V2 to V3. 3. Autonomic dysfunction may have a role in both V1 and V2. 4. No change in Resting Energy Expenditure (REE) V2 = V3 5. BMI not a good indicator for weight loss: >50% were either overweight or obese at V2

Abstract number: P-062
Abstract type: Poster
Swallow Screen and Test by Nursing Staff in Advanced Cancer

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Introduction: Swallowing is a complex process with four phases. It initiates digestion and is essential for proper nutrition. Difficulty swallowing independently correlated with cancer survival. We retrospectively evaluated the prevalence and incidence of swallowing problems in acute care palliative medicine unit. BMI and survival were also examined.

Methods: Electronic Medical Records (EMR) 2010-2012 was reviewed. Assessment comprised of 3 steps: nurse survey on patient condition (coma, intubation, PEG/feeding tube, patient condition), 19% through screening questionnaires and 6% by face-to-face visits (V1: Visit 1, V2: Visit 2 & V3: Visit 3) were returned at the following time points were as questionnaires returned at the following time points were as 771 invitations were sent out, 189 patients were randomised. The randomisation was done in a randomised controlled trial. The study was carried out within in-patients, out patients, day care and in community settings, in accordance with the Medical Research Council framework for developing and evaluating complex interventions. Patients were randomised to treatment groups 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 identification of swallowing difficulties.

Participants were asked to complete three short research questionnaires (MYCAW, EQ5D and PEI at 2 weeks, suggesting that the intervention did not have a detectable effect.

Conclusions: This negative trial result calls into question the utility of SPARC in specialist palliative care services. A process evaluation of the trial is currently underway, findings and

Abstract number: P-063
Abstract type: Poster
Assessment & measurement tools

Feasibility Study of the Sheffield Profile for Assessment and Referral for Care (SPARC): A Holistic Needs Questionnaire

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Aims: To explore the content and feasibility of the Sheffield Profile for Assessment and Referral for Care (SPARC) questionnaire.

Background: SPARC is a multidimensional holistic screening tool which provides a profile of needs (i.e. physical, psychological, social, spiritual) to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease.

Methods: A randomised controlled trial was undertaken to establish whether using SPARC improves care (impact on quality of life, interventions, consultations, and referrals within supportive and palliative care), and to compare between patient groups.

Results: The method was carried out within in-patients, out-patients, day care and in community settings, in accordance with the Medical Research Council framework for developing and evaluating complex interventions. Patients were randomised to treatment groups 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 identification of swallowing difficulties.

Participants were asked to complete three short research questionnaires (MYCAW, EQ5D and PEI at 2 weeks, suggesting that the intervention did not have a detectable effect.

Conclusions: This negative trial result calls into question the utility of SPARC in specialist palliative care services. A process evaluation of the trial is currently underway, findings and
Abstract number: P1-066
Abstract type: Poster
Do Physicians Underestimate Non-pain Symptoms in Advanced Cancer Patients? Referring to Patients to Pain Clinic Helps Identify Other Distressing Symptoms
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Background: Pain is one of the most common symptoms at advanced stages of cancer disease. Cancer related non-pain symptoms receive less attention from oncologists as compared to pain-related symptoms, which can be easily underestimated if physicians missed the comprehensive assessment of physical and psychosocial aspects. Aim: This study seeks to identify the prevalence and intensity of the most common uncontrolled symptoms in advanced cancer patients and the role of referral to pain clinic in management of such symptoms.
Method: A prospective survey studies 140 patients with metastatic cancer disease referred to pain clinic due to uncontrolled cancer pain. Questionnaire based on ESAS (Edmonton symptom assessment scale) were distributed to patients in the first interview. Patients were asked to identify and rate the severity of the 10 most common distressing symptoms. Results considered positive if patients rates the severity > 6.
Results: From 140 patients referred to our cancer pain clinic 18 were excluded. The remaining 122 patients 72 female and 50 male were eligible. 88% reported fatigue as the most disturbing symptom, followed by nausea 61%, worse being 57%, depression 51%, anxiety 48%, constipation 47%, nausea 41%, dyspnea 32% and diarrhea 21%.
Conclusion: The data emphasize that many symptoms can be more distressing than pain and it is not sufficient for oncologists to focus only on cancer pain during the treatment of patients with advanced cancer; a more global approach to symptom management is necessary. Referring cancer patients to pain clinic may be an alternative option for comprehensive symptom management in the absence of well established palliative care service.

Abstract number: P1-067
Abstract type: Poster
Implementing Patient Reported Outcome Measures (PROMs) in Palliative Care Clinical Practice: A Systematic Review of Facilitators and Barriers
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Background: Many patient reported outcome measures have been developed in the past two decades, and they play an increasing role in routine care in palliative care. However, their routine use in clinical practice has been slow and difficult to implement.
Aims: To describe facilitators and barriers to the implementation of patient reported outcome measures in the clinical care of patients with advanced or long term progressive physical illnesses.
Design: Systematic literature review and narrative synthesis.
Data sources: Medline, PsyInfo, CINAHL, Embase and British Nursing Index were searched limited to studies published after 1985. Hand searching of reference lists for all included articles and relevant review articles were performed. Results: 386 articles were screened. 31 articles met the inclusion criteria. Facilitators, barriers and lessons learned were independently assessed for recommendations for implementation on outcome measures at management, healthcare professional and patient levels were drawn from findings within three different test data sets: facilitation, implementation and assessment/improvement.
Conclusions: Identifying and addressing potential barriers to the implementation of patient reported outcome measures in clinical practice by using appropriate facilitators seems to be vital. The most important facilitator has to do with acceptance and familiarity with the patient reported outcome measures, providing adequate education and training to healthcare professionals prior to the implementation, which will help insuring that clinicians are familiarised with the patient reported outcome measures. Even though estimating pain with a validated tool is one of the parameters in the National Register of Quality in Palliative Care, there is a lack of using such tool in a specialized Palliative Care Unit at a university hospital in Sweden.
Aims: Finding routines for using a validated tool to estimate pain in dying patients to ensure the quality in pain relief. Method: In September 2012 started a pilot study with one nurse to find a routine to estimate pain in inpatients at the palliative care unit. From November 2012 each nurse at the ward will use the Pain Visual Analogue Scale-tool (VAS) and the Abbey Pain Scale-blank (APS). At least twice a week, an estimate of pain should be done with one of the validated tools, for every patient who has an ongoing pain relief. In addition, an estimate shall be done every time the patient suffers from breakthrough pain, just before an extra dose is administrated as well as 20-30 minutes after the given dose. The VAS should be used for patients who are able to participate and the APS for patients who cannot.
Conclusion: Training and gradually introducing is one way for nurses to find routines for estimating pain with validated tools.

Abstract number: P1-070
Abstract type: Poster
Validation of the Palliative Performance Scale Version 2 (PPSv2) Into Spanish for its Use in End of Life Oncological Patients
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Background: Research has become a major challenge in recent years for professionals involved in palliative care (PC). Most of PC assessment tools have been primarily developed in English so it is mandatory their internationalization to provide effective tools and to facilitate researchers to compare results more scientifically. The main objective is to validate the Spanish version of the PPSv2 in assisted by PC teams.
Methods: Validation of the PPSv2 into Spanish was carried out in three different steps: Firstly, the translation was based on the conceptual equivalence of the terms used under linguistic supervision. Second, cultural and grammatical adaptation of a sample (n=15) of oncological palliative patients was carried out in order to test inter and intraobserver reliability (intraclass correlation coefficients) and internal consistency. Finally, the content validity and the interrater reliability, three independent researchers used SyMPeC to retrieve symptom-specific interventions with the nurse-led palliative care unit. Results: Intr and intraobserver reliability was good with intraclass correlation coefficients of 0.753 (0.264 - 0.917), p<0.007 and 0.894 (0.684 - 0.964, p<0.001), respectively. Content validity was assessed by Cronbach’s alpha 0.990 (0.988 - 0.992, p<0.001). The psychometric properties of the validation process tested with the Pearson’s correlation coefficient showed values of 0.854 and 0.927 (both with p<0.001), respectively. Conclusion: Psychometric and qualitative properties of the Spanish version of the PPSv2 showed to have high validity and reliability. These results support the use of the Spanish PPSv2 to test functional status in advanced oncological patients attended by PC teams in a hospital environment.

Abstract number: P1-068
Abstract type: Poster
Development and Validation of a Checklist for Symptom Management (SyMPeC) in Patients Treated with Chemotherapy in Palliative Intention Using the Data of the Test of the Trial SAKK 96/06
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Aims: Patients with advanced cancer suffer from a variety of symptoms with varying intensity. During chemotherapy oncologists perform a range of pharmacological and non-pharmacological interventions in order to manage these symptoms. We aim to develop and validate a symptom management checklist (SyMPeC) for medical chart review in the oncology outpatient clinic.
Methods: A consensus of the content of the check-list was undertaken. The parameters were extracted and quantified from a test data set (half of the data set) to assess the inter-rater reliability. The parameters were the presence of neuropathy, 24 patients were included. The checklist was used SyMPeC on a random sample (10%) of the test data set and Fleiss’ Kappa was calculated. For validation a comparison of retrieved symptom specific interventions with the nurse-led assessment of patient perceived oncologists’ interventions was performed on the whole data set.
Results: 5 expected interventions emerged: fatigue, pain, nausea/dyspepsia, depression/anxiety, 247 patients from 84 oncologists from 8 centers were in the data set. In the test set (123 patients) 402 unique pharmacological interventions and 260 that could be assigned to specific symptoms were identified. Non-pharmacological interventions could not be assigned to symptoms. In the 12 patients analysed by three researchers Fleiss’ Kappa for symptom detection was K = 0.67 and for interventions K = 0.66. When compared with nurse led assessment in all 247 patients, there was a match in 1003 (8220 visits) and a mismatch in 164 visits (14%). If analysed per case, 118 visits (41.2%) had a perfect match and 125 (40.1%) were a mismatch or less.
Conclusion: Chart review by SyMPeC seems reliable and valid for symptom management in oncology outpatient clinics. Non-pharmacological interventions were difficult to assign to a specific symptom. A checklist for documentation could improve standardisation.

Abstract number: P1-071
Abstract type: Poster
Evaluation of Symptom Markers Cystatin C, CRP, and Procalcitonin as Prognostic Parameters in Palliative Care Patients
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Aims: Lack of clarity about palliative patients’ prognoses poses a huge burden on both patients and their family and friends. Surprisingly early deaths can be grievous when relatives cannot take leave of their beloved one, while unexpectedly prolonged survival can be excruciating for patients and relatives. Recent studies identified certain serum markers as valid predictors of the life expectancy in elderly citizens. However, the significance of such markers in a palliative care setting is unknown. The aim of our study is to identify possible prognostic parameters of life expectancy in patients at a palliative care unit (PCU).
Method: In this study, blood samples are collected from 100 patients in our PCU from 01.08.2012 to 30.03.2013, regardless of underlying disease. 46 samples were collected from 01.08.2012 to 10.12.2012. Serum cathespin B and interleukine 6 (IL-6) levels are determined by ELISA. Cystatin C levels are measured by nephelometry. Further parameters include blood count, HLD, LDL and cholesterol. Clinical data comprise survival time, Karnofsky performance score and clinical data comprise survival time, Karnofsky performance score and cardiovascular risk factors (smoking, hypertension, diabetes, dyslipidemia and family history). Results are correlated with survival time, Karnofsky performance score and clinical data comprise survival time, Karnofsky performance score and cardiovascular risk factors (smoking, hypertension, diabetes, dyslipidemia and family history). Results are correlated with survival time, Karnofsky performance score and clinical data comprise survival time, Karnofsky performance score and cardiovascular risk factors (smoking, hypertension, diabetes, dyslipidemia and family history). Results are correlated with survival time, Karnofsky performance score and clinical data comprise survival time, Karnofsky performance score and cardiovascular risk factors (smoking, hypertension, diabetes, dyslipidemia and family history). Results are correlated with survival time, Karnofsky performance score and clinical data comprise survival time, Karnofsky performance score and cardiovascular risk factors (smoking, hypertension, diabetes, dyslipidemia and family history).
Results: Data from 23 already deceased patients indicate a correlation between the average survival time (average 8.9, 9.7, 7.7 years) and serum levels of cystatin C (P-values: r = 0.54, r = 0.6, r = 0.37), c-reactive protein (r = 0.41) as well as
Poster sessions

Karnofsky performance score (r = 0.56).

Conclusion: Our data identify potential prognostic parameters of survival time in a palliative care setting. A combination of such parameters may prove to be a valid predictor of life expectancy at PCUs in the future and warrant further validation. This project did not receive external funding.

Abstract number: P-073
Abstract type: Poster

Responsiveness to Delirium Severity Variations, Neurobehavorial and Global Cognitive Factors of the Memorial Delirium Assessment Scale

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Background: The Memorial Delirium Assessment Scale (MDAS) is a reliable and validated instrument with which to assess delirium. Responsiveness to delirium changes detected by the MDAS has not been investigated. Two factor loads in the MDAS, neurobehavioral and global cognitive, have been previously defined. This study’s primary objective was to evaluate the MDAS’ responsiveness and analyze individual factors on this questionnaire.

Methods: Study subjects included 85 advanced cancer patients in a palliative care unit who were diagnosed who were admitted to 3 palliative care units. Delirium diagnosis was determined by clinical DSM IV TR criteria; the Confusion Assessment Method Instrument. Two factor loads were used baseline (0) and 72 hours with the Delirium Rating Scale- Revised 98 (DRS-98), Mini Mental State Examination (MMSE) and MDAS.

Results: The variation in DRS-98 scores shows a correlation of r = 0.93, with variation in MDAS scores at P = <.001. The variation in MDAS scores at P = .01. Factor L, neurobehavioral (reduced awareness, reduced attention, perceptual disturbance, delusions, altered psychomotor activity, and sleep-wake cycle disturbance) correlated moderately with MMSE at 0.56. Factor G, global cognitive (disorientation in time and place, impaired social interactions, digit span, and disorganized thinking), correlated strongly with MMSE and MDAS. Factor L was significantly more reliable than 1 − r = 0.7, P = .01.

Conclusions: The high responsiveness confirms the value of the MDAS for ongoing delirium assessment. The existence of 2 differentiated factor loadings points to a potential future need for MDAS subscales.

Abstract number: P-074
Abstract type: Poster

Early Recognition at Home, a Pilot Study

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A pro-active approach of palliative care problems ameliorates quality of life of patients and family caregivers. A study regarding early recognizing nursing interventions in palliative home care patients was conducted.

Aim: To develop a feasible set of nursing interventions to optimize palliative care for patients and their caregivers at home.

Method: From February- June 2012 a longitudinal pilot study was conducted. Palliative care patients receiving nursing care at home and their primary caregivers were included. Nurses received coaching to integrate early recognition in daily practice. Study outcomes: symptom intensity, Karnofsky (K) burden, use of health care facilities, attrition rate and missing data, use of study tools in daily nursing practice. Data collection was performed by a nurse independent of the DT. Data was collated and analysed. Descriptive statistics were performed.

Results: Fifteen patients were selected, 12 patients were enrolled (K=55,85 years) during a mean of 53 days. Attrition rate was 33%, missing data 8% patients, 32% caregivers. In average patients experienced 6 symptoms. Fatigue, caring disorders and pain occurred most frequent and intense. Sleeping disorders and early safety increased; quality of life decreased concurrently. Caregivers experienced high burden of care and their primary caregivers were included. Nurses received coaching to integrate early recognition in daily practice. Study outcomes: symptom intensity, Karnofsky (K) burden, use of health care facilities, attrition rate and missing data, use of study tools in daily nursing practice. Data collection was performed by a nurse independent of the DT. Data was collated and analysed. Descriptive statistics were performed.

Conclusions: The Problem Checklist is the most highly valued aspect of the tool reported by patients and its use has added to the quality, consistency and documentation of holistic assessments in this setting. The tool will be extended next to the Hospice at Home Service and then evaluated.

Abstract number: P-076
Abstract type: Poster

Applicability of the Swedish Version of the Fronmellt Attitude Toward Care of the Dying Scale (FATCOD) among Nurses and Nursing Students and Factors Influencing the Attitudes

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Background: To improve quality of life of patients with life-limiting illness is important in palliative care, and to this quality nursing care for dying patients is essential. Nurses need to be prepared to meet dying patients, therefore, nurses’ attitudes toward caring for dying persons and factors influencing nurses’ attitudes toward caring for dying persons are needed to be explored. One instrument investigating these attitudes is the Frommellt Attitudes Toward Care of the Dying (FATCOD) scale, which has not previously been translated into Swedish.

Objectives: To compare FATCOD scores among Swedish nurses and nursing students with those from other languages, to use factors of subscales and evaluate influences of earlier experiences on attitudes toward care of dying patients.

Methods: A questionnaire consisting of 30 items concerning attitudes toward caring for dying persons. FATCOD scores of 113 Swedish nurses from hospice, oncology, surgery, and home care and 100 nursing students were compared with published scores in similar populations from the USA, Israel and Japan. Descriptive statistics and regression analyses were used.

Results: Swedish FATCOD mean scores did not differ from published means from the USA and Israel but were significantly more positive than Japanese means. Factor analysis yielded a two-factor solution. Total FATCOD and subscales had low Cronbach’s alphas. Hospice and palliative team nurses had more positive attitudes to care of the dying than the inpatient oncology and surgery teams.

Conclusions: Although our results suggest that the Swedish FATCOD may comprise two distinct scales, the total scale may be the most adequate and applicable for use at 6 Swedish. Nurses’ professional experience and the workplace culture affect their attitudes; therefore, focusing care to dying patients. Factors influencing student nurses’ attitudes and the benefit from education need to be further explored.

Abstract number: P-077
Abstract type: Poster

Palliative Prognostic Index: Further Validation in Hospice Cancer Patients with a Multi-center Prospective Study

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Background: Predicting prognosis is important for patients and caregivers, potentially helping in decision making about treatments, referral to appropriate services and preparing and planning for a patient’s remaining time. The Palliative Prognostic Index (PPI), a prognostic tool calculated using clinical indices alone (oral intake, oedema, dyspnoea at rest, delirium and palliative performance scale) was first validated in cancer patients admitted to hospice care in Europe in 2008 and Subramanian in 2010. This study aims to further test the accuracy of the PPI in hospice patients with advanced cancer, using a larger sample drawn from multiple sites.

Methods: A multi-centre prospective study aiming for a cohort of 1000 adult hospice inpatients with advanced cancer. Statistical advice sought from a local university and ethical approval granted. Sequential start of data collection from 10 UK hospice sites and a correlation coefficient of r = 0.84, with variation in MDAS scores at P = .01. The variation in MDAS scores at P = .01. Factor L, neurobehavioral (reduced awareness, reduced attention, perceptual disturbance, delusions, altered psychomotor activity, and sleep-wake cycle disturbance) correlated moderately with MMSE at 0.56. Factor G, global cognitive (disorientation in time and place, impaired social interactions, digit span, and disorganized thinking), correlated strongly with MMSE and MDAS. Factor L was significantly more reliable than 1 − r = 0.7, P = .01.

Conclusions: The high responsiveness confirms the value of the MDAS for ongoing delirium assessment. The existence of 2 differentiated factor loadings points to a potential future need for MDAS subscales.

Abstract number: P-078
Abstract type: Poster

Development of a Pain Body Map for Tablet Computer Center for Use in Patients with Advanced Cancer

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Background: Computerized assessment tools ease data collection and facilitate integration of self-report data in electronic patient record systems. However, advanced cancer patients have special needs regarding usability of computerized tools. We have previously tested a computerized pain body map (CPBM) for pain location in advanced cancer patients. The aim of the present work was to develop an improved version of the CPBM for tablet computer.

Material and method: A stepwise, user-centered approach was performed. This included repeated testing (iterations) of a prototype of the program in patients from the target
group. During four iterations patients were observed and instructed to "think aloud", audio and video recordings were made, and each participant interviewed after each round. The first iteration yielded a paper sketch, while the subsequent iterations were performed on a tablet. Based on responses and feedback, the prototype was improved and refined.

Results: The program was tested in 23 advanced cancer patients (mean age 64.9 years, 13 females, 10 males). The mean MMSE score was 26.4. Multiple regressions were calculated including MMSE as a predictor for four of the four dimensions of the MacCAT. These regressions indicated that MMSE score was a significant predictor for all four dimensions of the MacCAT. Understanding (R² = .43, F(3,91) = 22.94, p < .001), Appreciation (R² = .12, F(3,91) = 1.97, p > .01), Reasoning (R² = .25, F(3,91) = 10.03, p < .001), and Choice (R² = .16, F(3,91) = 5.89, p < .01).

Conclusion: It is very likely that the MacCAT and MacCAT demonstrate concurrent validity. Although all dimensions were significantly predicted by MMSE scores, there was still a large percentage of variability in MacCAT scores. Therefore, clinicians in hospice care who are determining patient capacity to provide informed consent to treatment and to make decisions are multicollinear with a multifaceted way of instruments such as the MacCAT. Additional analyses will explore differences between inpatient and community subjects.

Abstract number: P1-080
Abstract type: Poster

Do Patients Want to Tolerate Unrelieved Pain?
Nurses' and Patients' Experiences with Pain Management in Hospices

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It's over ten years since preparation for death was identified as one of the most important quality of life (QOL) attributes for patients at the end of life, yet this primary domain is still rarely captured in health services research. Suboptimal measurement of QOL could lead to missed funding opportunities for valuable palliative care programs. Consequently, this research aimed to develop and validate a new, supplementary, single-item EOLPRO to measure end-of-life QOL. Nine cognitive interviews were conducted with purposively sampled Australian palliative care patients to evaluate content validity. Construct validity, test-retest reliability and responsiveness were assessed using data from the multi-site, double-blind, Phase II, dose titrated, Phase III Australian Palliative Care Clinical Studies Collaborative randomised controlled trial comparing subcutaneous ketamine and placebo for the management of cancer pain (n = 184).

Analysis of cognitive interviews provisionally supported the content validity of EOLPRO. However, the analysis of significant correlation between baseline performance status and EOLPRO scores demonstrated convergent validity (r = 0.37, p < 0.001). Correlations between baseline EOLPRO and MMSE scores and proximity to death were in the expected direction but not statistically significant. Pre- and post-treatment EOLPRO scores were moderately agreed (n=14, κ = 0.52 [95% CI 0.19, 0.84]). The EOLPRO's apparent lack of sensitivity to discriminate between those who prefer to tolerate pain management may have been confounded by other factors (n = 104, χ2 = 0.43, unadjusted p = 0.98).

Very few validated questionnaires measure the ability of patients with a life limiting illness to finalise their affairs at the end of life. Within this context, the EOLPRO has promising properties as a tool to add to existing questionnaires, plaguing the QOL assessment gap. Funding: Australian Government & Flinders University

Abstract number: P1-082
Abstract type: Poster

Nursing Diagnosis in Palliative Care: The Case of a Palliative Care Hospital Support Team

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Introduction: Nursing documentation in palliative care...
Development of an Instrument to Assess the Capacity for Families to Provide Home Care in Portugal

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Some studies shows the importance of adequate family supports if palliative patients are to be cared at home. Assessing their capacity to provide support is therefore an essential component of a home-based care plan. A Portuguese instrument, called the “Escala de Capacidade para a Residência em Casa” (ECCP), has been developed to assess this capacity, taking into local culture and realities.

Aim: Explore the initial face and content validity of the instrument.

Method: Instrument development occurred in phases. Items were based on a literature review and a framework emanating from previous work at a large Portuguese Centre by one of the investigators. The initial instrument was then reviewed by a panel of palliative care professionals (4 physicians, 5 nurses and a psychologist) as well as 10 family caregivers (Phase 1). Modifications were made to the instrument based on their input. The modified instrument was then reviewed by the panel using a mixed methods approach: a) “think aloud” qualitative method (cognitive debriefing) and b) a survey with a Likert Scale (1-5) in which to rate the house (notorious in 6 out of 11 patients at the first assessment and in 5 patients at the last moment), to give advice to patients identified in 5 of 11 patients from the first until the last moment of evaluation).

Conclusions: The most common nursing diagnosis identified in the patients suffering from pain and distress were related to the ability to bathe, to dress/undress, and to clean the house. The most common nursing diagnosis identified in the patients suffering from pain and distress were related to the ability to bathe, to dress/undress, and to clean the house. There was a decrease in the importance of the presence of almost all diagnosis over time. Findings reinforce nurses’ role in palliative care, particularly promoting psychological, physical, and social support, and helping patients to fulfill their needs of self-care.

Abstract number: P1-085
Abstract type: Poster

Health-related Quality of Life among Breast, Prostate and Colorectal Cancer Patients Receiving Palliative Care

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Aims: To explore health-related quality of life (HRQoL) in breast (BC), prostate (PCa), and colorectal cancer (CRC) patients receiving palliative care, to compare the results of different HRQoL instruments, and to explore predictors of poor HRQoL.

Methods: Patients for this cross-sectional observational study were recruited from the Oncology Hospital palliative units and from a hospice in the Helsinki area. HRQoL was assessed using two generic instruments, the EQ-5D and the EQ-5D-3L, including its visual analogue scale (VAS), and the cancer-specific EORTC QLQ-C30. In addition, clinical and demographic information was collected. A linear stepwise regression model, including clinical and demographic factors, and EORTC symptoms as explanatory variables, was used to assess predictors of poor HRQoL.

Results: 138 palliative care patients were included in the analysis. Of them 27 had BC, 39 PCa, and 73 CRC. The mean age was 70 (range 35-86), PCa patients being eldest. 47 of the patients died within six months after having answered to the questionnaire and 46 within three to six months after the response. The mean HRQoL scores varied widely depending on the instrument used. The mean overall (5.76 ± 0.35) in EQ-5D-3L measured with 1SD was 0.73 ± 0.14 (0.47 ± 0.14) with EQ-5D-5L (0.33), and with VAS 53.9 ± 20.2, respectively. Fatigue was the most common symptom, followed by pain and insomnia. Closer to death, the role of fatigue, dyspnoea, appetite loss, and constipation increased. In the regression model the most important factors predicting deteriorated HRQoL of life turned out to be fatigue and financial difficulties, which was associated with depression.

Conclusions: Among palliative cancer patients, those with fatigue and financial difficulties had a clear negative impact on HRQoL which needs to be taken into account when supporting palliative patients HRQoL.

Abstract number: P1-087
Abstract type: Poster

Application of Single-items for Measuring Quality of Life in Children with Life-limiting Conditions - At which Age Does It Work?

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Introduction: Preserving the highest possible quality of life (QoL) is a major important aspect in palliative care for pediatric patients with progressive life-limiting conditions (PPC). For the evaluation of different therapies or procedures methods are needed, that are able to assess QoL in an efficient and accurate way. Due to the usually time-consuming and have other disadvantages like high complexity, having them from regular application in PCC. Single-items (SI) have the advantage of simplicity and time-effectiveness, and can therefore be used in longitudinal studies. On the other hand abstract thinking is required for some SI, which makes it difficult to use in young children. For evaluation of SI in measuring QOL in children 8 years old or younger with life-limiting conditions different SI were used and analyzed in different age-groups.

Materials and methods: Three different SI were used (visualized as visual analogue scale) to assess quality of life, in a group of 101 children (age range: 8-18 years) with life-limiting conditions, defined according to ACT (Association for Children with Life-threatening or Terminal Conditions and their Families) 2001 criteria. The sample was two-valued SI and widespread multiple-item indices have been used (KINDL, Kidscreen 27).

Results: There were significant variations of correlation-coefficients between all three SI and the multiple item indicies for the different age-groups. An age-dependent influence of the correlation-coefficients was observed. The correlation-coefficients varied between 0.3 - 0.47, age specific correlations varied between 0.05 - 0.74.

Discussion: This study could observe significant differences between the age-specific correlation-coefficients of the different SI and the multiple-item indices, although there was no general tendency related to the specific SI and age. Therefore we conclude that the used SI are applicable from 8 years of age. Further studies are needed to determine the value of SI in measurement of quality of life in pediatric palliative care.
Validation of the Palliative Prognostic Index and the Palliative Prognostic Score in an Inpatient Palliative Care Team Setting

End of Life

Measuring Pain and Comfort in Dementia at the Curie Palliative Care Research Unit, London, United Kingdom,

Conclusion:

other concepts (sadness and fear).

such as “positive” items (eye contact, content facial expressions) may be larger than between a pain tool and a

instruments (e.g., PACSLAC and Doloplus in addressing facial

indicating changes, or broader concepts requiring some

ADL domains. However, there was less agreement on a

Results:

and epidemiologist undertook a conceptual analysis,

Aim:

This study aims to clarify the predictive value of two

prognostic prediction tools, the palliative prognostic index (PPI) and the palliative prognostic score (PaPS), in an inpatient palliative care team setting.

Methods: This prospective cohort study, conducted from July 10, 2009 to December 12, 2011, includes all patients older than 18 years, hospitalized with an advanced cancer, and referred to the palliative care team in an acute hospital in Japan; two hundred forty-seven patients are included in the PPI study, and 187 patients are included in the PaPS study.

For PPI validation, the sensitivity (Sn) and specificity (Sp) of predicting survival for less than 3 weeks with a cut off PPI > 6 is 63% (95% CI: 50-75) and 91% (95% CI: 86-94), respectively, the positive predictive value (PPV) and negative predictive value (NPV) are 89% (95% CI: 83-93) and 0.95 (95% CI: 0.95-0.99), respectively.

The Sn and Sp of predicting survival for less than 6 weeks with a cut off PPI > 4 are 80% (95% CI: 75-85) and 95% (95% CI: 94-96); the PPV and NPV are 0.75 (95% CI: 0.68-0.82) and 0.97 (95% CI: 0.60-0.79).

The difference in survival is highly significant (<0.0001).

For PaPS validation, the sensitivity (Sn) and specificity (Sp) in a group A (PaPS ≤ 3), 55.2% in group B (PaPS 3.1-5), 49.3% in group C (PaPS 5.1-7), 49.5% in group D (PaPS > 7), respectively; the positive predictive value (PPV) and negative predictive value (NPP) are 0.64 (95% CI: 0.53-0.76) and 0.73 (95% CI: 0.62-0.83), respectively.

Conclusion: The results suggest that although PPI and PaPS successfully divide patients into three groups with significantly different survival times, discrepancies exist between the original studies done in a hospice setting and the current study in predicting the actual length of survival.

Aim:

To map and compare items and domains covered by tools to assess pain and comfort in severe dementia or dementias at the end of life.

Methods:

We examined each individual item and descriptors if available in thoroughly tested tools to assess pain (PAINAD, PAGI-SAC, Paliplus+) and comfort (Paliplus+) and their domains related to number of PC consultations performed (21 items). Scores representing one domain. Petal length represents the amount of points earned in the domain. The PCI was piloted in inpatient palliative care unit, Southport, United Kingdom.

The PCI was piloted in an acute care palliative medicine team in Belgium.

Domains. Comfort tools include a broader item pool. Some items (lack of positive indicator) may be tested for additional domains. Other concepts (sadness and fear).

This audit has enabled an improvement in

Reasons for ineligibility: 7 declined, 5 too ill, 2 language barriers, 305 (2, 90 points; median=70; mean=59). Scores related to number of PC consultations performed (≥51, <105).

Background: Patients with advanced disease may require blood transfusion as part of ongoing symptom management. To evaluate the effectiveness of this intervention an audit was undertaken with a specialist palliative care unit, reviewing documentation & recording of pre & post transfusion symptoms & initial haemoglobin concentration. Comprehensive symptom assessment both before & after transfusion is essential to assess response to transfusion. Disease related fatigue is often significant in this patient group thus it is important to monitor the clinical impact of this intervention to ensure benefits of transfusion outweigh burdens. Does the recording of symptoms prior to & following transfusion improve patient care & allow for treatment only when benefit is likely?

Method: Initial audit to determine recording of symptoms pre & post transfusion against standard of pre-transfusion symptom recording, benefit vs burdens conversation prior to transfusion & post transfusion recording & transcription. A random sample retrospective case note review of clinical details were reviewed in 10 patients who received blood transfusions.

Poster sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
Aims: The study explored factors affecting continuity of care following discharge from the hospital by the palliative care unit at Mulago Hospital, Kampala. The study objectives were to find out the factors that affect continuity of care and to what extent these factors affect the continuity of care. Our secondary objective was to understand the patient and care experience following referrals.

Methodology: This was a qualitative study using semi-structured interviews for (13) patients and carers based on the phenomenological approach. Data was collected using telephone interviews for both the patients and the carers which were recorded, transcribed and thematic evaluation undertaken.

Results: The findings of the study indicate the following factors; referral pathways and expectations, patient and carers' understanding of illness, patient seeking behaviour, unrealistic promises, communication about practical issues on discharge, infrastructure, poverty and transport costs, pain relief, distress, planning, age, spiritual and cultural issues, family support. The results also indicated that these factors were interrelated with one complicating the other. Discussion: These factors which affect the experience of patients and carers include; the patient's general condition on discharge, the lack of available financial and family support. The referrals and discharges which are unreconciled affected continuity of care. Further more, patient and carer understanding of illness, spiritual and cultural issues and identified practical issues during discharge planning will all affect continuity of care.

Recommendations: There is need for proper communication, documentation and established functional referral system and community sensitization.

Abstract number: P1-097
Abstract type: Poster

Factors Affecting Continuity of Care from Mulago Hospital Palliative Care Unit

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Aim: The study explored factors affecting continuity of care following discharge from the hospital by the palliative care unit at Mulago Hospital, Kampala. The study objectives were to find out the factors that affect continuity of care and to what extent these factors affect the continuity of care. Our secondary objective was to understand the patient and care experience following referrals.

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Recommendations: There is need for proper communication, documentation and established functional referral system and community sensitization.

Abstract number: P1-097
Abstract type: Poster

Successful Recognition of Patients Entering the Terminal Phase and Use of the LCP - Retrospective Audit of All Adult Ward-based Deaths Within an Inner City Teaching Hospital

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Aims: As part of the UK initiative in improving end of life care outcomes, it was important that 25% of expected deaths within the hospital should be supported with the LCP (Liverpool Care Pathway). The aim of this audit was to ensure the hospice was notified and whether involvement of the palliative care team affected rates of deaths of the LCP.

Methods: Retrospective audit conducted quarterly looking at all adult deaths occurring within the hospital setting over a one month period. Eligible deaths were identified through examining the medical records held in the bereavement service.

Results: A series of five months was audited. 277 eligible deaths were identified, cancer was the primary cause of death for 77 (28.4%) of patients, with 41 (14.8%) of patients dying from either end stage chronic obstructive pulmonary disease or heart failure. Over 60% of patients were apparently recognised as entering the dying phase and commenced on the LCP; (45.5%) patients had no malignant diagnoses, and 36% (50%) had anticipatory medications in the home. The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of the care at the end-of-life. Aim: To define basic quality indicators of the domain of Ethical and Legal Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

Methods: First, we conducted a Systematic Review, to indentify the indicators to use in the study. 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study. 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively.

The results reported here show that hospital services to fill gaps in end of life care for patients whose preferred place of care is home. Care is provided predominantly by assistants, and a small number of registered nurses (RNs). RNs receive consent training in their nursing studies. The aim was to achieve a standard of 100% that all hospice at home care plans should clearly state consent status documentation and care interventions given.

Consent to valid treatment and care is central in all forms of healthcare: patients have a fundamental, legal and ethical right to determine their own care. Many patients are unconscious and unresponsive when care interventions occur. Hospice policy states 'Consent status must be documented for all personal and invasive procedures. It was difficult to see if a glance if consent status was recorded in the care plan.

Method: A retrospective (random) audit of 204 care plans was performed to determine if consent status for personal care was documented. Confidentiality was maintained at all times. 77% records completed by HCAs and 23% by RNs.

Cycle 1 - 74% of care plans had consent status recorded. 26% records had no mention of consent status documented. Further analysis identified only 37% of RNs had recorded consent status. Training needs were identified and implemented in various ways to include Consent, Mental Capacity Act (2005), and Record keeping.

Cycle 2 - Re-audit 6 months later using same criteria and data collection tools.

- 93% of care plans had consent status recorded for personal care, improvement in the number of RNs recording consent status - 77%.

Results: Care plans now checked daily to identify staff not adhering to policy.

The need to replicate audit in other areas of the Palliative Care Services was highlighted.

Abstract number: P1-099
Abstract type: Poster

An Audit of the Provision of Anticipatory Medications in the Community for End of Life Care

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Aim: To define basic quality indicators for palliative care services using Delphi technique with palliative care experts.

Methods: First, we conducted a Systematic Review, to indentify the indicators to use in the study. 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study. 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively.

The criteria to determine the agreement and consensus were:

- Very High: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0 - High: ≥70% of agreement + Median rating 4 on the 5-point agreement scale + IQR = 0 - Moderate: Median rating 3 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1 - Low: Median rating ≤ 4 on the 5-point agreement scale + < 60% of agreement + IQR = 1 - To define the standard we use the median rating on the 10-point scale (10-100) - only the indicators that obtained the classification of very-high or high were chosen.

Results:

- A total of 11 from 11 quality indicators were defined. These indicators 3 are related to structure, 7 of process and 1 of outcomes (their description and standard will be done in the presentation).

Conclusions: We found a total of 11 basic quality indicators which belong to the domain of "Ethical and Legal Aspects of Care". So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.

Abstract number: P1-100
Abstract type: Poster

Basic Quality Indicators for Palliative Care Services in Portugal: Ethical and Legal Aspects of Care

Copes M.L.1, Nobal M.3, Rosa F.C.2

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Introduction: The Portuguese Palliative Care Program is growing, with a significantly increase in last years. So it is an important measure the quality of care provided to promote the improvement of the care at the end-of-life. Aim: To define basic quality indicators of the domain of Ethical and Legal Aspects of Care, for palliative care services using Delphi technique with palliative care experts.

Methods: First, we conducted a Systematic Review, to indentify the indicators to use in the study. 92 experts, who had more than 3 years of experience in working in Palliative Care were invited to collaborate in the study. 3 rounds were done (2 to define the QI, and one to define the standards) of Delphi Method, with 71, 66 and 65 participants, respectively.

The criteria to determine the agreement and consensus were:

- Very High: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0 - High: ≥70% of agreement + Median rating 4 on the 5-point agreement scale + IQR = 0 - Moderate: Median rating ≤ 3 on the 5-point agreement scale + 60% - 79% of agreement + IQR = 1 - Low: Median rating ≤ 4 on the 5-point agreement scale + < 60% of agreement + IQR = 1 - To define the standard we use the median rating on the 10-point scale (10-100) - only the indicators that obtained the classification of very-high or high were chosen.

Results:

- A total of 101 from 120 quality indicators were defined (22 of structure,63 of process and 16 of outcomes).

33 quality indicators belong to the domain "Structural and Process Aspects of Care",16 to the domain "Physical Aspects of Care", 14 to the "Psychological and Psychiatric Aspects of Care", 9 to the "Social Aspects of Care", 3 to the "Spiritual, Religious and Existential Aspects of Care", 2 to the "Cultural Aspects of Care", 13 to the "Care of the Irremediably Dying

Abstract number: P1-101
Abstract type: Poster

Basic Quality Indicators for Palliative Care Services in Portugal

Copes M.L.1, Nobal M.3, Rosa F.C.2

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Poster sessions

86 13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
and end of life care service for people with dementia is required. This would facilitate the provision of improved care at this difficult time for people with dementia and the range of carers who support them.

Abstract number: P1-105
Abstract type: Poster

Dying Peacefully in Residents with Dementia in Long-term Care Facilities: A Good Quality Indicator?

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Background: Little is known about whether people with dementia in long-term care facilities may be influenced by the (palliative) care provided. If so, dying peacefully may serve as a quality indicator for palliative care in dementia.

Objectives: (1) To describe the proportion of residents with dementia in long-term care facilities that dies peacefully.
(2) To explore whether the available quality indicator “the percentage of relatives who indicate that the patient died peacefully” captures quality differences between different facilities and hence is a discriminative and useful indicator.

Methods: We used written questionnaires about quality of dying composed of 52 questions. Respondents were 108 patients in the Dutch End of Life in Dementia study, performed in 34 long-term care facilities in the Netherlands between January 2007 and July 2010.

The percentage of residents dying peacefully was calculated for each facility and Generalized Estimating Equation models were used to explore associations between long term care facility characteristics and the proportion of peaceful deaths.

Results: Of 233 residents with dementia indicated that the resident died peacefully in 56% of cases. The percentage ranged from 38-93% across facilities. This range points to the discriminating power of this quality indicator, enabling a comparison of care provided by long term care facilities to residents with dementia. Residents were more likely to have died peacefully in facilities with a moderate (versus low) perceived influence of religious and spiritual issues at the moment of death decision making, and when “families know what to expect”.

Conclusion: According to their relatives, about half of Dutch people with dementia die peacefully. This proportion varies between care facilities. Differences in scores appeared to be related to characteristics of the long-term care facilities, which suggests that the percentage of residents with dementia dying peacefully is an indicator of the quality of care in this setting.

Abstract number: P1-106
Abstract type: Poster

An Audit of Opioid Prescribing at a Large Teaching Hospital

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Introduction: In 2008, the National Patient Safety Agency (NPSA) issued guidance on the prescribing, dispensing and administration of opioids. The report was based on reports of 5 deaths and over 4,000 safety incidents.

Aims and objectives: To undertake an audit to assess whether prescribing of opioids (for both terminal and chronic conditions) to patients with malignant disease is consistent with the NPSA alert and the new guidance set out by National Institute of Clinical Excellence (NICE) CG146.

Method: This was prospective audit which took place over a four week period. All medical and surgical wards were covered. Suitable patients were identified by ward pharmacists.

Results: Data was collected for 30 patients. The majority (21 (70%)) of patients were prescribed an opioid for pain or short acted drug. In 5 patients (17.3%) nausea and vomiting had been prescribed an opioid for rescue medication and one third of these received inappropriate doses. In 53.3% (n=16), regular laxatives were prescribed, in contrast, 73.3% (n=22) received anti-emetics, either regular or on a ‘when required’ basis.

Of the patients initiated on an opioid at admission (n=9), 66.7% were on regular sustained release morphine, with the majority (83.3%) prescribed a daily dose of 20-30mg. All these patients were offered an appropriate opioid at an appropriate dose for rescue medication. The results showed 70% of the initial prescribing was undertaken by FY1 doctors at the Trust.

Discussion: Two fundamental issues were highlighted by the audit. Firstly, the audit identified a concern relating to the prescribing of an opioid for rescue medication. Secondly, the audit highlighted the need to address one of the most common adverse effects of opioid therapy - constipation. Since initial prescribing of opioids was undertaken mainly by junior doctors, the audit emphasises the need for further education and training.

Abstract number: P1-107
Abstract type: Poster

“The Please Describe a Typical Case of an Error in Palliative Care” - Open-ended Qualitative Results of a Survey in Palliative Care Professionals

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Context: Patient safety is a relevant concern in medicine and handling of medical errors poses a challenge. In palliative care, the definition and understanding of an error is particularly difficult, and there is a lack of clinical evidence about the special nature and causes of medical errors in this discipline.

Objectives: We aimed to explore palliative care professionals understanding of what constitutes an error and what possible areas and consequences of errors in palliative care might be.

Methods: In the context of a mixed-methods survey among 13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
Abstract number: P-108

Audit of Steroid Prescribing and Monitoring in an Inpatient Specialised Palliative Care Unit (SPCU)

Pavithra A., Field-Smith A.H., Sathyathana I.

Methods: Retrospective case note review of admissions to a SPCU over 3 months using a data collection proforma in patients defined as taking steroids.

Results: 74 admissions, 69 case notes reviewed of which 61% were taking steroids (76% admitted on steroids, 24% started during admission). Indication and duration of steroids not documented in 26% and 31% respectively. 79% had steroids reviewed within 7 days and in 12% steroids stopped or weaned as no benefit. 79% patients were taking PPs, 26% were on concomitant NSAIDs, 1 patient not on a PPR. 26% were on steroids inducing anti-epileptic, 1 of whom had steroids dosed adjusted. 50% had blood glucose monitoring, 1 developed hyperglycaemia. 16 patients in the end of life situation, 8 of whom did not have benefit/need of continuing steroids clearly documented. 20 patients discharged on steroids, 18 of whom had a documented plan for weaning. No steroid cards issued.

Conclusion: The audit demonstrated that steroids were reviewed appropriately in most cases but documentation in certain areas recommended. Recommendations are: a weekly drug chart review with the pharmacist to identify appropriate dose adjustments; written prompts on the drug chart; blood glucose monitoring at least weekly on all patients on steroids; steroid cards for patients taking corticosteroids for >3 weeks. The plan is to develop local guidelines for steroid prescribing and monitoring to improve practice.

Abstract number: P-109

Abstract type: Poster

Successful Implementation of a National Research and Quality Assurance Database: The Danish Palliative Care Database (DPD)


The Danish Palliative Care Database (DPD) was launched in 2010, and is one of the few national registries aiming to include ALL patients referred to specialised palliative care (hospice and palliative care teams/units), irrespective of whether they are admitted or not. The aims were to analyse the feasibility, data completeness, and the results of the DPD for the first two years, 2010-11.

Methods: A web-based data reporting system was established for the specialised palliative care units.

Results: In 2010, all 36 units in Denmark reported their patients; totally N=40,041 cancer patients were referred (3.8% had other diagnoses). DPD patient completeness was >95%. Completion of data was 98.6%. Results for the five quality indicators:

<table>
<thead>
<tr>
<th>Indicator</th>
<th>N (%)</th>
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<td>1) 76.5% of the referred patients were admitted (Standard 80%)</td>
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<td>2) 81.5% were admitted within 10 days from referral (50%)</td>
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<td>3) 27.6% of all patients dying from cancer were admitted (15%)</td>
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<td>4) 38.1% were screened with Q2-C15-PAL (55%)</td>
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There were very large regional and inter-institutional differences. Records from the highest performing unit (3.891 patients referred), and small improvements in 4 of the 5 quality indicators. Survival from referral to death: mean 31 days (II), median 75 days, palliative teams 41, mean 67 days (hospice 43, teams 80). Conclusion: A national database with exceptionally high data completeness, high variation of data standards were measured over 5 indicators. Results are clinically meaningful, showing marked variations in quality according to the five indicators between regions and between teams and hospices. It is expected that DPD will contribute to securing Danish patients equal access to high quality palliative care.

Abstract number: P-110

Abstract type: Poster

Home Care Sweet Home Care: An Audit of Hospital Attendances from Care Homes

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Aim: 1.5% of the population in this retirement area, reside in 109 care homes. There was an incidence of deaths occurring in care homes is increasing (22% in 2010), but it is unclear why the number of local people transferred from care home to hospice is decreasing. Local Clinical Commissioning Groups (CCG) commissioned an audit to understand the reasons for, & identify whether measures could be put in place to reduce the number of hospital admissions.

Design: The agreement & assistance of all care homes, hospital departments & CCG were obtained. All acute hospital, care home attendances, during October/November 2011 were identified & data collected from review of admission notes & a telephone interview with the care home.

Results: Of 366 identified attendances, 1/3 had resided in a care home for more than one year, over half had dementia & 3/5 had 3 or more co-morbidities. Despite the initial call for help being “in hours” the majority were assessed in hospital “out of hours”. In over half the call was directly for an emergency ambulance, yet 51% returned home in less than 24 hours suggesting community management may have been possible.

Since then, 29 care homes have participated in the Six Steps to Success programme. A care homes conference enabled staff to meet with palliative care staff, CCG leads & other health & social care professionals & was well received. A supportive care register is embedded within the acute hospital & advanced care planning training continued across the locality. The re-audit of some elements after 1 year will be available for this poster.

Conclusion: Understanding the circumstances of many short, acute hospital, attendances from care homes, has resulted in collaborative projects between care homes, primary, secondary & tertiary palliative care, improved communication & guided Advance Care Planning promotion. Anticipating care needs & collaborative working should improve experience of care home residents.

Abstract number: P-111

Abstract type: Poster

Regional Re-audit of the Management of Hypercalcaemia of Malignancy on behalf of the North West Audit Group (Palliative Medicine NWAG)

Baron K., Harrison S., Waterman D., Thorley F., Reid S., ‘North West Deanery, Palliative Medicine Trainees, Manchester, United Kingdom, ‘University Hospital of South Manchester, Manchester, United Kingdom, ‘Stockport NHS Foundation Trust, Stockport, United Kingdom, ‘North Western Regional Trust, ST4 Palliative Medicine, Manchester, United Kingdom, ‘Central Manchester Foundation Trust, Manchester, United Kingdom.

Aims: To assess the management of patients with hypercalcaemia of malignancy including fluid rehydration, checking and recording of renal function, medication review, timing, dose, dilution and rate of bisphosphonate treatment, timing of repeat blood calcium after treatment and to compare the results to those of the original NWAG audit carried out three years previously.

Methods: A multi-centred, cross-regional retrospective audit of case notes from patients with cancer and hypercalcaemia as defined by their local biochemistry laboratory. The original preforma was revised slightly in line with the latest evidence and disseminated to palliative care services in the region. The data was analysed centrally by NWAG and a selection of individual reports were disseminated to participating organisations.

Results: A total of 79 proformas were returned from ten organisations comprising data on palliative care patients admitted to hospices sites. Of the eight audit standards, there was an improvement in adherence to seven when compared to the original audit. The most significant change pertained to the correct dilution and rate of bisphosphonate infusion. The only lower standard was recording of a patient’s eGFR prior to treatment. This may have been because the standard was amended from the original audit to specify eGFR rather than renal function.

Conclusion: This re-audit demonstrates an improvement in the management of hypercalcaemia of malignancy across the region in the three years since the original audit. The results were disseminated to organisations for local action plans to be developed.

Abstract number: P-112

Abstract type: Poster

Audit of Regional Metastatic Spinal Cord Compression Clinical Guidelines and Pathway

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Aims: Metastatic spinal cord compression (MSCC) occurs in 10–15% of patients with vertebral metastases. It may cause paraplegia and loss of bladder and bowel function. Early investigation and treatment are therefore essential to avoid neurological damage. Regional guidelines were introduced in May 2012 to support healthcare professionals in identifying and managing MSCC appropriately and urgently. The guidance also outlines the action that should be taken when MSCC is confirmed. This audit aims to assess adherence to these guidelines within an acute hospital.

Methods: A retrospective audit will be conducted to assess compliance with regional guidelines over a five-month period. Patients who have had Magnetic Resonance Imaging (MRI) of the spine for suspected MSCC, as well as those who have had an incidental finding of cord compression on MRI, will be identified. Their clinical notes will then be reviewed to assess whether the guidance and guidelines were followed appropriately. All patients will be followed up.

Results: This audit is currently in progress and results are awaited.

Conclusion: It is intended to use the results of the audit to improve clinical practice and as the basis for education of health professionals in this area.

Abstract number: P-113

Abstract type: Poster

Overcoming the Chaos: Terminology and Definitions in Palliative Care

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Background: In the intense discussion on outcome indicators in palliative care (PC) neither the terminology nor the definition of outcome quality (IQ) are applied.
uniformly. The conception of a consistent terminology and a definition of DOQ in PC that considers its multidimensional approach was the goal of this project.

Methodology: Theoretical and methodological foundation for the quality evaluation is the differentiation between constructs (latent variable), criteria (observable dimension) and indicators (measures).

Three preceding publications of the project team on aims and methods of PC were referred to, as well as others described criteria for a high quality. Constructs were critically examined and items categorized as criteria were examined regarding their applicability to the above identified constructs.

Results: Constructs mentioned directly were “dignity”, “achievement”, “fear”, “burden” and “personality” as well as “quality of life”. The criteria related to the identification of two additional constructs: “physical wellbeing” (symptom control, general physical well-being) as well as “social trust and care” (social interactions of the patient).

Conclusion: The evaluation showed that constructs are multidimensional and cannot be differentiated clearly from each other. Especially “quality of life” might not be an independent construct, and further evaluation is needed to determine how far it is included in other constructs or whether it might even be synonymous with the outcome quality of palliative care as such.

Method: In the step in the project will be an investigation of the individual constructs and the identification of adequate criteria for each construct.

Funded by the German Cancer Aid (grant no. 108726)

Abstract number: P1-114
Abstract type: Poster

Audit of Empirical First Line Antibiotic Therapy for In-patients at St. Andrews Hospice, Airdrie

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Introduction: Antibiotic usage within the hospice setting is increasing with the rise in elective admissions for symptom control. This is the first audit to review adherence to the regional policy in NHS Lanarkshire in the hospice setting. An antibiotic prescribing policy exists because antimicrobial resistance is increasing and this causes a threat to patient safety and increases risk of antibiotic associated infection. Aim: The NHS Lanarkshire antibiotic prescribing policy is standard care for patients with infection at St. Andrews Hospice, Airdrie. The purpose of the audit is to review first line antibiotic prescribing for in-patients at St. Andrews Hospice, Airdrie to ensure prescribing meets the current standard.

Method: Retrospective analysis of patient kardex and notes, for admissions in months - August 2009 and October 2011. Results of cycle 1 were reviewed at a medical management meeting and fed back. Changes were implemented and practise reviewed in cycle 2 October 2011.

Results:
1st cycle 60 patient admissions August 2010
19 (32%) patients administered with antibiotic therapy
2nd cycle 60 patient admissions October 2011
15 (25%) patients administered with antibiotic therapy

Abstract number: P1-115
Abstract type: Poster

Has the Liverpool Care Pathway improved the Care of the Dying Patient in NHS Lanarkshire?

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The Liverpool Care Pathway ensures a high standard of care for the patient in their last days of life. Aim: Five years after its initial introduction this review provides an insight into the extent and standard of use of the LCP within hospice care. Method: A retrospective analysis of deaths in the three acute NHS Lanarkshire Hospitals - Hairmyres Hospital, Monklands Hospital and Royal Brompton General Hospital during February 2012. Case records were reviewed for patients who had died.

Results: 166 patients died across the 3 hospices in February 2012. 56 (34%) Patients were cared for on the LCP. The percentage of patients from each hospice cared for on the LCP was:
- 54% of patients in medical wards
- 50% of patients in surgical specialties
- 45% of general surgical patients
- 41% of patients in care of the elderly wards

The LCP was used mainly in patients with malignant disease:
- 45% of patients with malignant disease were on the LCP
- 28% of patients with non-malignant disease were cared for on the LCP.

110 patients did not die cared for using the LCP. For the 56 patients on the LCP version 11:
- 73% of patients had no essential medications discontinued

Conclusion: As required medications for symptom control prescribed for:
- Pain in 91% of patients
- Agitation in 91%
- Dyspnoea in 82%
- Respiratory Tract Secretions in 82%
- Nausea and Vomiting in 79%

Methodology: In NHS Lanarkshire the LCP was used to care for less than 50% of patients who died in February 2012.

The LCP was applied to most common indication of patients with malignant disease. Less than a third of patients with non-malignant disease were cared for using the LCP. This is disappointing as LCP was shown worldwide that patients managed on the LCP receive a higher quality of care in their last hours and days of life.

When the LCP was used on the ward of St. Andrews Hospice it has been used appropriately and medications for relief of symptoms are prescribed in the majority of patients.

Abstract number: P1-116
Abstract type: Poster

Blood Transfusions in Palliative Care: A Retrospective Audit

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Blood is a valuable resource. It is good practice to consider the clinical context and not just the patient’s haemoglobin (Hb) level when considering transfusion. This is particularly true in the palliative setting. Accurate documentation of the process is an important aide to safe transfusion. Aim: To assess:
- Is blood being prescribed for an appropriate indication, as per national standards?
- Are transfusions being documented appropriately?
- Are transfusions achieving the desired outcomes?

Methods: The audit population were hospice in patients who received transfusion of one or more units of blood over an 8 month period. There were a total of 41 units transfused to 15 patients over the designated time. An audit proforma was completed for each patient; results were compiled and compared to audit standards.

Results: The indication for the transfusion was documented in all patients, with more than one reason being given in 14 out of 15 patients. The most common reason cited was low Hb, with the range being 3.4 to 9.1. The most common symptoms and indications were shortness of breath and fatigue. The outcome following transfusion was documented in 7 out of 15 patients and varied from clear symptomatic improvement to none. Out of the 15 patients, 9 died during the same admission. The range of time between blood transfusion and death was 5 to 32 days. The standard of documentation was satisfactory and good, with some areas highlighted for improvement.

Conclusions: Physicians are practicing holistically by using more than one indication for transfusion in the majority of patients. The short survival times post transfusion may raise questions over whether some of these were indeed justified. However, the most common and important outcome for palliative patient is symptomatic improvement. Recording outcome is often an forgotten part of the process. Routine addition of this may have a positive impact on patient transfusions, and prevent inappropriate use of a valuable resource.

Abstract number: P1-117
Abstract type: Poster

Audit of Usage of Short Acting Fentanyl (Oral and Nasal) in a Tertiary Oncology Unit in UK

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Background: Fast acting fentanyl preparations are sometimes used for breakthrough pain and as a last resort in terminal incident pain, where conventional IR opioids are ineffective. They are licensed for opioid tolerant cancer patients (>160 mg morphine equivalent daily dose MEDD). Starting dose does not equate to background opioid dose and must be individually titrated. These medications are strong opioids with potential risk of toxicity. They are also expensive, hence usage should be appropriate, monitored with clear outcomes recorded.

Methodology: Retrospective case notes review of patients identified from pharmacy data January to December 2011. Case notes, Electronic Patient Records, Drug charts and Nursing notes were reviewed against clear audit standards using a specifically designed proforma.

Results: 81/91 patient notes were available and 75 included data on adult patients consuming fentanyl. 34% of patients had died. There was poor documentation of use of conventional IR opioids (80%: 87/101 were on ≤60mg MOR). Background opioids (patient had received morphine (3%) and fentanyl (2%) Dose/titration/review: 46/65 (71%) patients started on the recommended dose of 100 mcg. However, 21 started at doses <100mcg, 5 at 50mcg, and 4 at 200-400 mcg. Where effect could have been assessed documented, 25 patients had benefit, 15 had no benefit and 27 had no documentation of assessment of benefit. Of the 34 patients who were titrated and discharged, 28% used 200mcg, 5% 300mcg, 8% 400mcg and 8% >600mcg.

Conclusion: Use of fast acting fentanyl warrants clearer guidelines, documentation re rationale, assessment of benefit and follow up plans. Guidelines have been drafted and clinical practice will be re-audited following implementation. This baseline data will aid monitoring of prescribing trends within the Trust.

Abstract number: P1-118
Abstract type: Poster

Beneficial Effect of Jelled Elemental Diet in Patients with Head and Neck Cancer

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Aims: Either combination or monotherapy of radiation and chemotherapy in patients with head and neck cancer results in worse nutritional status, because unfavorable incidence occurs followed by eating and swallowing disturbance. We supplied jelled elemental diet in 300cal/day and examined to see the persistency and the effects on the nutritional status.

Method: Prospective interventional study.

Methods: Participants were 57 patients with various cancers who were hospitalized in Shimane University Hospital (2010.4-2012.2.), 16/16 (Ajinomoto Pharma Co., Ltd) of 300cal/day was jelled with a flavor at patient’s choice and supplied for each meal in 100ml or 200ml (diluted with water). Nurses and dentists coached and encouraged them to eat. Rate of eating of each patient was recorded. Statistical difference was determined by Mann-Whitney U-test.

Results: Patients with head and neck cancer (n:19, group A) had taken jelled Enteral® significantly longer time than patients with other cancer (n:38, group B). The ratio of patients who kept taking Enteral® at 14 days was 74% (14/19) in A and 47% (18/38) in B. In this population, serum albumin (AB) level was significantly increased at 14 days in A (3.1±0.6 to 3.6±0.6 g/dl, p<0.001) compared with those of group B which was not shown in B. In addition, AB was not changed in 5 patients in A who stopped the diet within 4 days (3.6±0.3 to 3.6±0.9 g/dl, p<0.001). It was suggesting that at least combination therapy in patients with head and neck cancer is beneficial to show the potential benefit of elemental diet. Main cause of the cessation was stomatitis and appetite loss.

Conclusion: Jelled elemental diet may be beneficial in patients with head and neck cancer when persistently taken for 14 days or more.
Abstract number: P1-119
Abstract type: Poster

Impatient Palliative Care - Is there a Role for Medical Process Management? A Qualitative Approach

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Introduction: Patients in Palliative Care (PC) have individual and changing needs. Multiprofessional and patient-centered care is crucial to achieve the objective, but at the same time this can be challenging as it involves many interfaces. The newly established specialized palliative care units (SAPV) in Germany are treated by general practitioners and other healthcare professionals. The possible role of medical process management (MPM) - often referred to today in terms of efficiency and efficacy - is unclear in PC. Therefore we conducted a first study to describe processes and learn about the role of MPM in PC.

Materials and methods: A five step approach was performed.

1. Participant observation,
2. Expert interviews to detect processes, the individual person responsible for a single process and the main interfaces on IPCU,
3. Discussion of the results in expert-rounds,
4. Visualization of detected processes and
5. Analysis of current procedures and proposed options.

Results: Four key processes have been identified and examined in detail: Transfer / admission, diagnosis, therapy and change. Emerging uncertainties as to responsibilities for the key processes as well as the importance of systematic documentation and the appointment of process owners have been observed. Following this study, the interface between the referring service and the PC service has been restructured to optimize admission and to provide the staff with clear roles and responsibilities. But necessary to quickly address the needs of newly admitted patients (5).

Conclusions: To our knowledge this is the first study on MPM in PC. The systematic analysis of processes and structures helped to optimize the workflow, to detect obstacles in the treatment process and to provide a secure and reliable service for the patient. MPM was of key importance to clarify responsibilities within the team. So, MPM in PC can help to reduce administrative workload and thereby gain resources for what the palliative care team stands for: best possible patient care.

Abstract number: P1-120
Abstract type: Poster

Have Changed the Prejudices against Opioid Therapy in the Last 10 Years?

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Research aims: The majority of terminal ill patients in Germany are treated by general practitioners and other physicians in private practices as part of the general outpatient palliative care (AAP = Allgemeine ambulante Palliativversorgung), most of them without training in palliative care. The newly established specialized palliative home care (SAPV - Spezialisierte ambulante Palliativversorgung) was implemented as a right for every patient in need beginning in the end of the year 2008. The results of our survey can help to improve SAPV and AAP.

Methods: We sent out 600 questionnaires to randomly selected general practitioners in the States of Brandenburg Western Pomerania/Germany in April 2008 (response rate: 34.3%; n=207). They consisted of 46 questions about palliative care and SAPV. We compared our data collected in 2008 with those of the earlier survey conducted in 1999 (n=205).

Results: 74% of the physicians would prescribe no higher doses than 200 mg of oral morphine at any time in the course of the disease to cancer patients in pain. 19.6% of the general practitioners would not prescribe morphine in these circumstances. It is very careful when prescribing narcotics because of the danger of addiction; in the subgroup of physicians treating cancer pain patients this fear is significantly lower than in those not treating cancer pain patients (p<0.001), also in group of general practitioners this fear is lower than in other physicians. The also professional training (p<0.01) and personal experience (p=0.038) reduce this possible impediment to opioid prescription. Compared to 1999 there is no significant change.

Conclusion: Based on our survey the treatment of cancer pain patients by their physicians has not improved much in the last ten years. More than one quarter of the physicians (26.7%) would generally limit the daily morphine dose. General practitioners in primary care are the most influential. There are still deficits. Training of all active physicians and medical students in palliative medicine should be compulsory.

Abstract number: P1-121
Abstract type: Poster

Communication: The Interface between Community Specialist Palliative Care and Primary Care

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Aims: An approachable, responsive specialist palliative care team (SPCT) is crucial in supporting primary care, with SPCT commonly being the link between hospital specialties and the community. We were keen to ascertain what primary care consider the best way to communicate to them as well as determining how effectively we currently communicate. This was explored in a 12-week pilot study. Alongside this we were keen to investigate how effectively we document our communication to primary care in our case notes. This was explored via a primary care survey.

Methods: The survey was sent to all General Practitioners (GPs) within our locality and we asked the following questions:

• How primary care would like us to respond to the urgent/non urgent referrals sent from primary care
• How primary care think we perform with regard to specific communication domains
• The audit was a retrospective review of nurse case notes over a period of 6 months following an urgent referral from primary care, looking primarily at:
• Following our review whether the patient was placed on the GP palliative care register
• How the SPCT responded to the referral
• Only half of respondents had referred a patient to the SPCT in the last 12 months

Results:

• Urgent reviews - written letter
• Non-urgent reviews - written letter
• Satisfaction scores - majority rated as good
• Total of 59 case note records

Conclusion: Since this piece of work we have now developed a communication pro-forma to fax to primary care following any urgent review by the SPCT. The pro-forma has been designed to ensure it is easy to complete and easy to read quickly.

Acknowledgement: This research was supported by a grant from the Macmillan Cancer Support.

Poster sessions
Malignant Bowel Obstruction in Patients with Advanced Ovarian Cancer Admitted to a Regional Oncology Centre

Abstract number: P1-126
Abstract type: Poster

Malignant bowel obstruction (MBO) in patients with advanced ovarian cancer (AOC) is challenging. It is a common presentation and may require inpatient admission. The aim was to examine bowel obstruction aetiology, management, and outcomes.

Methods: Retrospective review of all AOC patients with MBO admitted to a regional oncology centre (ROC), their baseline characteristics, management and outcomes.

Results: 78 consecutive AOC admissions were screened. 8 patients had MBO. Median age 56 (IQR 36-77) with 72% of MBO patients were of non-Caucasian ethnicity. The average duration of admission was 18 days (range 8-36). 3 patients had complete resolution of MBO and were discharged home. 3 patients had MBO at discharge (1 discharged to 4 palliative care home, 2 to a hospital). 2 patients died during admission. Of the 6 discharged, 3 died within 30 days and 2 more died within 6 months. Of the 2 patients who were discharged from hospital following a DNACPR order, 36.7% died subsequently. 12 patients were listed on the local supportive care register (ROC).

Discussion: This audit does not prove that patients with a DNACPR order will die in the next 6 months. DNACPR status may be a marker for severe disease. Where patients have had inpatient DNACPR orders are discharged from hospital, realistic discussions about the state of their health should form part of their compassionate care register and advance care planning may be appropriate.

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Symptom Assessment System (ESAS) was used revealed that 46% of patients were asked what they hoped the admission will achieve and whether they had SMART objectives on admission. Only 16% of patients reported some or all SMART objectives, 30% had inadequate comments and 10% did not record SMART objectives. The initial audit showed 80% of patients had SMART objectives on admission, 30% of patients achieved some/all of these, 53% had discussions about end of life support, 30% had discussions about VTE prophylaxis, and 30% had discussions about the state of their health.

Conclusions: Fewer AOC inpatients had MBO than was expected. Anticipated bowel obstruction is common. Management strengths included initial assessment, use of CSCI medications and discharge planning. Weaknesses included referral for a specialist examination and poor documentation of vomiting. A result, local guidelines have been updated to assist in the management of antiemetic treatment.

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P1-126
P1-127

Patient Involvement in Care & Treatment - An Audit

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Introduction: The Care Quality Commission states that patients should be involved in decision-making about care and treatment. The audit examined whether patients were asked if new objectives were set as circumstances changed. Re-audit was carried out in March 2012 following a training, revising documentation and timing of reviews. Re-audit showed improved practice: 87% of patients had SMART objectives set on admission, 60% of patients had achieved some/all of these, 30% had inadequate comments and 27% had discussions about end of life care.

Conclusions: Most patients were able to identify and achieve some or all of their objectives during admission. The objectives were useful in guiding patients to their desired care.

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Poster sessions – 91

VTE (Venous Thromboembolism) Prophylaxis in a Palliative Inpatient Unit: To Administer or Not, that is the Question

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Aims: The National Institute for Health and Clinical Excellence has rolled out guidelines for VTE prevention for England and Wales which all NHS trusts have adopted. They aim to reduce preventable deaths in VTE in hospitals, causing 25,000 deaths per year. There is strong evidence that VTE is preventable in a general hospitalised population; this is less evident in the palliative inpatient population. The guidelines dichotomise terminal care for palliative patients, recommending only to treat the potentially reversible acute pathologies. Prophylaxis can also increase the risk of bleeding. We assessed the suitability of VTE prophylaxis in our hospice population.

Methods: A retrospective review of inpatients from January to March 2012 in a 10-bed hospice using the Oxford Radcliflfe NHS Trust online VTE risk assessment tool.

Results: Over the 3 months, 37 patients were admitted to our inpatient unit. 56% (21/37) males and 44% (16/37) females. Their average age was 72.11% (n=4) were in for respite. 43% (n=16) admitted for terminal care were not suitable for VTE prophylaxis. 92% (n=34) died. 46% (n=17) were in for symptom control but only 24% (n=5) met the criteria for VTE prophylaxis. Eventually all 4 died. 41% (n=7) had increased bleeding risk which negated the VTE prophylaxis. One patient was already being treated for confirmed VTE 12% (n=2) were mobile and not at risk. None had a VTE event.

Conclusions: Generally, cancer patients have higher risks of thromboembolism and bleeding. With palliative inpatients, it is difficult to determine if initial symptom control has transitions to support once this becomes evident. Whether VTE prophylaxis should have been started. From our cohort of symptom control patients, only 26% (10 of all patients admitted) met the criteria for VTE prophylaxis but all eventually died. We conclude that the benefit of VTE prophylaxis as prescribed by the guidelines is questionable for the palliative care setting. The chlorine trial (Lancet 2009) are required.

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As Needed” Psychotropic Medications in a Long Term Hospital

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Introduction: Pro Re Nata (PRN) or as needed psychotropic medications associated with routine medication is a common practice in mental health centers and nursing homes. However, it has not been established that the use of specific guidelines governing this practice. The aim of the study is to describe its use in a long-term hospital including four wards: patients with mental illness, elderly, dementia, brain damage and convalescence.

Materials and methods: A retrospective review of PRN medications in patients admitted from April 2009 until August 2012 was performed. Pharmacy medication records
were reviewed to number the patients who are prescribed psychotropic PRN, the main drugs involved and the condition for its administration.

Results: During the study period 774 patients were admitted to hospital, initially assigned to one of the four palliative care wards. Nine out of ten patients were prescribed one or more CPR medication. A total of 1,318 CPR psychotropic medications were prescribed. More than half of the patients were included in one of the 23 drugs recorded (264 patients hypnotics or anxiolytics, as n2, 212 neuroleptics, 8 antidepressants and 18 antiepileptics). The main drugs were fentanyl, midazolam, risperidone and haloperidol. Regarding a German University Hospital, “as needed,” “insomnia,” “agitation,” “anxiety” and titration accumulated 79% of PRN prescriptions. The remaining were ambiguous or combined conditions.

Conclusions: Just as in other hospitals, psychotropic drug prescription is a common problem in our hospital. The conditions for administration expressed by the prescriber are in many cases inaccurate to interpret correctly. Although all patients are documented, they are recorded in the nursing chart and discussed by the health care team, this inaccuracy may lead to different interpretations by nurses and an overseer of these drugs unnecessarily. Developing best practice consensus would reduce discretion in decision making.

Abstract number: P1-131
Abstract type: Poster

First Quality Manual for Hospice and Palliative Care Services in Europe

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Aims: Aim of this project was a quality manual assisting hospice and palliative care services in the designating and processing of their daily activities.

Methods: For each of the six types of hospice and palliative care services (palliative care units, in patients hospice, day hospice, mobile palliative care teams, palliative care hospital support teams, volunteer hospice teams) a model process was developed for the following situations:

• Start of Care
• End of Care

These processes were developed by the joint effort of GÖG/ÖBIG (Austrian Federal Institute for Health Care), Hospiz Austria and the Austrian Palliative Care Association (ÖPCA). All 260 hospice and palliative care institutions in Austria were invited to participate in this quality management project. About 60 of them became partners in the project thus ensuring an outcome meaningful for the daily practice. The project group started by assessing the actual practice and the daily routine. It was carried out during a festive event hosted by GÖG/ÖBIG and the Ministry of Health. All hospice and palliative care institutions in Austria were invited.

Conclusion: Two aspects make the manual unique: the first is the involvement of all services working in the field of hospice and palliative care resulting in a great alignment with regards to basic structures of processes. The second is that one manual was created for all types of hospice and palliative care services. The project was funded by public funds.

Abstract number: P1-132
Abstract type: Poster

A Cost-effectiveness Analysis of a Rehabilitation Service for Survivors of Cancer

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Aim: To evaluate the cost-effectiveness of a rehabilitation service for people living with and beyond cancer, delivered in a hospice day care unit.

Methods: Clinical and economic data were collected as part of a cost-utility analysis undertaken using Monte Carlo simulation. The main outcome measure for the economic evaluation was quality adjusted life years (QALYs). Costs were measured from the perspective of the National Health Service (UK). Uncertainty in the observed data was captured through probabilistic sensitivity analysis. Scenario analysis was conducted to explore the effects of treatment being maintained beyond the observed trial period.

Results: Forty-one patients entered the study. Preliminary results show an incremental cost-effectiveness ratio for the base-case analysis around £19,500 per QALY. At a societal willingness to pay of £20,000 per QALY the intervention is likely to be cost-effective in 55% of simulations when compared with usual care. The likelihood that the intervention is cost-effective increases with the length of time after the intervention improvements in quality of life are maintained.

Conclusion: This rehabilitation intervention may offer a cost-effective use of resources for the benefit of cancer survivors, especially if benefits are sustained long term. There is significant uncertainty in the results; we recommend collection of further data to improve cost-effectiveness over longer time periods and in different settings.

Abstract number: P1-133
Abstract type: Poster

A Study to Predict Serum Concentration of Transdermal Fentanyl in Cancer Patients by SKIN-CAD®

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Aims: Serum concentration of fentanyl patch (FP) may have wide variation among cancer patients because absorption rate of FP on skin might be unpredictable to some extent. Therefore, we conducted a prospective study to predict serum concentration of FP by using SKIN-CAD (CAD). Methods: Patients applied transdermal fentanyl patches and those of which type (FP-M) were 35 and those of which type (FP-M) were 9 respectively. Blood samples were collected at 24, 48 and 72 hr after application of FP. We calculated the normalized serum concentration by CAD and the method (INFU) that hypothesized transdermal administration as continuous intravenous infusion, and compared the results by both methods. Mean absolute prediction error (MAE), mean prediction error (ME), root mean squared error (RMSE) of each serum concentration at 24, 48, 72 hr after application were computed, and probability of prediction was evaluated.

Results: MAE, ME and RMSE of FP-P calculated by CAD were 4.063, -1.864, and 1.569 at 24 hr, 3.471, -1.161, and 1.306 at 48 hr, and 1.194, 0.682 and 0.433 at 72 hr, and those calculated by INFU were 4.687, 1.732 and 2.141 at 24 hr, 3.775, -0.459 and 1.459 at 48 hr, and 1.176, -0.295, and 0.540 at 72 hr. In contrast, MAE, ME and RMSE of FP-M calculated by CAD were 0.081, 0.059, and 0.062 at 24 hr, 0.498, and 0.626 at 48 hr, and 0.128, and 0.058, and 0.060 at 72 hr, and those calculated by INFU were 1.336, -0.365 and 0.676 at 24 hr, 1.498, and 0.873 at 48 hr, and 1.215, 1.215, and 0.750 at 72 hr.

Conclusion: The numerical values of MAE, ME and RMSE calculated by CAD were smaller than those by INFU. It was indicated CAD was more predictable. However, values of FP at 24 hr were unpredictable and it was considered serum concentration of FP was not predictable during 24 hours after application. Therefore careful monitoring is essential during 24 hours when FP is administered. This is the first clinical trial used by CAD if it was suggested CAD could be predictable to some extent.
Purpose: Although advance care planning (ACP) is recognised as integral to quality cancer care, it remains poorly integrated. Given cancer patients’ unpredictable disease trajectories and equivocal treatment options, a disease specific ACP model may be necessary. This study examines how Australian cancer patients consider ACP. Results will inform development of an Australian Cancer Council’s ACP programme.

Methods: A constructivist research approach within grounded theory design was applied. Eighteen adults from lung and gastro-intestinal tumour streams participated. Participants first described their experiences of ACP, then were asked about values, memories, personalities, health perceptions, and iteratively. Reactions can change over time and are informed by values, personalities, health perceptions, and trust or doubts in others.

Conclusion: ACP may be acceptable to patients who initially reject the advice of healthcare professionals. Policy makers may need to broaden criteria for ACP outcomes to include the choice not to discuss care plans, and discourage ACP facilitation. Further exploration and research is required to accurately capture how these forums are conducted in other health-related subjects. This is because a key area of discussion around online support is how these groups are moderated (eg peer versus professional support). Similar issues may arise in other health care environments.

Abstract number: P1-142
Abstract type: Poster

Relatives’ Satisfaction with Care of Terminally-Ill Patients at Different Places of Care

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Research aims: The aim of the study was to assess relatives’ satisfaction with care of terminally ill patients at different inpatient places of care in the federal state of Rhineland-Palatinate, Germany.

Study design and methods: The cross-sectional survey was based on a random sample of relatives in 69 hospitals from Rhineland Palatinate that had died between 25 May and 24 August 2008. Relatives of these randomly drawn deceased patients were interviewed by field workers. Of the 1,378 relatives who responded, 753 evaluated the quality of inpatient care during the last four weeks before death. The final analysis included all of them. Subject heading and free text searches were conducted in PsycINFO has been conducted using the thesaurus term “bereavement” in “cancer” as a subject heading in all of them. Subject heading and free text searches were conducted in PsycINFO with the terms “bereavement” and “cancer” as subject headings.

Conclusion: This group of young people now have the knowledge that despite the difficult times that may lie ahead they have the confidence and inner greatness to face the future and make positive choices that will transform their lives.

Abstract number: P1-141
Abstract type: Poster

Bereavement, The Bright and Dark Side of Online Discussion Forums

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Introduction: This explorative work commenced with a literature search on how the internet impacts on the bereavement experience. Four themes emerged: 1) new opportunities of bereavement and cognitive therapy online, 2) memorial websites, 3) information on bereavement and 4) bereavement support online (eg internet online discussion forums).

This presentation provides the findings of the last theme: the benefits and difficulties of online support.

Methods: A literature review on Medline, CINAHL and PsycInfo has been conducted using the thesaurus term “bereavement” in each database as a subject heading in all of them. Subject heading and free text searches were combined with bereavement using the terms “internet,” “social media” and “online.” To date, bereavement has been researched and written on the subject and, most importantly, there is no definitive research, on how health professionals have developed good practice in this area.

Results: Initial results found 23 relevant results from Medline, 25 from Psychology and 22 from CINAHL. There are few sources that focus on good practice on the use of discussion forums and bereavement. Although they provide some useful material, the search has been extended to retrieve records using the term “moderated” online” aiming to capture how these forums are conducted in other health-related subjects. This is because a key area of discussion around online support is how these groups are moderated (eg peer versus professional support). Similar issues may arise in other health care environments.

Conclusion: This literature survey provides some guidelines on whether and how health professionals could host online discussion forums as a part of their work with bereaved people, in the future. The final analysis will also incorporate findings from a survey of bereavement organisations, mainly in the UK, to ascertain the opportunities and challenges of this area of work.

Abstract number: P1-140
Abstract type: Poster

Support for Bereaved and pre Bereaved Siblings within a Palliative Care Context

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Purpose: To date, 60 patients could be included. The study examined the benefits and difficulties of online support.

Conclusion: This group of young people now have the knowledge that despite the difficult times that may lie ahead they have the confidence and inner greatness to face the future and make positive choices that will transform their lives.

Abstract number: P1-137
Abstract type: Poster

Understanding how Cancer Patients Actualise, Relinquish and Reject Advance Care Planning: Implications for Practice

Michael N.1, O’Callaghan C.1,2, Clayton J.3,4, Pollard A.5, Stepanov...
evaluated better than in other care settings. Relatives were also highly or mostly satisfied with pain treatment in palliative care units. Concerns is the majority of the relatives were satisfied with professional inpatient care, particularly in palliative care units, nevertheless there was a high degree of variation. Physicians perceived active and supportive skills deficits in standard hospital wards could be tackled by appropriate training programmes.

Abstract number: P1-143
Abstract type: Poster
Recording Voices in Palliative Care: How Does Providing an Oral History at the End of Life Influence Well-being of the Individual and the Bereaved?

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Aims: This research is assessing the impact of creating an oral history with palliative care patients and seeks to understand how family and friends regard audio recording in bereavement.

Background: An oral history and photography service for patients has run successfully in the Sheffield Macmillan Palliative Care Unit (UK) since 2007. The British charity Macmillan Cancer Support is working with the Sheffield team in developing further services in the UK, with a focus on the impact of audio recordings on the participant and the bereaved. Qualitative data is the recording of unique experience, it captures and preserves voices and individuals are involved in the process of producing their own history. The focus of the research is to see if recording a story can be the chance to create a lasting life story record. Oral history is accessible as a form of biography since it provides an opportunity for participation across a range of abilities.

Methods: This is a mixed method study. We are conducting a literature review, identifying other services involved in life story recording in palliative care and exploring views about oral history with patients and the bereaved using an interview and questionnaire approach, and analysing an oral history record.

Findings: To date indicate that oral history is well received, patients and relatives were invited to have the opportunity to create an audio life history and family and friends are pleased to have a voice record of the deceased. However this research is equally identifying barriers to participation and addressing whether oral history is always welcome in bereavement. Results from this study are shaping the direction of present and future oral history services in palliative care.

Abstract number: P1-144
Abstract type: Poster
How Do Children and their Parents Experience a Family Bereavement Group - A Longitudinal Qualitative Survey

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Research aims: More than 50 projects for bereaved children are available in Germany. We investigated motivations to participate and perceptions of effectiveness in children and parents participating in one of these groups (Tria Dich Traumen).

Methods: Using a mixed method design, an open questionnaire was sent to children and parents 6 weeks after the bereavement group answered. In addition, families were interviewed at the end of the group. Recruitment was stopped when saturation was achieved. Content analysis was used to evaluate the questionnaires and transcribed interviews.

Results: From 2005 to 2010 160 children and 72 adults participated in 19 bereavement groups. The study included 97 questionnaires (47 children, 20 interviews rate 30% and interviews with 8 children and 4 adults. Half of the children and 70% of the adults were attending because they expected a positive effect for themselves (e.g. communication about emotions). The parents attended because they wanted an expert assessment and support for their child. The majority of parents reported to feel better physically and better psychologically. They also wanted to communicate about handling loss and grief with experts and other parents. Some children (14%), however, have not attended because they didn’t want them to feel. The vast majority rated the bereavement group as a positive experience (45 children and 20 adults), 22% of the communication with other participants (16), the atmosphere in the group (12) and the breaks (19). Most parents (19) mentioned a positive effect to their children. The participants attribute to the group that it creates a community spirit and a possibility for the grieving process, it gives orientation in the time after a loss and it reduces insecurity.

Conclusion: A bereavement group is experienced as helpful by children and parents. The perspective of participants added relevant categories in the discussion of impact of bereavement support.

Education

Abstract number: P1-145
Abstract type: Poster
Which Topics Should be Integrated in Undergraduate Palliative Care Education? Views and Expectations of 253 German Medical Students

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Introduction: In Germany, palliative care was introduced as a compulsory subject in the curriculum for undergraduate medical students of the 3rd, 4th and 5th year students. The candidates must have been trained in palliative care. There has been some debate concerning topics and contents of the new subject. Some universities decided to focus on pain and symptom control while others put more effort to convey the multidisciplinary approach of palliative care. This study was aimed to gain insight of wishes and expectations of medical students.

Methods: Before the implementation of palliative care as a compulsory subject in the curriculum for the 3rd, 4th and 5th year medical students of the University of Munich, Germany university were asked to answer a questionnaire mainly including numeric rating scales from 0-10. Results: 253 from 442 distributed questionnaires have been completed. 55 (from 82) questionnaires from 3rd year, 136 (170) from 4th year and 62 (87) from 5th year students. The majority of 5th year students felt that palliative care has been taught to a sufficient extent to them (mean 2.5 ± 2.4 standard deviation). Overall, “knowledge and skills in pain and symptom control” were rated as important (7.8 ± 2.1). However, “advis and support in reflecting the own role as physician in the “physician’s role in terminal illness” was rated as almost equally important (7.5 ± 2.2). Furthermore, “To obtain information and aids how deal with difficult ethical questions and treatment decisions in terminal illness” was rated as the most important topic (8.4 ± 1.8). Conclusion: Before implementation of palliative care as a compulsory subject in the curriculum for the 3rd, 4th and 5th year students of the University of Munich, Germany, the students attributed to the group that it created a community spirit and a possibility for the grieving process, it gives orientation in the time after a loss and it reduces insecurity.

Abstract number: P1-146
Abstract type: Poster
Nursing Students’ Attributed Impact to Palliative Care Learning: Better Nurses at the Bedside

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Teaching Palliative Care on Wheels: An Undergraduate Palliative Care Education? Views and Expectations of 253 German Medical Students

Students were asked to answer a questionnaire mainly including numeric rating scales from 0-10. Results: 253 from 442 distributed questionnaires have been completed. 55 (from 82) questionnaires from 3rd year, 136 (170) from 4th year and 62 (87) from 5th year students. The majority of 5th year students felt that palliative care has been taught to a sufficient extent to them (mean 2.5 ± 2.4 standard deviation). Overall, “knowledge and skills in pain and symptom control” were rated as important (7.8 ± 2.1). However, “advis and support in reflecting the own role as physician in the “physician’s role in terminal illness” was rated as almost equally important (7.5 ± 2.2). Furthermore, “To obtain information and aids how deal with difficult ethical questions and treatment decisions in terminal illness” was rated as the most important topic (8.4 ± 1.8). Conclusion: Before implementation of palliative care as a compulsory subject in the curriculum for the 3rd, 4th and 5th year students of the University of Munich, Germany, the students attributed to the group that it created a community spirit and a possibility for the grieving process, it gives orientation in the time after a loss and it reduces insecurity.

Abstract number: P1-147
Abstract type: Poster
Teaching Palliative Care on Wheels: An Undergraduate Palliative Care Education? Views and Expectations of 253 German Medical Students

Students’ perception after receiving Palliative Care teaching was asked at the end of the course. Answers written by the students presented in the room (n=248) were analysed through content analysis by three researchers independently and periodical meetings were held to review the analysis and achieve consensus. Ethics Committee approved the study. A comparison with a similar study, presented in this congress, undertaken with medicine students, is offered.

Results: Categories were, a) PC learning provided a holistic view of nursing. b) had a special contribution in their education. c) qualified them to care for terminally ill patients and d) promoted a personal growth.

The students’ emphasised PC learning showed them clearly that person care is the essence of the profession and highlighted the human part of the profession. Students identified that PC learning has its own entity and should be compulsory for all nursing students. Students stated that the subject had qualified them to understand better the patient and to know how to act with him. Finally they identified that PC teaching made them question about end of life, while helping to know them better and understood the psychological development. In comparison with medicine students is observed that nurses give more relevance to practice aspects of palliative care training.

Conclusion: The sample of nursing students explored aise to PC learning a positive effect on them at professional and personal level emphasizing its clinical applicability.

Poster sessions

Poster sessions

Poster sessions

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Poster sessions

Poster sessions
Palliative Medicine as an Elective in a Medicine School in Argentina, Austral University

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Palliative care is not yet an independent specialty in Sweden. It is an intense educational modality that is performed in a bus and in the place where the student is staying. (the hospital).

Objectives: To describe the CeC in Argentina.

Method: While travelling to the place where the patient is, the clinical case is presented. Once at the destination, the patient and his her family are interviewed by a faculty and 1-2 students, a 2 way communication system allows the student to experience the patient’s last hours. The student then follows and participate in the interview. Back on the bus, discussion of the case takes place during transportation to visit of another patient.

Discussion: The CeC provide a particularly useful educational activity: the student experiences the PC model. It is possible to reach primary care providers in their working places.

Abstract number: P1-149
Abstract type: Poster

Palliative Care Education for General Practice Trainees

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Aim: To assess the benefits of high fidelity simulation training in end of life care for medical and general practice trainees.

Methods: Two courses have been developed to provide simulation training in end of life care for non-specialist doctors undergoing core medical and general practice training. Scenarios based in acute hospital or community settings provided trainees with life-like experiential learning in order to develop their knowledge and skills in end-of-life care. Trainees were given the opportunity to engage in multidisciplinary settings and to work with patients, colleagues and relatives. Several high fidelity mannequins allowed the recognition of symptoms and appropriate role-players were used as members of the clinical team and relatives. After each scenario, feedback was given to participants using video playback of the scenario and the observations of facilitators and other participants.

Results: From a small group of medical doctors who completed the course assessments, students expressed an improvement in their comfort levels in the evaluation and treatment of pain and other symptoms, psychosocial and spiritual support to patients and their families and bad news.

Discussion: The addition of Palliative Medicine provided students knowledge concerning the main areas of Palliative Medicine. The experience gained by the students’ direct contact with patients and their families was highly valued. It is an important opportunity to integrate the issue of care people with life-threatening diseases in advanced stage in the Medicine curriculum.

Abstract number: P1-150
Abstract type: Poster

Certification of Nurses in Palliative Care

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Certification is a way of ensuring quality of care and underlining the nurses’ responsibility and competence in palliative care.

Abstract number: P1-151
Abstract type: Poster

Clinical Scenario Based High Fidelity Simulation Training in End of Life Care for Medical and General Practice Trainees

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Heart of England NHS Trust, Wolverhampton, United Kingdom

Aim: To assess the benefits of high fidelity simulation training in end of life care for medical and general practice trainees.

Methods: Two courses have been developed to provide simulation training in end of life care for non-specialist doctors undergoing core medical and general practice training. Scenarios based in acute hospital or community settings provided trainees with life-like experiential learning in order to develop their knowledge and skills in end-of-life care. Trainees were given the opportunity to engage in multidisciplinary settings and to work with patients, colleagues and relatives. Several high fidelity mannequins allowed the recognition of symptoms and appropriate role-players were used as members of the clinical team and relatives. After each scenario, feedback was given to participants using video playback of the scenario and the observations of facilitators and other participants.

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Abstract number: P1-150
Abstract type: Poster

Advanced Learning: PhD in Palliative Care - Three Years of Experiences of a Distance e-Learning Doctorate within the International Observatory on End of Life Care

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Aim: The PhD in Palliative Care was developed by the IOELC to enable palliative care professionals to develop specialist knowledge and research skills within their field. The innovative part time programme permits students to study via e-learning (2 years) and to undertake research from their home setting, with an annual academy based in Lancaster.

Results: The programme was launched in June 2010. Analysis of the 3 current cohorts show 29 international students (including Brazil, Bangladesh, North America and Slovenia) and 20 UK students. Some of the applicants were unable to take up their places due to lack of funding. The students’ professions reflect the multidisciplinarity of palliative care, including: medicine (n=11), nursing (n=5), social work (n=8), pharmacy (n=7), service directors (n=6), mostly medicine/nursing, chaplains (n=3), coordinators (n=2); and others (n=6). The distance e-learning modules allow study at an advanced level and the asynchronous nature permits study at a convenient time from any geographic location. This learning approach facilitates collaboration between students and teaching staff through discussions on the virtual learning environment and tools such as webinars and wikis. Peer interaction is encouraged through cross cohort presentations of research ideas at the annual academy.

Conclusions: There is an interest in developing scholarship and research careers across the professional spectrum of palliative care. The e-learning nature of the PhD Palliative Care facilitates learning and collaboration irrespective of location. Despite the popularity of the programme, insufficient funding remains an issue and mechanisms for funding resource-poor students are required.

Abstract number: P1-153
Abstract type: Poster
A Vision to Integrate an Undergraduate Palliative Care Curriculum: Lessons Learned for Program Development

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After the implementation of the 2003 Canadian EPPEPC program, the Division of Palliative Care at our university developed a vision to build and integrate palliative and end-of-life care (PEOLC) education into the undergraduate medical curriculum. An interprofessional (IP) team representing medicine, health sciences, palliative care educators and community hospice was established. Our vision included promoting and developing opportunities for IP PEOLC across faculties, seeking funding for collaborative educational research, participating in potentially relevant academic conferences, taking leadership roles in curriculum renewal planning, actively seeking out teaching opportunities. A 2004 needs assessment showed that most learning needs for, and receptivity to, a PEOLC curriculum.

Pre-2004: No consistent ugmte palliative care input. Less than 5 medical students/year choose PEOLC electives.

-2006-2008: A new ugmte curriculum integrated national PEOLC competencies and introduced first year students (MD1) to concepts of suffering, holistic care, and IP learning.

MD1: PEOLC teaching in ethics (2 hours); MD3 PEOLC session (2hrs); Electives: 36 hour IP course 'Death Made Visible'; IP on module 'Total Pain'; increased opportunities for clinical electives.

2008-2010 New elements added: mandatory selective rotations in palliative care (IM3), 2 hrs by manual basics review lecture (MD1, 1hr); Team OSCe, new elective IP PEOLC course.

2010-11: New PEOLC curriculum for MD-2 1 week Pain, 1 week PEOLC; exam 2011-12: MD2 - Ethics (2 hrs)


Curriculum change requires an approach which draws on pedagogy, through innovative, IP learning approaches; prioritisation with extension of compulsory elective; recruiting/retaining students (MD1-4) - requiring electives in palliative care.

Background: A historical distinction exists in medical education between formal (undergraduate) and informal (postgraduate) learning. Empirical is now increasing on formal learning in postgraduate training, with increases protected teaching time away from the workplace. Increasing reliance on formal learning may impede trainees’ and supervisors’ ability to recognise the learning embedded in workplace activity.

Aim: To explore how trainees’ learner preferences are changing and thus influence specific educational strategy.

Methods: Online surveys of palliative medicine trainees (MD1-4) and supervisors were inherent during a 1-year period at one UK Deeney plus semi-structured interviews of trainees (purposive sampling). Survey response rates were 77% for trainees and 66% for supervisors. Survey data was analysed using simple descriptive and comparative statistics (Fisher’s exact test). Following member checking, interview data was analysed using open coding.

Results: 65% of trainees and 88% of supervisors value opportunistic workplace learning more than learning in protected teaching sessions. 50% of 1st-2nd year trainees report workplace learning as more important than 85% of 3rd year.

Results: This paper revealed few institutions with key content specifically related to self-care and palliative care. Thematic key from policy (EU-US) will be presented. We have developed a conceptual framework for use in education and practice in palliative care and self-management will be presented.

Conclusion: The key outputs; curriculum guidelines in relation to self-management and palliative care for us in both US and EU nursing schools will be presented.

Abstract number: P1-162
Abstract type: Poster
Title: Concept Analysis of Self-care in the Context of Palliative Nursing
Authors: Johnston B.M., Marcoulskaite J., Cholewka P., Blazieniene A., Rogerson E.
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Background: Palliative care aims to improve quality of life of patients and their families through the diagnosis and treatment of any physical, social or psychological aspect of illness they may be suffering. While statutory bodies recognize palliative care education should be provided at undergraduate level little has been done to implement same. Aim: To investigate the knowledge levels of final year student nurses in the area of palliative care.

Methods: A cross-sectional survey research design was employed. The sample comprised of 48 final year bachelor of science in nursing students. Using the Palliative Care Quiz for Nursing Students, the researchers examined final year student nurses knowledge of palliative care. The PCON) consists of 20 statements regarding palliative care that are answered either true, false or I don't know. Two rank order questions were given to ascertain the importance of the participants to give to two of the highest and lowest ranked items.

Results: Results revealed the sample had a modest knowledge of palliative care with a mean of 9.28 out of 20. A notable finding of this study was that not only was there a lack of knowledge of palliative care but the personal experience had significantly higher percentages of correct responses than those of any colleague with previous personal experience. Caring was ranked as the most important virtue the participants ranked the top three in order of highest to lowest, respectively: caring, compassion, and kindness. Two rank order questions ascertained the importance the participants gave to a number of virtues and activities to the role of the palliative care nurse. The results are as follows:

- Caring: mean 4.42 of 5
- Compassion: mean 4.31 of 5
- Kindness: mean 3.92 of 5

Conclusion: The results of this study indicate modest knowledge of palliative care in final year student nurses. Aims: To gain a better understanding of the philosophical issues of palliative care and pharmacology in symptom management. Educational initiatives and clinical placement could enhance student nurses knowledge and in turn improve practice.

Abstract number: P1-161
Abstract type: Poster
Title: EU-USA Collaboration Project Integrating Self-management and Palliation Concepts (IMPACT): Health Policy and Nursing Education Implications
Authors: Johnston B.M., Rogerson E., Cholewka P., Marcoulskaite J., Blazieniene A.
Affiliations: 1University of Dundee, School of Nursing and Midwifery, Dundee, United Kingdom, 2New York City College of Technology, CUNY, New York, NY, United States, 3Kaunas University of Medicine, Faculty of Nursing, Kaunas, Lithuania

Aims: This paper reports an EU-USA collaboration utilising experts from two European Union (EU) institutions and two United States (US) institutions to facilitate palliative care courses in order to support self-management, empowerment and palliative care.

- To develop a conceptual framework for use in education and practice in palliative care.
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- To develop a conceptual framework for use in education and practice in palliative care.
- To develop a conceptual framework for use in education and practice in palliative care.

Methods: 1. Research and key policy documents were examined for their relevance to self-management, empowerment and palliative care.
- 2. Survey conducted across all nursing schools in EU and US to ascertain the importance of the relationship between self-care and palliative care.
- 3. A training program was developed and approved for accreditation in Oct 2012 by the ISP, utilising recommendations from the EAPC task force on PC SW and the UK recommendations for the role of generalist social work.

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Training of Volunteer Students of Medical University for Work in Multidisciplinary Team on Palliative Care

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The palliative help is the overall health, the overall health to the patient having an incurable disease. Therefore there necessarily should be some volunteer alongside the doctor, nurses, psychologists to help the patient, to support the patient during his palliative care journey from maintaining normal life to preparing for death and can be incorporated into a practice framework, which in turn the importance of robust assessment and gives equal weight to both the process and outcome of palliative care.

Abstract number: P1-163
Abstract type: Poster
Title: Teaching End-of-Life Communication: A Novel Way to Engage Residents

Koh M.

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Aims: Palliative Care practitioners and educators play an important role in teaching End-of-Life communication skills to Medical Students, Residents and Fellows.

1. Research and key policy documents were examined for teaching ‘Breaking Bad News’ to Residents and shared the data collected about the effectiveness of this teaching style.
2. The teaching module comprising of Mini Lecture, Mock-Patient and Semi-Role-Play session. The half hour first (30 minutes) was a didactic lecture, included the ‘SPIRES Protocol’ and simple communications skills, and achieved a positive demonstration video about ‘Breaking Bad News’ as well.
3. The next half hour (30 minutes) was a role-play whereby each resident role-played a scenario for 10 minutes. They would then become the Surgeon for their colleague for the next 10 minutes. This process was observed by a skilled facilitator (Fellow or Attending) who debriefed them during the last 10 minutes. The ratio of Facilitator to Residents was about 1:4:6.

We ran this module 3 times and taught 30 Residents (average about 10 each session) in total. We needed about 3 facilitators during each session as a total of 9 facilitators (Fellows or Attendings).

Conclusion: The Residents were asked to rate their experience on a Likert scale ranging from Not Helpful to Slightly Helpful / Average / Helpful / Very helpful.

- Most of the Residents felt the session was either helpful or very helpful.
- 1. Lecture on ‘Breaking Bad News’ - Helpful - 50.0% / Very Helpful - 20.0%
- 2. Role-modeling (Positive demo) - Helpful - 26.7% / Very Helpful - 63.3%
- 3. Patient Role-Play - Helpful - 13.3% / Very Helpful - 80.0%
- 4. Faculty Critique - Helpful - 21.4% / Very Helpful - 72.6%

Conclusion: A short, concise teaching method comprising 30 minutes of didactic lecture, including a positive demonstration video and another 30 minutes of Resident Role-Play was effective in teaching Residents the End of Life communication skill of ‘Breaking Bad News’.

Abstract number: P1-164
Abstract type: Poster
Title: Development of Social Work Training as Part of the Strategy to Develop Palliative Care in Serbia

Firth P.H., Downing J., Hayes L.

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Aims: Palliative Care (PC) is well developed in Western Europe. In Eastern and Central Europe development can be hampered by factors such as poor access to health services, decentralisation of services, poverty & lack of training. Thus we aimed to develop a Serbian PC Social Work (SW) training program as part of a larger multidisciplinary program aiming to embed PC within the state health & social systems. Methods: A scoping exercise was conducted to examine the social work system, its legal foundation and the current education & practice of SW in relation to the integration of PC. Since 1995 SW training was endorsed by the Ministry of Social Welfare. A training program was developed & approved for accreditation in Oct 2012 by the ISP, utilising recommendations from the EAPC task force on PC SW and the UK recommendations for the role of generalist social work.

Prior to attending this course, all course participants

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Ethical and cultural aspects of palliative treatment. Modern principles of the report of bad news. Legislative and legal questions in the palliative help. Work of multidisciplinary team in the palliative help. Scaling up development of volunteers movement. A role of volunteers in multidisciplinary team.

Summary: Following the results of the Summer school 26 volunteers from 6 medical universities of Kazakhstan were trained, who now work with incurable patients and carry out work on creation of the National volunteer network in the palliative help of Kazakhstan.

Conclusion: The role of the professional volunteer possessing the basic medical knowledge and trained for work in multidisciplinary team is very important.

Abstract number: P1-165
Abstract type: Poster
Title: Development of Social Work Training as Part of the Strategy to Develop Palliative Care in Serbia

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Prior to attending this course, all course participants

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undertake a multi-disciplinary course on the philosophy of PC & on PC knowledge & skills development. The further two-day SW training was developed & includes content reflecting the experiences of PC professionals & volunteers in PC in endorsed by social workers, their managers & the & Elements of the course will be addressed in this roundtable:

Conclusion: Course evaluations will provide opportunities to reflect on the content & impact of the training. It is currently the only European group endorsed accredited course in PC for generalist social workers & will make a contribution to the next stage of the EAPC Task Force on SW in PC, which aims to develop a set of core competencies & qualifications for social workers & post graduate social worker education across Europe.

This contribution is part of the project 'The Development of PC in the Republic of Sweden' (Europeapo/219796/C/SER/RS)

Abstract number: P1-166
Abstract type: Poster

Transforming End of Life Care: An Integrated Education & Support Initiative Run by Palliative Care Specialists for Non-specialist Health Care Professionals Who Provide End of Life Care in Hospital & Community Settings in England

Aims: Radical transformation in the National Health Service is critical to the development of hospital and community services. We are at the forefront of this change and the development and implementation of tools to improve patient care at the end of life. Effective training remains scarce and expensive, but integration presents opportunities for those who do not normally meet to learn together. The National End of Life Programme has endorsed use of national end of life care tools e.g. AMBER care bundle & Liverpool care pathway. These are practical but need to be seen in context of the broad principles of Palliative Care within the context of End of Life care tools and local delivery. It has been well received and feedback confirms its usefulness. We aim to reach a wider range of health care professionals, carers their experiences during their diagnosis and treatment. The health care workers were asked about their roles and how the differing professions worked together. Students were encouraged to ask about the impact of the work on the healthcare team and the session was facilitated by the patient or individual worker rather than by a member of the university thus enabling a personal view.

Results: Students were divided into small groups with no patient or individual worker rather than by a member of the university thus enabling a personal view.

Conclusion: This method of teaching introduced to students learn well in small groups and can start to understand the importance of the patient, carers and professionals at a very early stage. Conclusion: This method of teaching introduced to students learn well in small groups and can start to understand the importance of the patient, carers and professionals at a very early stage.

Abstract number: P1-168
Abstract type: Poster

Challenges in Implementation of Palliative Care Educational Programs in Former Soviet Countries - Georgians Experience

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Research aims: Beginning of XXI showed remarkable increase in global aging, together with rising incidence and prevalence of oncological diseases, AIDS and chronic progressive illnesses. All these have led to huge numbers of incurable patients, requiring the relevant complex medical and social care, to cure or to help them to spend their remaining time with dignity and in their families. A new direction in public health, called Palliative Care (PC), serves to this very aim. Between former soviet countries (FSC), Georgia was one of the leaders to develop PC services. Since 2002 and several successful steps have made during this period. The research aim of the study was to identify the main challenges in implementation of PC education in FSC in example of Georgia.

Study design: The interviewing of 150 health care professionals, health care administration staff and representatives and society in Georgia, Kyrgyzstan, Armenia, Tajikistan and Azerbaijan was performed. This method of teaching introduced to students learn well in small groups and can start to understand the importance of the patient, carers and professionals at a very early stage.

Results:
• In most FSC PC still on very basic level of implementation. The clear understanding of the substance, role, place and importance of PC in clinical practice is still lacking. PC still remains one of the most essential challenges on the way of implementation PC Educational Programs and its incorporation in the national healthcare system as well.
• Conclusion: According the Georgian experiences the most frequent and similar challenges were noted in implementation of PC educational programs in FSC. Understanding of PC, missing the palliative care modules and courses in all level of medical education; Education for medical professionals; Missing the recognition of palliative care in medical societies and between authorities; Lack of resources (medical services, human and financial); Opioids Availability and epipodiphobia in Society and between the Medical Professionals; Stigma; Laws and Regulations.

Abstract number: P1-169
Abstract type: Poster

Pain Management and Home Care Services - An Unequal Equation? Barriers to Implementing an Adequate Home Management in Home Care Settings

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Abstract number: P1-171
Abstract type: Poster

Palliative Care Education: Building Resilience for Communities to Care for AIDS Patients in an African Kingdom - A Case Study Kwepembe Home Care, Uganda

Guma S.1, Komugisha S.2, Nkwaggo G.3, Amaranje Y.4, Mejje J.4, Ellenhove J.2,1, Kwepembe Home Care, Kampala, Uganda, University of Liverpool, onlineochen in many countries to improve the quality of palliative care for people with HIV/AIDS and Cancer. The organisation works with communities to provide services and support to individuals who have advanced AIDS or Cancer. They monitor and support medication adherence, give basic nursing care and psychosocial support. The volunteers are identified among the patients who are living positively with AIDS and are recommended a
community leader. The volunteers then undertake a five day education programme on home based palliative care using the World Health Organisation care givers booklet and the Georgia Oncology home care manual. A three year survival rate was 86.4% for 235 patients. The average CD4 at enrolment was at baseline, 6, 12, 18, 24 and 30 months was 136, 395, 409, 628, 489 and 525 cells/mL respectively. Baseline average weight was 55.3kg and average study weight was 61.4kg. Baseline weight in 226 subjects showed that 12 and 18 months tests revealed 83.7% and 86.4% viral suppression.

The results showed high three year Survival rate and high level of viral suppression and considering good treatment outcomes. These results may in part be attributed to the support of the community network of care for the community-based medication adherence support. Further research studies should include randomisation of this intervention to further substantiate the evidence base.

Abstract number: P1-172
Abstract type: Poster

Educational Programs of Cancer Prevention Center in Palliative Care in Georgia

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Background: Hospice and Palliative Care (PC) is a relatively new but rapidly developing medical discipline in Georgia. Still PC is not included in a list of medical specialties and it is subspecialty for different specialties. In 2007 aspects of Palliative care components were integrated into Georgian legislation. 

- Law of Healthcare
- Law of medical activity
- Law of patients’ right
- Law of the narcotics, psychotropic drugs, precursors and narcotic substances

Goals: These changes develop necessity of providers of PC in Georgia and initiative of undergraduate and postgraduate education for Georgian physicians and nurses in PC. Inclusion of this discipline in undergraduate and postgraduate education was initiated by the Cancer Prevention Center and started by Department of Oncology of Tbilisi State Medical University (TSMU) in 2006.

- Curriculum development and undergaduate education
- More than 200 medical students educated since 2007
- More than 100 nurses educated since 2007
- Postgraduate education
- Short courses in Pain Management and Symptom Control
- Course for specialization in Palliative Care

Results: The candidates completed all of the questionnaires. When comparing the Self Efficacy Scale results from such a questionnaire we found a small change from before and immediately after the course, but a statistically significant change both before and 6 months after the course was completed and post course and 6 months later when comparing the Self Efficacy Scale results from such a questionnaire we found a statistically significant improvement in self efficacy scores pre and post course, pre course and 6 months after course completion and a significant improvement pre course and after 6 months.

Conclusions: This study shows that the European Certificate in Essential Palliative Care course is significantly effective way of improving palliative care throughout a variety of settings across a range of professions.

Study funding: From the hospice. Ethical and R&D approval gained

Abstract number: P1-175
Abstract type: Poster

Palliative Care Education for Medical Students: Analysis of an Exercise on “Delivering Bad News”

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Objective: Systems for palliative care education have not yet been established at medical schools. Only 10% of universities with medical schools have a palliative medicine course that covers palliative care education. Education at medical schools primarily involves underdiagnostic lectures, and practical education related to communication is rare. During the five-year period starting in 2007, our university provided 10 sessions for preclinical lectures for students in the third year of the six-year medical school program. Practical training reports were analyzed in order to obtain suggestions for future palliative care education.

Methods: Practical training on “Delivering bad news” was conducted on a total of 43 students who enrolled in a series of lectures on “Psychology in Medicine”. Practical training was performed in two 10-minute parts, after which feedback on the exercise was given by the simulated patients to students. Following this, students wrote a report in free response format. The report contents were then analyzed using Word® text mining software. Using all the words appearing in each report, and considering significant good treatment outcomes, these results may in part be attributed to the support of the community network of care for the community-based medication adherence support.

Results: A total of 31 subjects described the training as “difficult”, with the main reasons being “nerve-wracking” and “unease”. On the other hand, 25 subjects found the training “enlightening”, “important”, “professionalism”, and “relationships of trust”. In the item “Communication”, a relationship was observed between “importance” and “consideration”.

Conclusions: Incorporation of practical training related to communication into the early stage of medical education may not only enhance the students’ appreciation of the importance of communication, which forms the basis of palliative care, but also contribute to formation of physician responsibility.

Abstract number: P1-174
Abstract type: Poster

An Assessment of the Impact of an Interdisciplinary Teaching Programme on Self Efficacy and Attitudes Towards Caring for Palliative Care Patients between Candidates from Different Professional Backgrounds

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Aim: To evaluate the impact of an interdisciplinary teaching programme on self efficacy and attitudes towards caring for palliative care patients between candidates from different professional backgrounds.

Methods: A total of 33 subjects described the training as “enlightening”, “important”, “professionalism”, and “relationships of trust”. In the item “Communication”, a relationship was observed between “importance” and “consideration”.

Conclusions: Incorporation of practical training related to communication into the early stage of medical education may not only enhance the students’ appreciation of the importance of communication, which forms the basis of palliative care, but also contribute to formation of physician responsibility.

Abstract number: P1-175
Abstract type: Poster

Exploring Education and Training Needs amongst the Palliative Care Workforce in England

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Aims: Education and training are recognised internationally as essential components of providing quality palliative care. As part of a larger study to explore the extent of palliative care need in two acute hospital settings in England, we report the perceptions of healthcare professionals regarding their training and educational needs.

Methods: Phase 1 involved eight focus groups and four individual interviews with 58 health professionals from general practice, specialist palliative care and acute hospitals, exploring their experiences of palliative care and perceived education and training priorities. Phase 2 of the study involved a survey of palliative care need at two hospitals in England. Hospital based doctors and nurses completed questionnaires to identify patients with palliative care needs according to a standardised definition and to respond to questions about their training and education needs.

Results: Professionals identified that lack of training and education were among a range of barriers to the provision of palliative care. Participants felt that while care pathways were well established, they were not adequately trained to address prognosis and goals of care with patients and their families. In Phase 2 of the study, 171 nursing staff and 81 medical staff completed the questionnaire. Two thirds of this sample felt they required additional training in palliative care: 87% of doctors and 95% of nurses reported that they would take up palliative care training if it was made available to them.

Conclusions: More work is needed to examine and clarify the interplay of behaviour change, clinical and professional orientation, type of health professional, and nature of any educational intervention in order to effect sustained behavioural change.

Abstract number: P1-176
Abstract type: Poster

Cardiologists Fellowships in Palliative Medicine: Would this Improve Training in Advanced Heart Failure Management?

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Aims: It is accepted that palliative care for non-cancer conditions lags behind that for cancer. To equip future cardiologists with the necessary knowledge, skills and confidence, and end of life care has been incorporated into the 2010 UK Cardiology Curriculum. This survey evaluates the confidence of trainees in managing end of life issues in cardiology patients.

Methods: An online questionnaire was distributed to all UK registrar-grade British Junior Cardiac Association members. Results: 219 respondents: Clinical Experience:

- 69% of trainees experience difficulties in palliating patients with advanced heart failure.
- Less than 25% regularly start opioids, anticoagulants or laxatives and only 5% consider using anti-depressants.
- 73% felt that the care they provide patients with advanced heart failure is poor or only adequate. Over 50% do not feel equipped to discuss advanced care planning and end of life issues when seeing advanced heart failure patients in patient-out clinic.

Training:

- 94% of trainees feel that the palliative care team play an important role in the management of patients with advanced heart failure but only 54% seek specialist palliative care input when experiencing problems.
- 45% report receiving no training in palliation of advanced heart failure symptoms. 57% are unhappy with current provision of training.
- 86% think that end-of-life training is important or very important within the curriculum.

The recommendations include workplace based supervision with additional training days, closer links with local hospices and specific fellowships for cardiologists trainees in palliative care.

Conclusions: This survey shows that despite being part of the national curriculum for training in cardiology since 2010, training level of confidence in delivering good palliative care for heart failure patients still remains poor. To ensure that future cardiologists are equipped with the skills and confidence to deliver high quality palliative care for cardiac patients, we recommend the implementation of training days and workplace based supervision.

Abstract number: P1-177
Abstract type: Poster
Abstract number: P1-177
Abstract type: Poster

Palliative Care Education Program in a Tertiary Medical University in Bangladesh

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The article describes the palliative care post graduate education courses in a tertiary medical university in Bangladesh. Among the different courses there exist three day courses for doctors, nurses, community volunteers, family members, policy makers & media personnel. The 7 day courses are for MD residents and six week courses for doctors in palliative medicine (BCCPM) for doctors and palliative nursing (BCCPN) for nurses. The majority of the health care professionals working in hospitals and in the communities often look after patients with palliative care needs. The university recognized the urgent need to assist Bangladesh doctors in developing the medical skills required for caring for patients and their families who are faced with terminal illness and the physical, emotional, psychosocial, and spiritual distress associated with end-of-life issues. The three day courses are presented as six hour face-to-face teaching sessions for three consecutive days. The course is also designed to meet the needs of health care professionals who wish to develop specialist palliative care knowledge and skills with time. Since 2008, 93 doctors & nurses & 86 community volunteers for BCCPM & 14 nurses for BCCPN have registered for the course. A combination of availability of background material, interactive theory sessions and case based exercises are the core of the course. The courses have been jointly organized, run and evaluated by the centre for palliative care of the university as well as by the WHO Collaborating Centre at the Institute of Palliative Medicine of Calcutt, India. The participants of certificate courses are eligible to apply for the WorldPison International Busisness Scholarships. The University has run with a curriculum for the six weeks Basic Certificate Course in 2012 after three pilot courses and a consensus workshop supported by Bangladesh University Grants Commission.

Abstract number: P1-178
Abstract type: Poster

Developing the Role of the End of Life Care Key Worker in the Acute Setting

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National figures show that 58% of all deaths in England occur in hospitals. The delivery of high-quality end-of-life care (EoLC) should therefore be a part of the core business of Acute services however numerous reports describe the need for improvements (DoH 2008, National Audit Office 2008, NCEPOD 2009). In order to bridge this gap, one of our aims was to establish an End of Life Care Key Worker (EoLCKW) model, positioned in all patient critical areas to champion EoLC. A supporting document ‘Developing the End of Life Care Key Worker in Hospitals’ (June 2011) was produced by the Hospital Palliative Care Team in order to clarify the rationale, requirements and responsibilities of such a role. It was recognised that the undertaking of such a role must be underpinned by education, training and support and so a programme was developed to standarise and address the training needs of Health Care Professionals undertaking the role of EoLC Key Workers. The programme is based on the National End of Life Care Programme’s (NeOCP) The route to excellence in end of life care in acute hospitals (June 2010) and Common core competencies and principles for health and social care workers working with adults at the end of life (DOH 2009) and comprised the following study days.

1. Discussions as the end of life approaches
2. Assessment, care planning and review
3. Co-ordination of care
4. Delivery of high quality care in the Acute setting
5. Care in the last days of life
6. Spiritual care and presentations Training Needs Analysis and Skill Set Assessment was undertaken to both ensure educational needs were met and to assess the impact of the course. There is a trained EoLC Key worker on every in-patient area. Course evaluation demonstrates learning and increased knowledge, skills and confidence in EoLC. A sustainability plan is in place.

Abstract number: P1-179
Abstract type: Poster

Partnerships in Palliative Care Education. A Five Year Experience between Albania and United Kingdom

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Aim: The aim of this study is to highlight the importance of international partnerships between organizations working in palliative care in different countries. PCEC is an Albanian medical NGO that has been collaborating in palliative care education. PRIME is a UK medical NGO with more than 12 years of experience in palliative care in different countries. Both organizations have worked together in the last 5 years to develop palliative care education for healthcare professionals in North Albania. Palliative care education is crucial for the development of palliative care services in Albania and lack of education is one of the major obstacles to offer good palliative care services for cancer and chronic patients in Albania. PCEC and PRIME have organized together 13 palliative care courses. We have included on our training four regions of North Albania (Lezte , Shkoder, Kukes, Pejë) , 10 more than 500 healthcare professionals attended our courses.

Methods: Regular contacts with the health professionals have been maintained in order to inform them with the dates and venues for the courses. Regular contacts between PCEC staff and PRIME staff have been organized. The topics offered for participants were: principles of palliative care, history of palliative care, pain control, symptom control, communication, case law, legal, psychological, social, spiritual and bereavement support.

Results: 13 palliative care courses have been organized from November 2007 to November 2012, more than 500 participants attended, most of them general practitioners.

Conclusion: Palliative care education is vital for the development of palliative care services in Albania where palliative care is not a recognized specialty.Partnering with a palliative care education organization from a developed country is important to set up and to date palliative care education in a developing country.

Abstract number: P1-180
Abstract type: Poster

Developing an End of Life Care Community Forum

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Background: Embedding end of life care in nursing homes is difficult to sustain without education and support. Ongoing clinical support needs to be provided if change is to be sustained. A dedicated end of life forum model was developed to address this issue by establishing positive working relationships between generalist and specialist providers.

Methods: 18 nursing homes enrolled with a planned 6 evening meetings. Three local health professionals and four clinical staff members served as facilitators. The course included the following aspects of care: history of palliative care, pain control, symptom control, communication, case law, psychological, social, spiritual and bereavement support.

Results: 80% of respondents indicated that NPs influenced the quality of care provided to persons with palliative care needs. 75% of respondents indicated that NPs influenced the quality of care provided to persons with palliative care needs. 75% of respondents indicated that NPs influenced the quality of care provided to persons with palliative care needs.

Conclusion: Ongoing clinical support needs to be provided if change is to be sustained. A dedicated end of life forum model was developed to address this issue by establishing positive working relationships between generalist and specialist providers.

Abstract number: P1-181
Abstract type: Poster

Sharing the Load. A Collaborative Approach for Meeting the Needs of Palliative Care Practitioners for Genneral Practitioners

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Background: People who work in end of life care report the need for greater training in the knowledge and skills to give high quality of end of life care; for all this is particularly true for community and general practitioners in the rural areas. In Manipal and Cheshire Cancer Network GP education courses continue to be heavily subscribed to. Successful programmes have been running for over two years and a collaborative approach was adopted for 2012 to aid delivery across a wider area with a sharing of resources.

Course aims: To provide evidence based updates on a range of end of life management topics.

Poster sessions 100

To provide information about use of end of life tools.

To provide opportunities for facilitated group discussions.

Concrete delivery: The course was run between January and June 2012 and consisted of 6 evening meetings. Three local specialist palliative care teams delivered 2 sessions each enabling pooling of clinical time enabling further delivery of future courses. The course included the following aspects 60 minute seminar delivered by senior clinician in Palliative Medicine.

60 minute facilitated group work with feedback.

Each session was individually evaluated at the end of the course.

Results: Demand and attendance throughout the course remained high.

Conclusion: Accepted and successful model for delivering GP education.

Abstract number: P1-182
Abstract type: Poster

Nurse Practitioners as Mentors in Teaching Hospitals

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Aims: This is an exploratory study to describe the impact of palliative care nurse practitioners (NPs) as educators and mentors for medical students, residents and fellows. Mentoring is an advisory role, an experienced professional guides another individual in their personal and professional development. In the U.S. NPs in academic settings may serve as mentors to both nursing and medical students and residents. This is particularly true in newer specialties where physician mentors are fewer and in those specialties where interdisciplinary care teams (IDTs) are the norm. Additionally, in the U.S. where the development of identified palliative care physicians exceed their availability for both patient care and medical education, specialty trained and experienced NPs have a unique role.

Methods: Former medical students, residents, and fellows (N=21) rotated through this 544 bed tertiary care teaching hospital; palliative care and hospice services were surveyed with SurveyMonkey. The questionnaire was designed based on the palliative care literature, functioning of the NPs on the IDT, and literature on mentoring.

Results: Preliminary results of 12 respondents found that on a scale of 1-10 the mean rating of NPs as important mentors was 9.4, 7% reported that an NP influenced their choice of medical specialty. All respondents indicated that NPs modeled interpersonal skills in IDT meetings and when having difficult conversations with patients. NPs also assisted assisted families in making difficult health care decisions. At least 75% of respondents indicated that NPs influenced their decision in each of the 17 examples of mentoring listed on the survey.

Conclusions: NP involvement in medical education and mentoring may support future palliative care education, development, choice of specialty, and preparation for working in IDTs. Further study across academic medical settings is needed to fully elucidate NP role and relative contributions. The study was internally funded.

Abstract number: P1-183
Abstract type: Poster

International Medical Education in Palliative Care: Pilot Research on Undergraduates (IMEP)

Background: The provision of education and training in palliative care for medical undergraduates across Europe is variable. Hence, it is likely that newly qualified physicians entering practice with variable skill sets. Accordingly, assessing the preparedness and attitudes of newly qualified physicians in practising palliative care is crucial. Such data may help inform the ongoing development of medical curricula, which is crucial in light of demographic challenges facing Europe in the coming decades.

Aims: To establish four translations (Spanish, French, German & Italian) of two validated psychometric assessment tools (Self-Efficacy in Palliative Care - SEPC, Thanatophobia Scale), and collect illustrative pilot data across seven European countries.

Design: Organised as a Taskforce of the EAPC Steering Group on Medical Education, the IMEP study group will complete backward and forward translations of the SEPC and Thanatophobia Scale using EORTC criteria. Using convenience sampling, pilot data from each country (per country, n = 40) will be collected to test the applicability of the translated instruments and provide illustrative data for national medical education committees.

Results: To date, EORTC structured translations in French and Spanish have been achieved, and German and Italian translations are underway. A distinct national pilot has been completed late 2013. Pilot data already collected from Ireland and England will be collated with developing data sets from Spain and France, and to be collected from Italy and Switzerland.

Conclusion: The availability of multiple translations of these validated psychometric assessment tools will enable intra- and international assessment of how existing undergraduate curricula is preparing tomorrow’s doctors to meet the needs of the expanding cohort of palliative care patients. Furthermore, such data will inform the influence and strengthening of Palliative Medicine within existing undergraduate medical curricula.

Abstract number: P1-184
Abstract type: Poster

Using Reflective Diaries to Explore the Lived Experience of a Volunteer Training Program to Support Patients in the Last Hours and Days of Life

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Background: In the UK over 53% of patients die in hospital. Volunteers have a significant presence in many Hospitals, providing services to support staff and patients; however, few volunteers programs focus on the last few hours and days of life. A pilot training program (Care of the Dying Volunteers - CODV), using existing European models, has been developed and recently engaged within a large university teaching hospital in the North of England, to train volunteers to support patients (and their relatives/friends) in the last hours and days of life.

Aims: To examine CODV’s experiences of the training program through the analysis of reflective diaries.

Methods: 20 UK and 8 United States volunteers attended a 12 week training program. Data was collected via weekly reflective diary to record thoughts and feelings. Data was coded using NVivo 8 (QSR International) with a framework approach to identify emergent themes.

Results: A total of 19 volunteers, aged between 18-79 years, appeared to have completed diary entries were fielded. Three themes emerged:

(i) motivation for volunteering
(ii) impact on the donor
(iii) group dynamic

A common shared motivation for volunteering was that volunteers had an understanding of the potential impacts of volunteering on their own life.

Cohesiveness within the group provided the volunteers with a sense of belonging and shared experiences.

Conclusion: The findings have implications for the ongoing support of volunteers. Group sessions beyond training facilitated the development of increased sustainability. Further research is needed as the volunteers go on to support dying patients, to explore if their motivations and perceptions of impact change throughout the process, to inform future CODV training programs.

Poster sessions


Poster sessions

Pre-post test and course evaluation questionnaire shows significant improvement in knowledge of audience (average 67% correct answers in pre-test vs. 47% in pre-test, p<0.001). There was an increase by up to 70% in their satisfaction (measured by post-training evaluation questionnaire), but revealed problems and challenges as well. There was little training, difficulties with recruitment of trainers, their certification, completion of courses, delayed delivery and interest. All these challenges should be addressed, discussed, and overcome to improve and finalize the course.

Abstract number: P1-190
Abstract type: Poster

**Going For Gold - Enabling Generalists to Better Work Through Palliative Care in End of Life Care across the UK with National Adoption of GSF Training Programmes**

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Objective: The UK focuses on a broad definition of End of Life Care which includes palliative care provision for all people in every setting in the final year or so of life. The Gold Standards Framework (GSF) is a major step towards improving End of Life Care Strategy and focuses on enabling generalist provision of end-of-life care for all patients with any life-limiting illnesses in whatever setting. It improves quality of care, workforce collaboration, confidence and coordination with specialists and reduced hospitalization. It has had remarkable success in improving generalist palliative care in primary care and the specialist care homes palliative care programme in England. The National GSF Centre in End of Life Care is the leading provider of end of life care training for generalists in the UK, working with St Christopher’s Hospice as its first GSF Regional Centre and other hospices.

Method: This presentation provides an overview of GSF underpinning principles, use in primary care, care homes, hospitals and domiciliary care plus its support. Also evidence base, spread cascade, UK policy and political support, and becoming a national quality improvement programme, and includes use of e-learning, and IT developments. It will explore how GSF can enable Generalists to cross boundary care across a wide area. In addition examples of adapted underpinning principles, use in primary care, care homes, hospices and front line professional training.

Outcomes: GSF implementation in primary care is an important step in the context of end of life care in the UK, policy developments, hospice/specialist palliative care, care for non-cancer patients, long term care and practical suggestions on ways forward. Also lessons learnt in developing local and national momentum, gaining national policy and practice interest. It will include GSF training, tools and measures with suggestions for local use and development in generalist end of life care to enable the generalist frontline workforce and improve palliative care collaboration.

Abstract number: P1-191
Abstract type: Poster

**Palliative Care at Home: The PaTz-project**

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In the South of the Netherlands the Comprehensive Cancer Centre facilitated small groups of family doctors together with nurses from the public health service to start and entrain a register of palliative care patients. We followed the Gold Standard Framework translated and adjusted to the Dutch situation.

In meetings over six weeks they discuss the physical, psychosocial and spiritual needs and wishes of the patients and their relatives, in order to anticipate what will be important in the care for this patient. They discuss illness trajectories and also they make an inventory about patients wishes at the end of life. There is also attention for transfer to the emergency units who are available during nights and weekends.

We would like to present the results, the registers, the transfer forms and give some tools we're using to discuss all aspects of care.

Abstract number: P1-193
Abstract type: Poster

**Current Overview of Palliative Medicine Teaching in the Spanish University**

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Abstract type: Poster

Introduction: There are many recommendations of national and international organisations to incorporate palliative care teaching in the medical school. European Higher Education Area (Bologna process) has supposed review of the curriculum in every academic degree. The aim of this study was to determine which medical schools in Spain have included palliative care in their new curricula.

Method: We reviewed the curricula of medicine from all Spanish faculties identifying subjects with the words “Palliative Medicine” or “palliative care” included in their denomination.

Results: 20 of 39 medical schools have a palliative care course. In six faculties it was taught as a single subject, with an average of 3 academic credits. When palliative care is taught with other subjects (as Oncology, Geriatrics, Family Medicine and so on) the number of credits varies. In 14 of 20 centres is a mandatory subject.

Conclusions: A half of medical schools in Spain including a palliative care course in their new curricula. Palliative medicine is gradually incorporated into the training of future physicians Spanish.

Abstract number: P1-194
Abstract type: Poster

**What Makes an Objective Structured Clinical Examination (OSCE) an Effective Method of Learning in Undergraduate Cancer Care Education?**

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Introduction: Objective Structured Clinical Examinations (OSCEs) are commonly used in healthcare education to assess clinical skills. They are widely used as assessments for progression (subsequently and post graduate) but potential use of OSCEs as assessments for learning (formative) was highlighted by Hare and colleagues who developed the OSCE in the early 1980s. A teaching OSCE has been used in the 4th year Cancer and Continuing Care course at Leeds University School of Medicine (UK) for the last 2 years. It has evaluated very highly but is unclear from the literature and from local evaluations why students find this method of teaching so useful.

The aim of this research was to look in more depth at students’ beliefs about the cancer care teaching OSCE to determine what makes it a useful/valuable learning tool.

Methodology: Q methodology is useful to analyse opinions, perceptions and attitudes in clinical and non-clinical settings (Valenta et al 2001) and has been used in palliative medicine education to assess learning competencies (Gaebehr-Uhlig 2004). Statements about the teaching OSCE were generated from the literature and previous evaluations. Following informal consent students were asked to complete a “Q sort”; that is rank the statements from agree to disagree. This allows a more useful analysis of students’ current beliefs about the OSCE rather than asking students to complete questionnaires about the OSCE. Ethical approval was granted by the University of Leeds Research Ethics Committee.

Results: The Q sort analysis of the student’s beliefs about the value of this method of teaching in cancer care education will be presented. The results compare components of a teaching OSCE in undergraduate education will be discussed along with suggested application in other medical schools.

Abstract number: P1-195
Abstract type: Poster

**Does a Junior Doctor Rotation Post in Palliative Medicine Impact on Career Choice and Does It Improve Future Clinical Practice?**

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Aims: In the UK, Modernising Medical Careers (MMC) has restructured training doctors’ career progression, with medical graduates entering a 2-year Foundation Programme (FP) of mixed specialties. During the 2nd year they then choose & apply for specialty training. There are relatively few palliative care posts available during the FP. This study aims to find out (1) if undertaking a palliative care post during the FP influences future clinical practice; (2) if the post helps with skills for future clinical practice.

Methodology: A cross-sectional retrospective survey using a web-based, anonymous questionnaire of all doctors participating in a foundation year 2 (FY2) programme of mixed surgical and medical specialties in a UK hospital trust, which includes a 4-month hospice based post in palliative care. Summary statistics are used to describe data.

Results: 13 doctors had previously undertaken this post and were contacted, 10/15 replied (67% response rate). Prior to starting the post, 6/10 (60%) had considered pursuing a career in palliative care, whereas after finishing the post this figure had risen to 8/10 (80%). 7/10 (70%) reported that completing this post had influenced their career choice. Additionally, 9/10 (90%) felt that this post had changed the way they practice medicine, specifically by improving communication skills, symptom control, advance care planning and team working.

Conclusions: Results suggest that completing a junior doctor training post in palliative medicine influences doctor’s career choice, making them more likely to consider palliative care as a career. In addition, future practice was changed in the majority of participants, and skills specific to palliative care were learnt. Limitations of this study are its size and possibility of response bias. To further support the evidence that posts of this nature are beneficial, we propose to repeat this study within all deaneries in the UK.

Abstract number: P1-196
Abstract type: Poster

**The Use of Drama in Palliative Medicine Education for British Medical Students**

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Introduction: Medical humanities and arts-based teaching to offer an opportunity to achieve competencies required in undergraduate palliative education. Humanities disciplines can help students to reflect, develop multiple perspectives, and consider implications of illness, life and death in combination with their clinical experience.

Aims: To design, implement, and evaluate a pilot teaching session using medical humanities to inform the core palliative care curriculum for medical students.

To use drama as a stimulus for discussion and reflection of communication and issues in palliative care, with relation to their experiences.

Abstract number: P1-197
Abstract type: Poster

**Poster sessions**
To collaborate with the University arts faculty to create an innovative drama performance.

To assess preliminary feasibility for integration into the curriculum of other medical schools in Taiwan in the future.

To systematically review the evidence on the attitudes and practices of nurses towards palliative care.

Aim: Palliative care is an essential part of medicine, but medical students have limited opportunities to develop palliative care skills. In Japan, following the establishment of the Cancer Control Act in 2008, the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education (PEACE) was launched to educate physicians in basic palliative care.

Methods: Knowledge of, attitudes to, and difficulties regarding palliative care were evaluated before and after the one hour course. A total of 200 physicians have completed the program. The aim of the present study was to determine whether PEACE improves physicians’ knowledge of and attitudes towards palliative care.

Results: In all, 217 physicians participated in the study. Significant improvements were noted on the PEACE-Q33 questionnaire (nine domains, 33 items). Attitudes and difficulties regarding palliative care were self-reported practice scale (PCPS; six domains, 18 items) and the palliative care difficulties scale (PCDS; five domains, 15 items), respectively.

Conclusions: Participation in PEACE improved physicians’ knowledge and attitudes towards palliative care.

Abstract number: P1-197
Abstract type: Poster

Nation-wide Physicians’ Education Project for Basic Palliative Care in Japan: Outcome of Evaluation of the Palliative Care Enhanced Program on Assessment and Management for Continuous Medical Education (PEACE)

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Aims: Palliative care is an essential part of medicine, but medical students have limited opportunities to develop palliative care skills. In Japan, following the establishment of the Cancer Control Act in 2008, the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education (PEACE) was launched to educate physicians in basic palliative care.

Methods: Knowledge of, attitudes to, and difficulties regarding palliative care were evaluated before and after the one hour course. A total of 200 physicians have completed the program. The aim of the present study was to determine whether PEACE improves physicians’ knowledge of and attitudes towards palliative care.

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Conclusions: Participation in PEACE improved physicians’ knowledge and attitudes towards palliative care.

Abstract number: P1-198
Abstract type: Poster

The Effects of Medical Students’ End-of-Life Care and Medical Humanities Training in the Community

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Research aims: Palliative care education course about end-of-life care in the community was still not enough at the medical education in Taiwan. Our study designed the students participate in the real practice of end-of-life care in the community and surveyed the effect of reflection of medical humanities based on previous palliative care curriculum.

Methods: Our study developed the course about end-of-life care at different levels in the community according to the student’s competence by the method of “action research”. The tutors of the field adjusted the course contents by the comprehension of nurses’ reflection and review to fit the real situation. In the meanwhile, they taught the students should foster the communication skills and compassionate attitudes related to the medical humanities during the interactive courses with patients and their families at the different care sites in the community. The tutors and the students shared the care experiences in the small group after every activity of caring interaction.

Conclusion: Our result confirmed the five day training course about end-of-life care at the rural community in the middle Taiwan. The students finished the lecture of the end-of-life care was not only in the five day summer or internet before they entered the course. The students showed high satisfaction about the interactive activities after completing the whole course. Learning feedback statements were as the following: comprehensive awareness of end-of-life care, the importance of the role of home care nurse and physician, the function of qualified nursing and long-term care facilities to afford palliative care at the community, the cultural needs of patients to wish to be at home accompanied by their loved family.

Conclusions: Our model of the training course about end-of-life care to the medical students will be shared to the formal curriculum of other medical schools in Taiwan in the future.

Abstract number: P1-199
Abstract type: Poster

Attitudes and Practices of Nurses towards Palliative Sedation Therapy: A Systematic Literature Review

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Background: Palliative sedation therapy is increasingly used within given circumstances, in selected palliative care patients, by practitioners in Europe. Nurses perform a number of important roles during this therapy. Aims: To systematically review the evidence on the attitudes and practices of palliative sedation therapy by nurses, and to make recommendations to inform clinical guidance.

Method: Electronic databases, relevant journals, reference lists of included studies Review Methods: This review was limited to empirical studies written in English language published between July 2002 to July 2012, of sedation within a palliative care context only. Studies were excluded if they were not solely related to nurses, involved patients < 18y, and if the sedation was for procedural or ICU use.

Results: Following paper selection and data extraction, nine studies were included: four quantitative studies, four qualitative and mixed methods. Younger nurses, with fewer years of experience, less palliative care training were more unsatisfied with the practice of palliative sedation. Also, nurses who worked in the hospital (e.g. oncology, NICU) agreed on palliative sedation much less frequently than nurses who worked at home, involved patients < 18y, and if the sedation was for procedural or ICU use.

Conclusions: The process of deciding for palliative sedation appears a challenging one in itself. However, hospice and palliative care unit nurses appear to have a professional attitude when the indications were clear and communication with patients, family members and physicians were in place. was the fear of not recognising the appropriate moment to start patients on the protocol.

Aim: To analyze the application of the terminal care protocol in the first 3 months of introduction of this protocol in our palliative care service.

Methods: A retrospective study of files of patients dying in our palliative care service in the first 3 months of implementation of the protocol. We specifically analyzed the document presentation concerning the terminal care protocol from the files.

Results: In the first 3 months after the implementation the protocol 122 patients died in our care in the inpatient or home. The protocol was used in 65.6% of patients. Initiation of protocol correlated directly with the number of days of care (p < 0.05). The principal finding was the difference between the implementation of the protocol by inpatient unit or home care staff. The length of application of the protocol was for 84% patients in favor of inpatient unit but 90% among patients met all the criteria for the applying of the although just 2 out of 4 were required by the protocol. Reasons for the non application of protocol were: the sudden deterioration, patients transferred to other medical services, patient and family refused the application protocol and that staff waited patients to fulfill all inclusion criteria.

Conclusions: Although the end-of-life protocol was the first protocol implemented in our unit and the study was performed in the first phase to the protocol, the medical staff managed to use it in proper time and with proper results.

Abstract number: P1-201
Abstract type: Poster

Topic - Organisation of Services

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Current UK government initiatives in End of Life Care (EOLC) are keen to reduce the fragmentation and disjunctive working of organisations when coordinating care at end of life. End of Life Palliative Care Funding Review has clearly recommended that a lead provider for palliative care be identified in every Clinical Commissioning Group to coordinate palliative care services.

An established hospice recognised the need for a more clearly defined model for coordination of EOLC and undertook an initial fact finding project to identify how EOLC is currently accessed and coordinated across the areas served by the organisation. A recommendation from this report was to develop a model with an end of life provider as our preferred partner in collaboration with other providers. The rationale being that the hospice can provide end of life expertise alongside the out of hours provider providing call handling and OOH expertise. This would be the first phase towards coordinating EOLC.

The hospice and out of hours provider brought together a group of palliative care nurse specialists and nurse advisors (EOLC) to develop a greater understanding of both their differing roles and the established palliative care care pathway. From this, they developed ‘triggers’ to refer patients to the appropriate professionals and a system to refer directly to the nurse specialists. A system was also put into place that allows any professional working out of hours to refer directly to the registered nurse advisors provided for 1 year by the hospice and with a contribution towards funding from NHS Commissioners if certain targets are met.

Initial results show that whilst it has been slow to take off, patients have benefited by having access to a nurse specialist out of hours that has ensured consistent symptom management, prevention of admission and relieving family distress. The Care advisors have gained in knowledge and confidence in handling palliative care patients.

Abstract number: P1-202
Abstract type: Poster

Emotional Vulnerability & Burden Care in Palliative Care Patients and their Family Caregivers

Barea-Martin P.1, Perez-Marin M.1, Soixedra Muñoz G.1, Díaz-Cardenales J.L.2, Fombuena-Moreno M.1, Trul-Marsella E.1, De La Torre-Hernandez O.1, Diego Pedro F.1, Rueda-Castillo T.1, Balsó Díaz P.1, Mosoiu D.1, Mosoiu D.1, Gonzalez-Hernandez E.1
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Background: Terminal care protocol was the first protocol to be introduced in our service. Our service offers services in several settings. In a qualitative study with staff going through the process of implementing the protocol one issue

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
Aim: To audit advance care planning (ACP) for MN patients under the care of a Regional MND Centre multidisciplinary clinic, with reference to discussion about end of life care and documentation of the patient’s wishes. Secondly, to assess the sharing of information between the hospital and the hospice/community setting.

Method: Retrospective Case note review of MND deaths during a 2 year period.

Results: Data was collected from 38 deaths. 38% of patients died in hospital, 14% at home, 22% died within 7 days of hospital admission, 7% were admitted and died, 4% died within 12 months of diagnosis. Place of death was hospital (47%), home (29%), care home (8%) and hospice (10%).

Conclusions: An audit of advance care planning for MND patients is recommended. A care plan should be in place at the time of diagnosis.

The wish for persons with ID to stay in their own home (47%) or to stay at home was based on ensuring emotional security and autonomy according to persons with ID, relatives as well as care professionals, and also reflected the needs of care professionals to care for their clients until they pass away. Elements that seemed to determine perceived quality of care were the available nursing competencies, self-efficacy in providing end-of-life care, availability of 24-hour care and housing facilities. The emotional security of other residents also played a role. Concerning the second aim of the research, the influencing factors for the place of death are present in concomitance, the probability of the patient dying at home was 83.7%.

Conclusions: In a culture where we do not generally allude to end of life in conversations, approaching the subject with pts and families together elevates greatly the chance of the patient dying at home.

The AMBER Care Bundle: The Reliable and Rapid Implementation of Best Practice End of Life Care in Acute Hospital Wards

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Abstract number: P-207
Abstract type: Poster

Aim: To standardise the delivery, alongside existing treatment pathways, of key elements of care to hospital patients with uncertain potential for recovery. These patients have limited Clinical Goals of Care (CGOC) and are judged to be at risk of dying in the next 1-2 months.

Methodology: A care bundle was developed using the Institute for Healthcare Improvement methodology. The concept of reliability emphasises the importance of measurement of adherence to process alongside patient outcomes to general perform poorly in this regard. The focus of the AMBER care bundle is to ensure the delivery of each of the key elements of care which, based on casefile review, are: 1. a clear medical plan 2. an escalation plan 3. nursing and medical staff dialogue and consensus 4. patient and/or carer engagement and discussion of prognostic uncertainty and preferences.

Reliability of implementation was assessed by case file sampling and compared with baseline case file reviews conducted prior to the implementation of the care bundle. Results: Baseline sampling of 7% of referrals of uncertain recovery showed: 79% patients’ care contained element 1, 58% element 2, 37% element 3, 37% had all 3 retrospectively measurable elements of the bundle addressed (element 3 was excluded at this stage). Follow-up
sampling of 44 patients suitable for the care bundle (Jul 10 to Sep 11) showed: 100% patients’ care contained element 1, 93% element 2 and 82% element 4. 77% patients received all 3 elements of care. Repeat quality sampling in 2012 showed 72% (n=40) received all four elements of care.

Conclusions: It is possible to implement a care bundle to reduce variability in the delivery of key elements of care for this group of patients. Feedback within our hospital and the national network currently implementing the care bundle suggests a meaningful impact on patient and staff experience. A mixed methods evaluation to formally assess these impacts is underway.

Abstract number: P1-208
Abstract type: Poster

Designing a Track and Trigger Chart to Guide Care of the Dying in Acute Health Care Facilities

Clayt K
Calvary Mater Newcastle, Palliative Care, Waratah, Australia

Aims: Quality health care is care that aligns with patients and families’ expectations. The aim of this presentation is to describe a proposed model of care to improve care of people dying in acute hospitals that best meets the needs of the person and closely mimics care delivered in acute situations.

Methods: A literature review to identify how patients and their families deal with the experience of dying in acute settings. A qualitative design with semi-structured interviews was used to explore the implicit information held by the Hospice Nurse Specialists (PCCNS) about the experience of dying in acute settings.

Results: Data relating to 2769 referrals show:

- Electronic referral protocols. Communicate professionals.
- Phase). Agree and document local criteria, collate comments and feedback within our hospital and the national network currently implementing the care bundle.
- The DCP is based on the theoretical model developed by Chochinov et al (2002). The DCP helps CNs deliver psychosocial care, which directly relates to the issues they have identified in practice.
- ChNs use the DCP helps patients receive individualised care, closely related to the issues they have identified as most distressing and of the greatest importance. The DCP was developed, implemented and tested in four theme categories and 16 subthemes.
- Experience of DCP, responding to my interests concerns, how illness affects me as a person, how illness affects my relationships. Participants found the use of the DCP beneficial. In the future, they would like the opportunity to discuss concerns that might not have been raised otherwise.

Abstract number: P1-210
Abstract type: Poster

Why do Hospice Palliative Care Clinical Nurse Specialists Admit Patients into Hospice at the End of Life?

Corry E
Hospice Isle of Man, Braddan, United Kingdom

Aim: To investigate why Hospice Palliative Care Clinical Nurse Specialists (CNSSs) admit the greatest number of patients into Hospice at the End of Life (EoL).

Methods: An interpretative phenomenological approach was used to explore the experience of CNSSs by the Hospital PCNCS by finding those that lead them to admit EoL patients into the Hospice. Semi-structured interviews were carried out, the questions being developed by the study team’s literature review about places for EoL. Each participant in the study checked the transcript to ensure accuracy and to enhance the validity of the study. The analysis into themes was carried out using an adapted Colatzki method. Two nurses interpreted the transcripts independently. The findings were also compared to the findings of the literature review.

Results: The four most prevalent themes identified as triggers for admitting patients to EoL were: decisions on the timing of hospice care, including who wishes hospice care; patients, their families and carers; the patient’s decision to enter hospice care; and the hospice as a place of end of life care.

Abstract number: P1-211
Abstract type: Poster

The Development and Testing of a Dignity Care Pathway (DCP) for Use by Community Nurses with People Receiving End of Life Care at Home: Patient Experience

Johnston B.M.1, Papadopoulou C.1, Hunter K.1, Andrew J.1, Olliff U.1, Buchanan D.1,2
1University of Dundee, School of Nursing and Midwifery, Dundee, United Kingdom, 2NHS Tayside, Dundee, United Kingdom

Aims: This study has developed, implemented and tested a complex intervention, the Dignity Care Pathway (DCP), providing an evidence-based approach to conserving the dignity of patients and their families receiving end-of-life care at home by community nurses. The aim of the study was to explore the feasibility and acceptability of the DCP from the patients’ and carers’ perspectives. A secondary aim was to explore the utility of the DCP for individual dignity-related needs to be assessed and subsequently met.

Methods: The DCP has 4 sections, a manual, Patient Dignity Inventory; reflective questions and evidence-based care actions. A qualitative design underpinned by the philosophical underpinning was employed for the evaluation of the DCP. Data collection included focus groups with CNs (n=9) at the beginning and end of the study, individual interviews with informal carers (n=4). Interview data were analysed using framework analysis.

Results: The analysis of the patient and carer interviews resulted in four theme categories and 16 subthemes. Experience of DCP, responding to my interests concerns, how illness affects me as a person, how illness affects my relationships. Participants found the use of the DCP beneficial. In the future, they would like the opportunity to discuss concerns that might not have been raised otherwise.

Abstract number: P1-213
Abstract type: Poster

Comparing Outcome Measure Tools among Cancer Patients in Bangladesh

Dhaka Bengal Palliative and Supportive Care Foundation, Dhaka, Bangladesh, 1Cardiff University School of Medicine, Department of Palliative Care, Cardiff, United Kingdom

Aim: Administrating and reviewing patient response to outcome measurement tools among cancer patients conducted backward translation at another site Dhaka Medical College Hospital. After testing and making required changes, our research methodology was descriptive cross sectional type of study; We chose the National Institute of Cancer Research and Hospital (NICRH) as our primary research site. We recruited patients from NICRH in the inclusion criteria (age > 18 years, confirmed diagnosis of cancer, cell phone access for follow up) informed consent was obtained. Data collected on this report (period from May 2012 to October 2012). We administered 5 types of assessment tools ESAT, BPS, M-MDASI, EORTC QLQ C 30 and EORTC QLQ PC 30. To reduce bias we named each questionnaire Q1to... Q5 administered Q1to Q2... Q5 patients and labeled as

Abstract number: P1-215
Abstract type: Poster

The Association between Assisted Living Organizational Characteristics and Palliative and Hospice Care Use in Florida

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Close to one million seniors live in assisted living (AL) settings in the U.S. Most ALs are non-medical community based living arrangements for older adults. Short-term care is designated for nursing home (NH); provide shelter food, 24-hour supervision/oversight and personal care services in activities of daily living. Palliative care is defined as caring for people with serious illness regardless of their lifespan and should trigger the recognition of meaningfulness of it from the diagnostic, monitoring and treatment to provoke a transition from a care viewpoint. We want to change these and point in time to be called Palliative Transition or Trigger point.

Abstract number: P1-209
Abstract type: Poster

In contrast, the clinical reality is that many people die with poorly controlled symptoms and families often feel quite isolated despite hospital care. Conclusions: As a traditional trigger chart for the dying has been developed aligning care of the dying with usual care in acute hospitals.

Abstract number: P1-210
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1University of Dundee, School of Nursing and Midwifery, Dundee, United Kingdom, 2NHS Tayside, Dundee, United Kingdom

Aims: This study has developed, implemented and tested a complex intervention, the Dignity Care Pathway (DCP), providing an evidence-based approach to conserving the dignity of patients and their families receiving end-of-life care at home by community nurses. The aim of the study was to explore the feasibility and acceptability of the DCP from the patients’ and carers’ perspectives. A secondary aim was to explore the utility of the DCP for individual dignity-related needs to be assessed and subsequently met.

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P1, P2, P3 and first patients received Q1 first day second patient Q2 and so forth. Data analysis was conducted using SPSS software.

Results: Among the total number of patients (n=330) we had 188 (56%) male. Almost 20% of them had lung cancer. Among women predominated breast cancer 75 (23%), Pain Score was 5.9 out of scale of 10 and it was consistent along all tools. Patients ranked the questionnaire to their liking

1. ESAS
2. EORTC QLQ C30;
3. EORTC QLQ PAL 15
4. BPS-SF and
5. M ADQ.

Conclusion: It is important to understand patients perspective before we use the common Outcome Measure Tools among culturally diverse group.

Abstract number: P1-214
Abstract type: Poster

Concordance and Discordance between Advance Directives and Health Care Proxy Opinions: A Randomized Vignette-based Study

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Background: A written advance directive can occasionally contradict the opinion of a health care proxy. How such contradictions affect doctors decision-making is not well known.

Methods: We mailed to a sample of generalists and internists (N=483) three vignettes that described medical decisions in incompetent patients. The vignettes were prepared in several versions and allocated at random. All vignettes were produced in 4 versions: one with an advance directive, one with a proxy opinion, one with both, and one with neither. In the first vignette the directive and the proxy agreed on the recommendation to forego further care, in the second one the advance directive opposed further care but the proxy agreed on the directive, and in the proxy the wishes were reversed. The outcome variable was the decision to forego a medical intervention.

Results: Concordance between directive and proxy opinion reinforced each other (odds ratio of avoidance was 5.73; p=0.001 compared to the absence of directive or proxy). When the directive and the proxy disagreed, the proxy effect was attenuated, but still favored foregoing the intervention (odds ratios of avoidance were 2.1 and 2.6 for the 2 discordant vignettes, both p<0.001). The average effects - i.e., odds ratios of a decision in the intended direction - were

4.4 (3.5 - 5.5) for an advance directive and 6.4 (5.0 - 8.1) for a proxy opinion when they opposed further care, and 2.9 (2.2 - 4.0) for an advance directive and 1.7 (1.2 - 2.3) for a proxy opinion when they favored further care.

Conclusion: Both written advance directives and proxy opinions influence doctors decisions. In case of disagreement general rule for the sever diseases appear to apply: Globally, directives requesting care were less effective than directives opposing care.

Abstract number: P1-216
Abstract type: Poster

Abstract withdrawn

P1-217

Abstract type: Poster

Preferences for Care at the End of the Life in the British Asian Hindu Community: A Qualitative Analysis Using Focus Groups

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Background: In the UK most people prefer to die at home but many still wish to die in a hospital. People from black and minority ethnic groups are even more likely to die in hospital but little is known about their wishes at the end of life.

Aim: To explore preferences for place of death among the British Hindu community and to identify barriers that prevent this.

Methods: Focus groups among Indian Hindus living in London. Data was analysed using the framework approach.

Results: All 14 participants considered home to be the preferred place of death. Barriers identified as underpinning the delivery of practical and emotional care at the end of life, multiple barriers to achieve homes were voiced among participants:

(i) Little knowledge of palliative care or hospice;
(ii) language and cultural barriers that hampered accessing help from statutory services;
(iii) the conflict between traditional Hindu culture with modernity;
(iv) difficulties in families becoming caregivers; and
(v) a reluctance to ask for help at this critical time.

Conclusion: The study adds to an emerging and important literature highlighting the complex challenges in realising home deaths among an ageing minority community. We recommend:

(i) that public health initiatives are developed to raise the profile of palliative care and (ii) that a greater emphasis among health service providers is placed on identifying and valuing the social capital present among the Hindu community. These will enable more people who wish to die at home to achieve this.

Abstract number: P1-218
Abstract type: Poster

Palliative Care Consultation Service and Palliative Care Unit: Why Do We Need Both?

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Background: Palliative care (PC) infrastructure has developed differently around the globe. Whereas some institutions consider the palliative care unit (PCU) as a valuable component, others report that the sole provision of a state-of-the-art palliative care consultation service (PCCS) suffices to adequately deliver high-quality PC. Aim: To aid institutional planning, this study aimed at gathering patient data to distinguish assignments of a (con)stantly run PCU and PCS at a large hospital and academic medical center.

Methods: Demographics, Eastern Cooperative Oncology Group performance status and problem burden, symptom severity, discharge modality, and team satisfaction with care for all 601 PCU and 851 PCS patients treated in 2009 and 2010 were retrospectively assessed.

Results: Patients admitted to the PCU versus those consulted by the PCS

(a) had a significantly worse performance status (odds ratio [OR], 1.48).
(b) were significantly more likely to suffer from severe symptoms and psychosocial problems (OR, 2.05), in particular concerning physical suffering and complexity of care; and
(c) were significantly much more likely to die during hospital stay (OR, 11.03).

For patients who were dying or in other challenging clinical situations (suffering from various severe symptoms), self-rated team satisfaction was significantly higher for the PCS.

Conclusion: This study presents a direct comparison between patients in a PCU and a PCS. Results further support the hypothesis that the coexistence of both institutions in one hospital contributes to the goal of ensuring optimal high-quality PC for patients in complex and challenging clinical situations.

Abstract number: P1-219
Abstract type: Poster

Nurses’ Role in Decision Making about Palliative Sedation

Zielvelder G1, Brinkkemper T2, Swart J1, Van der Heide A1, Zuurmond WW1,2, Perez R1, Amsterdam Rotterdam Sedation (AMROSE) Study
1VU University Medical Center, Anesthesiology, Amsterdam, Netherlands, 2Erasmus MC University Medical Center, Dept. of Palliative Care, Rotterdam, Netherlands, 3Erasmus MC University Medical Center, Dept. of Public Health, Rotterdam, Netherlands, 4EMGO Institute for Health and Care Research, Amsterdam, Netherlands

Context: Nurses play an important role in the care of patients undergoing palliative sedation. Despite this, only little research has been focussed on the nurses’ contribution to the decision making process leading to the application of palliative sedation.

Research aims: The aim of this study is to clarify the nurses’ role in the decision making process concerning this end-of-life intervention.

Study design and methods: 35 nurses from different palliative care settings were asked to participate in an in-depth semi-structured interview, conducted by six trained interviewers. Data collection occurred from October 2008 to April 2009. Data were analysed using the constant comparative method with NVivo software.

Results: Important nursing tasks in the process leading to palliative sedation were observing the patient and drawing attention to significant changes in their condition, therewith providing information on which the decision to perform palliative sedation was made. Respondents did not speak of themselves as final decision makers, but exerted influence through care planning and participation in multidisciplinary meetings, depending on their level of experience. The nurse was often the first contact person in communication with the patient and their relative.

Conclusions: The nurses role in the decision making process leading to palliative sedation encompasses many aspects, one of the most important being the role of declarant, for which observation of signs and symptoms was considered important. Nurses gain influence through their specific expertise in proposing or objecting to initiating communication within the care team and between care takers and patients and their relatives.

Funding: Funding for this study was provided by the Netherlands Organisation for Health Care Research (ZonMW) and the hospice kuta.

Abstract number: P1-220
Abstract type: Poster

Perceptions of Nurses Concerning Sedation Depth during Palliative Sedation

Van Zoonen S3, Brinkkemper T1, Rietjens J1, Van der Heide A1, Zuurmond WW1,2, Perez R1, Amsterdam Rotterdam Sedation (AMROSE) Study
1VU University Medical Center, Anesthesiology, Amsterdam, Netherlands, 2Erasmus MC University Medical Center, Dept. of Public Health, Rotterdam, Netherlands, 3EMGO Institute for Health and Care Research, Amsterdam, Netherlands

Context: Nurses play an important role in the management of continuous palliative sedation for dying patients with refractory symptoms. Little is known about their views concerning the required depth of sedation and prioritisation of sedation goals.

Aim: The aim of this study is to explore the views of palliative care nurses regarding sedation depth, and to assess differences between nurses working in different institutions.

Study design and methods: Data were collected in semi-structured interviews with 3 nurses in three different palliative care settings (home care, hospice and hospital), focusing on the last case of palliative sedation the nurse had been involved in. Interviews were coded and analyzed with qualitative data analysis software NVivo.

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Results: Perceptions with regard to the goal of sedation and communication emerge as major themes related to the depth of sedation. Achieving deep sedation was considered the most important goal by most nurses. Since 2009, adequate symptom control was mentioned more often by hospice nurses than by nurses working in other settings. However, achieving adequate symptom control remained in importance over the importance of maintaining communication, with which sedation may play a role in a eventual determination of sedation depth. The role of adequate monitoring in the guidance and maintenance of sedation needs to be explored further.

Conclusion: Based on nurses' perspectives, preconceptions with regard to the goal of sedation related to the provision for sedation may play a role in eventual determination of sedation depth. This phase of data collection will be used to inform further development in this area.

Abstract number: P1-222
Abstract type: Poster

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the transition of patients with complex symptom management and/or those requiring psychological support. Letters were sent to all HCPs involved in the individual’s care. Aim: A survey was undertaken to ascertain opinion of HCPs on the usefulness of the newly introduced discharge letter and identify ways in which information and care may be improved.

Method: SPCT discharge letters were sent over a six month period. A survey form comprising three closed questions and seven open-ended questions was sent to all community HCPs involved with each patient, one week following discharge. Recipients included GPs, District Nurses, Specialist Palliative Care Team, Hospice at Home, and professional carers. A thematic analysis was applied to the open-ended questions.

Results: 51 survey forms were sent, pertaining to 18 discharge letters. 33 replies were received, of which, 94% said the letter was “very useful” and that they wished to continue to receive them. The letter format was reported as being clear, concise, relevant, and succinct. 30% wanted a rationale for drug choices and titration. 65% had an opportunity to discuss prognosis with their GP, but this was considered not adequate. Many felt that knowledge of palliative care was needed and that palliative care was not always made available. 77% felt that the letter improved their communication with their community HCPs.

Abstract number: P1-227 Abstract type: Poster

How to Share a Terminal Patient’s Desire amongst the Medical Team? - From the Experience of a Nurse on Terminal Sedation

Abstract number: P1-228 Abstract type: Poster

A Retrospective Baseline Audit to Assess Current Practice in Identification, Communication and Care Planning for Christie Patients in the Last Year of Life

Abstract number: P1-230 Abstract type: Poster

Patients’ Experiences of Hospice Referral: A Phenomenological Study

Abstract number: P1-231 Abstract type: Poster

Symptom Clusters in Advanced Cancer Patients during Terminal Phase of their Illness in a Northern City of Turkey

Abstract number: P1-232 Abstract type: Poster

Poster sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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Background: A key focus of UK policy is improving patient experiences of palliative care across the spectrum of palliative care provision. Most palliative care occurs in a generalist setting rather than a specialist palliative care setting. Ensuring effective partnership working between generalist and specialist providers of palliative care is therefore necessary for improving patient care. Aims: To explore patient experiences of, and priorities for, partnership working between specialist and generalist providers of palliative care.

Methods: Semi-structured interviews were conducted with patients with palliative care needs (n=28) recruited in two hospices in northern England. Interviews were analysed using a modified thematic approach. Results: Findings highlight that not all patients can identify the main health care professional (HCP) supporting them. A few patients acknowledged the Community Matron as their main facilitator of care. Issues cited as important with regard to HCPs include good relationships, continuity, being able to talk about sensitive matters, and feeling helped, needed and willing in dealings with patients. The majority of patients said they had not experienced difficulties in the care they received, but this view was accompanied by concerns about poor communication and receiving conflicting advice from HCPs. Conclusion: There is a need for future development which would reveal that many are satisfied with their care, especially care provided by their local hospice. Asked about how care from health professionals (OHP) really know about this procedure and its use, a young discipline. There is no palliative care teaching in the national MBBS course, nor is there a nationwide palliative care policy. This can lead to poor health professionals’ knowledge of PSH. An educational approach is therefore necessary with a young discipline.

Abstract number: P-233
Abstract type: Poster

Healthcare Professionals’ (HP) Understandings of Advance Care Planning (ACP) in End of Life Care for People with Primary Brain Tumours (PBT): Qualitative Study

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Background: Patients with PBT have poor prognoses and early and prolonged palliative care needs. Significant, fluctuating and progressive cognitive decline is common. Early ACP may enable discussion of decisions about the future. Yet there is little evidence of ACP in practice. Aims: To explore healthcare professionals in PBT understand the palliative needs of patients and approach ACP in their work.

Methods: A qualitative study using semi-structured interviews. Participants are recruited purposively according to discipline (neurosciences, nurses, oncologists, clinical nurse specialists, allied HP), age, experience, sex, ethnicity (N=15). Data is analysed with framework analysis.

Results: Initial findings (n=5): ACP is complex in PBT patients. ACP discussions usually take place in the context of patients’ anticipated life-limiting decline. Accordingly, participants felt ACP discussions should happen early in a patient’s illness. Participants reported how ACP discussions involved discussing end of life illness, dying and death and they tried to approach discussions sensitively. They agreed ACP discussions should not be formal, or imposed on patients. Discussions often happen ad hoc. Participants felt ACP is shared amongst the multidisciplinary team, but worried that therefore one no one palliative care professional boards. They often felt that their patients don’t use a standardised way of documenting ACP. Generally, they chose to communicate content of discussions to their teams through informal means and at meetings.

Conclusion: The lack of standardised documentation and assumption of shared responsibility amongst professionals may lead to some patients feeling left out of discussions or their choices not being fulfilled. Given the nature of discussions, formalising their placing and content may be problematic. This is a key area for the development of ACP based intervention which can later be tested for feasibility and acceptability.

Funder: National Brain Appeal

Abstract number: P-235
Abstract type: Poster

Survey on Beliefs and Opinion of Oncology Health Professionals about Palliative Sedation


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Objectives: To explore how patients experience healthcare staff’s communication and poor ‘bedside manner’. Views of patients who participated in this study informed the development of a questionnaire to explore experience working from the perspective of health professionals.

Abstract number: P-236
Abstract type: Poster

A Randomized Controlled Study Including Healthcare Professionals Caring for Patients in Cancer at the End of Life: Results from an Educational Intervention on Existential Support

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Objectives: To determine the effects of an educational intervention focusing on existential issues on nurses’ perceived confidence in communication and their attitudes towards caring for dying patients.

Methods: A randomized controlled trial was conducted with an educational intervention focusing on existential topics as life and death, freedom, relationships and tolerance, and meaning. The intervention included five 90 minute sessions over an eight week period consisting of theoretical education combined with individual and group reflections. 102 nurses in oncology wards, hospice wards and palliative home care teams were randomised to either education group or non-education group. Primary outcomes, confidence in communication and attitudes toward care of dying patients were measured at baseline before the educational intervention started, immediately after, and five months later. Distribution was given as mean, SD, median, min and max, number and percentages. Data were analyzed with the Wilcoxon signed rank test, Chi-square test, Wilcoxon Signed rank test, sign test and Spearman’s correlation coefficient. Results: In the education group confidence in communication increased significantly from baseline, to both first and second follow-ups, i.e. immediately after and five months after the educational intervention. Towards care of the dying did not increase in the education group.

Conclusion: An education including existential topics with reflection over time improves healthcare staffs’ confidence in communication when caring for patients in cancer at the end of life. This is important information for healthcare providers with limited resources. Further studies are needed to explore how patients experience healthcare staff’s communication skills after such education.

Abstract number: P-237
Abstract type: Poster

Anticipatory Medication ‘as Stock’ for Residents who Are In the Dying Phase: A Project in 3 Nursing Care Homes

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The Gold Standards Framework for Care Homes (GSSFCH) and the Liverpool Care Pathway (LCP) guidance suggests the importance of obtaining anticipatory medication to control the symptoms in the last days of life for nursing home (NH) residents. There is considerable wastage however as NH residents are dispensed appropriately 1% of drugs on a namned patient basis. There is also evidence that these drugs are not available residents are hospitalised inappropriately. Aim: To determine the effect of an educational and a project workflow to reduce the waste of symptomatic medicines in the dying phase to explore whether there was a need for residents to have their own support using by existential thought. The idea was to develop an educational approach to explore how patients experience healthcare staff’s communication skills after such education.

Abstract number: P-238
Abstract type: Poster

Poster sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

Poster sessions
An exploration of the Role of the Key Champion in the Process of Implementation of the Liverpool Care Pathway for the Dying Patient in Intensive Care: A Mixed Methods (LCP ICU-MP) Study

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The LCP programme is a model of best practice to support evidence based high quality care for dying patients and their relatives/caregivers. The LCP ICU-MP was developed specifically for use in ICU settings and was successfully piloted across 10 ICU Services within the Cheshire and Mersey (C&M) Critical Care Network (CMMCN). A cascade model of training was adopted to support its implementation within these ICU settings. This approach involved the recruitment of Senior Nurses to act as key champions, to act as change agents in each site by becoming the conduit for education, training and support for staff in the use of the LCP ICU-MP in the clinical environment.

Aims: To elicit the views of key champions to understand their experience of undertaking this role, including the identification of associated benefits, barriers and learning outcomes.

To use these findings to refine and reframe the implementation model for use in future dissemination projects.

Method: A focus group comprising 12 key champions was undertaken to elicit their experience of this phase. The discussion was guided by a semi-structured topic guide, and was audio-taped and transcribed verbatim. A Thematic Analysis (TA) was used to extract common patterns.

Results: Three initial themes emerged that impacted on the success of the implementation process in each of the sites:

- Communication: Difficulties in the establishment of the role at various levels; Time constraints and competing work priorities; Role benefits and challenges.

Conclusion: The findings will be discussed in terms of their potential to facilitate the review and refinement of the Role of the Key Champion and the implementation process for use in future dissemination of the LCP ICU-MP.

This study was funded by Mersyside and Cheshire Cancer Network (MCMMC) on behalf of the CMMCN.

Abstract number: P1-239
Abstract type: Poster

Continuous Sedation (CS) until Death: A Bibliometric Analysis (1946-2011)

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Aims: Sedation at the end of life is a complex medical and ethical topic, increasingly debated in the palliative care literature. However, little is known about the characteristics and trends of scientific publications in this field of research. The aim of this study was to map the existing literature through the bibliometric analysis of scientific publications on continuous sedation until death.

Design: Four electronic databases (MEDLINE, PubMed, EMBase, and PsychINFO) were searched for indexed material published between 1945 and 2011. This search resulted in 273 published outputs that were analysed using bibliometric techniques.

Results: Evidence revealed a growing rate in scientific publications from the beginning of the 90’s falling into a wide range of publication types such as comments/letters (28.7%), clinical trials (23.0%), theoretical/conceptual articles (18.7%), reviews (12.8%), case reports (8.0%), and editorials (5.0%). Outputs were published in 94 journals of varying scientific types (medicine, palliative care, ethics, law), the majority of which (72.3%) was classified under Health and Medical Sciences.

Conclusion: This is the first bibliometric analysis on continuous sedation until death to provide a representation of the general characteristics and trends regarding the evidence as well as a baseline which to compare future studies.

Keywords: End-of-life care, continuous sedation until death, bibliometric analysis

Abstract number: P1-240
Abstract type: Poster

Sedation in End of Life Care: The Conceptual Debate over Terminology and Definitions

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Aims: The lack of consensus regarding nomenclature to describe sedation at the end of life has made interpretation and comparison of the results of studies and case analyses problematic and has created confusion in both clinical and research fields. This paper aims to explore and account for the conceptual debate over terminology and definitions assigned to sedation at the end of life over time.

Design: Six electronic databases (MEDLINE, PubMed, EMBase, AMED, CINAHL, and PsychINFO) and two high impact journals (NEJM & BMJ) were searched for indexed materials published between 1945 and 2011. This search resulted in bibliographic data of 328 published outputs. Terms and definitions were manually scanned, coded, and linguistically analyzed by means of term description criteria and discourse analysis.

Results: Terminology of sedation at the end of life was observed to have undergone many simple to complex terminologies. Definitions of sedation varied in length, comprising different aspects of the practice such as indications for use (to palliate; to relieve), pharmacology (psychotropic agents; sedative drugs), patient symptomatology (profound anguish; physical distress), target population (terminally ill; onset of severe distress), and goals of the intervention (to decrease distress; in the last phase of life); and ethical considerations (deliberately, without intending to cause death) in combinations of a minimum of two or more of these aspects.

Conclusion: Given the diversity in the terms used to describe sedation and the range of understandings associated with the meaning of the practice, reaching consensus is bound to be difficult. Still, the conceptual confusion that currently exists in the literature needs to be resolved and a base of commonality to be built on which to design research and enhance practice of sedation in end of life care.

Keywords: Sedation, end-of-life care, conceptual debate, terminology, definitions

Abstract number: P1-241
Abstract type: Poster

Is “Liverpool Care Pathway (LCP) for the Dying Patient” in Intensive Care to Be a Useful Instrument also for the Inpatients in a Palliative Care Unit?

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Liverpool Care Pathway was initially developed for better End-of-Life Care for institutions which in their daily routine do not have more than one specialist for dying patients (Elschewig). The aim we saw in the present investigation was to work out if the LCP also makes sense during End-of-Life Care of the inpatients in a Palliative Care unit, i.e. in a setting where death-and-dying is managed by an experienced stuff.

Procedure: Hereto we examined 40 completed LCP cases. The following criteria were evaluated:

1) duration of LCP care in days;
2) goals of the care;
3) interplay of the Palliative Care unit staff in following points:
   3.1. practicability in the everyday life;
   3.2. processing pressure situations, especially concerning the decision-making or recognising the transition point to turn to terminal care;
   3.3. influence on the process of communication within the interdisciplinary team.

Results: We found out that Liverpool Care Pathway (LCP) is helpful in managing critical situations also in a PC unit setting, especially due to

1) ensured transparency of what was done;
2) optimising and managing pressure situations;
3) more self-assured feeling to colleagues who are less experienced;
4) becoming a good training instrument for the PC stuff regarding the role in further implementation of LCP in other departments of the hospital.

Abstract number: P1-242
Abstract type: Poster

Appropriateness of Hospital Admissions at the End of Life: Perspectives of GPs and Nurses

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Aim: With many patients being transferred to hospital in the last days of life, we wanted to explore the perspectives of general practitioners (GPs) and nurses on hospitalizations at the end of life and how these perspectives can be used to describe the essence of such hospitalizations.

Methods: Five focus groups with GPs (N=37) and three with nurses working in hospital, home care or care homes (N=23).

Participants were asked about their experiences and opinions about hospitalizations at the end of life. They were prompted to assess the appropriateness and avoidability of such a hospitalization in patients with cancer, organ failure and dementia.

Abstracts of the focus groups discussions were analyzed by two researchers using open, axial and selective coding with QSR NVivo 10. Results were regularly discussed in the research team.

Results: The participants of this study generally agree that a hospitalization at the end of life is clinically appropriate in a limited number of events and conditions (e.g. gastrointestinal obstruction), and only when it is likely that there will be a comfort benefit from hospitalization (e.g. a suspected diagnosis or treatment in a hospital). On the other hand there was also agreement that a hospitalization at the end of life is inappropriate when the focus is on keeping the patient and/or relatives’ preferences (e.g. to take away anxiety) or when the current setting care is not able to provide adequate care. Adequate and alternative care settings are not readily available.

Conclusion: GPs and nurses agree that a large proportion of hospitalizations at the end of life are not appropriate. However, although they may be appropriate, taking into account the psychosocial benefits and the lack of adequate sub-acute alternatives. These findings will be used to develop an assessment procedure to evaluate whether a hospitalization at the end of life is appropriate or necessary.

Funding: This study is part of the FLEICE-study, funded by IWT.

Abstract number: P1-243
Abstract type: Poster

Results from the UNBIASED Study (UK - Netherlands - Belgium) (Sedation Study): Reported Practices of Physicians and Nurses in Three European Countries

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Background: Continuous sedation in end of life care is an important and frequently necessary but highly contested intervention in the care of dying patients with otherwise refractory distress. There have been few studies which allow international comparisons to be made and which investigate the perspectives of physicians and nurses from different care settings.

Aim: To understand what intentions and practices are reported by physicians and nurses involved in continuous sedation in end of life for cancer patients in the UK, Belgium and the Netherlands.

Methods: Qualitative case studies in hospitals, hospices and home care settings, comprising interviews with nurses, doctors, and physicians involved with the care of patients who had died of cancer and received continuous sedation for refractory symptoms.

Findings: We studied 84 cases (22 UK, 35 NL, 27 BE) 57 physicians (17 UK, 18 NL, 22 BE) 73 nurses (25 UK, 28 NL, 20 BE). UK respondents often described sedation as a side effect of their intent to control symptoms. They perceived a continuum to exist from the normal practice involving low doses of sedatives given on a regular basis, to rare situations where it was exceptionally challenging to bring suffering under control. In contrast, respondents in Belgium and the Netherlands described a clear intention of how they sought to respond to a patient's request for sleep or to enable patient's choice of sedation. Reported practice in the Netherlands was framed by national guidelines. In contrast in Belgium practice was typically reported as targeted at achieving and sustaining deep sedation.

Conclusions: continuous sedation at the end of life is
practised practised and perceived differently by physicians and nurses in the three countries, with the most notable feature being the caution reported by UK respondents, compared to those in Belgium and the Netherlands.

Abstract number: P1-244
Abstract type: Poster

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Abstract number: P1-245
Abstract type: Poster

The Impact of “Self-perceived Burden to Others” and “Posttraumatic Growth” on Quality of Life for Terminally Ill Cancer Patients

Abstract number: P1-247
Abstract type: Poster

Palliative Care in Hospitals and at Home

Factors Influencing End-of-Life Treatment Preferences of Older Latino Advanced Cancer Patients

Abstract number: P1-248
Abstract type: Poster

Factors Related to Place of Death among Cancer Patients Assisted by a In-home Palliative/Supportive Care

Results: Thirty-four baseline interviews with cancer patients and 43 with the companion group were completed. Forty-seven percent of patients compared to 66% of non-cancer participants had hope and positive coping strategies in the end-of-life care approach (P = 0.10). Cancer patients with high medical mistrust levels (79%) were more likely to prefer life extension compared to those with low or moderate levels (38%) (P = 0.049). Other factors associated with a palliative care approach preference were having high education levels (P = 0.055), having more than two comorbidities (P = 0.029), and biculturalism (P=0.025).

Conclusion: Our findings suggest that medical mistrust, post and well being, comorbidity burden and acclerating are associated with EOL treatment preferences in this population. Additionally, future research will further elucidate how the combination of clinical, demographic, psychosocial, cultural and system factors influence EOL treatment preferences. In order to develop a culturally appropriate communication and decision making strategies.

Abstract number: P1-249
Abstract type: Poster

Palliative Care in Hospitals and at Home

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Treatment in hospitals usually focuses on curative aspects. When patients need palliative care, this need is not always recognized. More attention is needed for symptom control and palliative care in end of life care. In 2011, a project named ‘Palliative Care in the hospitals’ started in the South of the Netherlands. In this project, among ten hospitals, the goal is to strengthen the Palliative Hospital Care and to contribute better cooperation with other out-hospital care givers. The hospitals are all willing to improve palliative care. In the period of 2011-2012 the hospitals are supported in the development of in-hospital Palliative Care Teams (PCT’s). Palliative care experts are member of this multidisciplinary team. A PCT can contribute to improve the palliative care for individual patients. The PCT supports the principal professional caregivers in giving the best palliative care, therefore the expertise in hospitals in general is increased. At present, the focus is to expand the cooperation with other organizations. Already a few hospitals constitute their PCT together with other organizations (homecare nurses, general practitioners; other palliative care consult teams). Aim is to support both in hospital and out hospital healthcare professionals in giving good palliative care. When teams cooperate, it also contributes to a better transfer from hospital to primary health care. The PCT’s register all care and advice they give, using a standardized registration form. Therefore, some care practices in end of life care is perceived, improving the knowledge about what factors are relevant for an effective PCT. To contribute to the further development of palliative care in the South of the Netherlands, we want to explore best practices of in-hospitals and transmural PCT’s. In may 2013 we will be able to present evidence from the registrations of the PCT’s. Awareness, cooperation, connection and communication are leading topics in this project.

Abstract number: P1-250
Abstract type: Poster

Understanding the Role of Nurses in Decisions to Use Anticancer Proscriptions to Manage Symptoms and Distress in the Last Days of Life

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Background: In the UK, a key approach to improving end of life care has been the use of ‘anticipatory’ or ‘just in case’ prescripions of anti-cancer drugs, as these are especially important in the community where nurses have the responsibility for deciding when to implement them. There is almost no research on nurses’ roles.

Aims: To examine how community nurse works with doctors
and pharmacists in making decisions to use medications prescribed just in case of difficult symptoms patients may experience at the end of life.

Method: An ethnographic study in two UK regions: the Midlands and the North West, with community nursing teams and nursing homes. Observations and interviews were conducted after aromatherapy massages. The data was transcribed and analyzed using an inductive analysis method.

Results: Based on the feedbacks, aromatherapy massage effects have been classified into seven categories: improve physical symptom (pain, fatigue, edema and hoynosis), less depression, help communication through touch, feel of being cared, time of special, acknowledgement of disease and empowerment.

Aromatherapy massage has provided the time of relaxation besides an improvement of physical conditions. Through human contact and massage, patients become less depressed or anxious and eventually led patients to speak out current mental or physical conditions. Moreover, patients starts to feel the time given for aromatherapy treatments as special, rewarding time, encouragements to share inner feeling with others, and empowering themselves to recognize the disease and positively live with cancer.

Conclusion: Aromatherapy massage has effects not only in physical symptom but also to quality of life of cancer patients who are under palliative care.

Abstract number: P1-253
Abstract type: Poster

**Home Going (from Acute Hospital to Home during the Very Last Phase of Life) - Terminal Discharges from the National University Hospital under the Palliative Care Service**

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**Background:** Preference for location of death is mostly at home. Some patients are admitted to the acute hospital for treatment, but the physician may not have sufficient time to discharge these patients in the hospital.

**Objective:** To examine the patient group who were terminally discharged from the hospital.

**Methods:** This is a retrospective review of data for all terminal discharge cases referred to palliative care service in NUH over a period of 3 years (2009 - 2011). We have collected and reviewed the demographic data of the patients, as well as comparing the care that the non-cancer patient. We have also connected with the community hospice services to follow up with patient's progress and family's coping.

**Results:** In year 2009, we have a total number of 47 cases under palliative care service who underwent terminal discharge. In year 2010, the number increased to 71 cases. In year 2011, the total number cases for terminal discharges were 95. Exact prognostication remained a challenge, as the condition of a patient is continuously changing and a longer than expected period after they were discharged.

**Conclusions:** We noticed an increase trend in terminal discharges, which is related to palliative care education among the doctors, patients and families. Therefore, we may need to advocate for more resources in the community for our home hospice partners to support the patients and the families, during these very last hours of their lives.

**Epidemiology**

**Abstract number:** P1-254
**Abstract type:** Poster

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**Abstract number:** P1-255
**Abstract type:** Poster

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**Abstract number:** P1-256
**Abstract type:** Poster

**Patients with Head and Neck Cancer in Palliative Care**

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Introduction and aims: Head and neck cancer patients are associated with particular problems related to its location causing a deep impact in quality of life. The aim of this study was review those problems in our patients.

Methods: This is a retrospective study, data were collected from the clinical records of the patients admitted to our palliative care unit. Besides demographic data, symptoms, medication and what happened to the patients were also collected. The statistical methods are descriptive as required by this type of study.

Results: Between 17/06/2007, unit opening date, and 30/06/2012, 1109 patients were admitted and 112 (10%) of them had head and neck cancer. 91 (81%) were men. The mean age was 58 years, 52 (47%) were located in larynx - 19 (17%) cases; pharynx - 17 (15%) case; face - 9 (8%); tongue - 9; pyofymus sinus 8 (7%). There were differences in the particular tumor locations between gender, besides the difference in the overall prevalence. 101 (90%) of the tumors were locally advanced, and the most frequent metastazation site was lymphp nodes - 53 (47%). The most frequent symptoms were: pain - 98 (88%); dysphagia - 67 (60%); fatigue - 67 (59%) and numbness - 54 (48%). There were differences in the particular symptoms between gender, the most frequent symptom was pain for women - 131 (90%) and for men - 64 (80%). The most frequent symptoms were: pain - 98 (88%); dysphagia - 67 (60%); fatigue - 67; sadness - 54 (48%). There were differences in the particular symptoms between gender, the most frequent symptom was pain for women - 131 (90%) and for men - 64 (80%).

Conclusions: Head and neck cancers are associated with many problems. Their location causes feeding and respiratory difficulties often requiring devices to overcome them. Neoplastic wound also are an important cause of suffering.

Abstract number: P1-257
Abstract type: Poster

**The Development of Do-not-Resuscitate Decisions over the Past 20 Years in the Netherlands**

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Research aims: Although cardiopulmonary resuscitation (CPR) can save lives, it has become clear that CPR is often unsuccessful. Moreover, it can have several consequences. As a result, decisions have to be made about who should or should not receive CPR in case of cardiac arrest. We examined trends in dnr orders in the Netherlands from 1990 to 2010 in order to find out whether the decision-making over the past 20 years in the Netherlands. Study design and methods: In 1990, 2001 and 2010 a nationwide study of a sample of patients that were discharged in 1990 from the clinical records of the patients admitted to our palliative care unit. Besides demographic data, symptoms, medication and what happened to the patients were also collected. The statistical methods are descriptive as required by this type of study.

Results: The response percentages were 76% (1990), 75% (2001) and 74% (2010). The frequency of individual DNR decisions in non-sudden deaths that were preceded by an explicit conversation increased from 56% in 1990 to 87% in 2001 and 87% in 2010. The frequency of institutional DNR decisions decreased from 11% (1990) to 9% (2001) and 3% (2010). Furthermore involvement of patient or relatives increased from 67% (1990) to 97% (2001) and 99% (2010).

Conclusions: Non-sudden deaths are increasingly preceded by DNR decisions that are discussed with patient or relatives.
Five-year Trends: Cancer Patients Availability of Specialist Inpatient Palliative Care. These years between the years of 2006-2011. We examined the trends in death registrations for all cancer deaths in the region. Conclusion: Health care providers often state that services are provided based on shared values. However, we do not know if this is true, if the different system for describing and measuring values driven health care. The input of affected users of health care is rarely included in the planning and decision making processes. Providers (including palliative care) may think they know better than patients how to die. Social and community involvement in health care is rarely discussed or the lack of transparency.

Method: This project was supported using qualitative data for formative and summative evaluation. For qualitative analysis telephone meetings, focus groups, individual interviews, and site visits were used. For quantitative analysis observational self-assessment and a modified version of the African Palliative Care Association Palliative Outcome Scale were used. Each site developed its own intervention to introduce and implement DVC with assistance from Altarum. Results: The project demonstrated that DVC could be introduced in different cultures and implemented in palliative care programs resulting in improvement in the quality of services.

Abstract number: P1-259
Abstract type: Poster

Five-year Trends: Cancer Patients Are Dying at Home

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Significant country differences in the proportion of patients with cancer dying at home, and they are influenced by country-specific cultural, social, and health care factors. There has been considerable international research of the place of death of cancer patients although no studies have attempted to analyze this issue in Russia.

Aims: Our aim was to examine the proportion of cancer deaths in the different regions of Russia in relation to demographic factors and to identify 5-year trends in home deaths from cancer.

Methods: The place of death was derived from death registrations for all cancer deaths in the region between the years of 2006-2011. We examined the trends in home deaths from cancer for the whole region, for the city and for the rural area.

Results: Within this period the percentage of home deaths from all causes significantly increased in the region from 55.67% to 73.68%, in rural areas from 60.10 to 82.12% and in the city from 30.32% to 66.37% (respectively 1.24, 1.37 and 2.19 times increase). The number of deaths from cancer in rural areas was consistently high and the rate of cancer patients died at home was 87.52% on average for this period. Older people were more likely to die at home (16-16% of all cancer deaths). Among all women and men died from cancer respectively 90.62% and 79.60% at home. Concerning the proportion of home deaths from both cancer and all causes to a certain extent is the result of reducing the hospital care system and still demonstrates low availability of specialist palliative care. These findings today highlight the need for a palliative care service establishment for cancer patients in the region paying special attention to home care. Home care should be considered when implementing structural reforms in primary care.

Abstract number: P1-260
Abstract type: Poster

Decent Care Values in Palliative Care Services: An International Demonstration Project

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Aims: The World Health Organization (WHO) led development of a framework for a global health care services with the needs of affected persons. This framework of “Decent Dying” (Dr. Mansel, 2012). It includes 6 values at three levels: Agency & Dignity at the individual level, solidarity & interdependence at the social level and sustainability & subsidiarity at the systems level. The aim of this project was to see if the values could be demonstrated by palliative care providers in actual practice. Palliative care was chosen because it is closely aligned with these values. Two demonstration sites were competitively chosen, Hospis Malaysia in Kuala Lumpur and Kibera Community Self-Help Project (KICOSHEP) in Nairobi, Kenya.

Methods: This project used qualitative & quantitative data for formative and summative evaluation. For qualitative analysis telephone meetings, focus groups, individual interviews, and site visits were used. For quantitative analysis observational self-assessment and a modified version of the African Palliative Care Association Palliative Outcome Scale were used. Each site developed its own intervention to introduce and implement DVC with assistance from Altarum.

Results: The project demonstrated that DVC could be introduced in different cultures and implemented in palliative care programs resulting in improvement in the quality of services.

Abstract number: P1-261
Abstract type: Poster

Ethical Challenges in Nursing Homes from the Patients Perspective: First Results from Different Norwegian Regions

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Research aims: The aims of the present study were to investigate ethical challenges in nursing homes from the residents’/palliative patients’ perspectives. What patients perceive as ethical problems in nursing homes.

Methods: Qualitative study in nursing homes with semi-structured interviews with residents. Structured questioning and open interview was used in this study. A total number of 25 patients from different regions and nursing homes participated in the study. Inclusion criteria: Participants who were living in a nursing home and had the ability to give full informed consent. Nursing home residents without the ability to give informed consent were excluded.

Results: 25 nursing home residents aged 66 - 100 years (mean 87.6) were included in the study. The inclusion of participants aimed for a maximal variation in the sample and included patients from nursing homes in different regions, big cities and small villages in Norway. The duration of the interviews varied from 10 - 71 minutes due to the participant’s wishes, attention and health condition. Different ethical challenges were described by the nursing home residents were e.g. the lack of resources (not enough time to talk to the patients, long waiting to get help) and self-determination and respect. Many participants reported on the importance of the relation to their caregivers as both giving and problematic.

Conclusions: A first analysis of our qualitative data from the interviews with residents on palliative care show that what resources, autonomy and especially the relation to the caregivers are the most important ethical challenges from the viewpoints of the nursing home residents. Focus-group interviews of relatives will help to answer our first results from the relative’s perspective.

Abstract number: P1-262
Abstract type: Poster

Time to Change: Proactive Palliative Care: Are We Ready?

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Palliative Care is more than symptom control. It must try to prevent suffering.

Aims: To establish reasons why palliative care institutions and teams lack resources to meet patients needs rather than proactively work to benefit or patients.

Methodology: This study looks at over twenty Specialist Palliative Care Units in Great Britain and Spain looking into institutional and professional attitudes towards the implementation of care.

Results: A vast majority of units, despite decades of experience looking at patients continue waiting for the sick to come calling rather than find mechanisms of offering early integrated specialist palliative care. This often means being too late.

Conclusion: There needs to be an important shift in institutions, organisations and we need to offer a more ethical, more humane and timely palliative care to those needing it.

Abstract number: P1-263
Abstract type: Poster

Ethical Dilemmas around the Dying Stroke Patient - A Qualitative Interview Study with Team Members in Stroke Units

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In Sweden, individuals affected by severe stroke are treated in specialised stroke units. In these stroke units, patients are attended by a multi-professional team with a focus on care in the acute phase of stroke, rehabilitation phase, and the palliative phase. Caring for patients with such a large variety in condition and symptoms might be an extra challenge for the team. Today, there is a lack of knowledge in team experiences of the dilemmas that appear and the consequences that emerge. The aim of this paper was to study ethical dilemmas among health care professionals working with the dying stroke patients in acute stroke units. Forty-one health care professionals working in a stroke team were interviewed either in focus groups or individually. The data were transcribed verbatim and analyzed using content analysis. The results and ethical dilemmas that appeared were depending on “Non decisions” about palliative care or discontinuation of treatments. The lack of decision made the team members act on their own based on individual skills, due to the absence of common communication tools. When a decision was made staff had “Problems holding to the decision” The devised and implemented plans could be revalued which was described as a setback to non-decisions again. The underlying problem was “communication difficulties” and was based on cultural dissimilarity and lack of knowledge of palliative care value.

The conclusion of this study highlights the importance of palliative care knowledge and skills, even for patients suffering from severe stroke. It makes a decision to hold on to that is a prescription in creating a credible care plan. However, implementing a common set of values based on palliative care with symptom control and quality of life might minimize the risk of the communication difficulties that may arise and increases the ability to create a health care that is meaningful and dignified.

Abstract number: P1-264
Abstract type: Poster

Ethical and Cultural Aspects of Decisions for Withholding or Withdrawing Nutritional Support in Palliative Care

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Nutritional support has increased markedly while prolonging survival of patients with neuromuscular diseases, especially among elderly. Meanwhile a large range of nutritional support can be provided: authorised or assisted oral feeding, using natural or supplemented food, naso-gastric tube, gastrostomy or IV nutrition. The decision of withholding or withdrawing nutritional support raises a daily ethical problem in the various care units and at home, whether one considers nutritional feeding as a medical treatment or a care. The French law in 2005 has stated that any treatment can be withheld or withdrawn, when medically futile, especially if requested in

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and/or accepted by the patient directly or through an advance directive.

Since then, nutrition has been considered as a medical treatment to stop or not a care, and therefore can be withdrawn. This has raised a societal debate: Is nutritional support a way of prolonging a meaningless survival and suffering until the patient is withdrawing, could one accept a slow death from hunger? Is an active euthanasia a more ethical and compassionate way of reducing or removing the consciousness of an incurably ill patient? Only an analysis of these representations - cultural, religious, symbolic, biographic - would allow a shared decision making with regard to the patient’s life. Therefore a good accompanying of patients in terminal care.

Abstract number: P1-265
Abstract type: Poster

Discharging Hospice Patients to a Nursing Home - What Happens and what Next?

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Background: NICE guidance promotes enabling patients to choose their preferred place of care; however special palliative care inpatient beds remain a scarce resource in the UK. Transfer of a hospice patient to a nursing home (NH) risks distorting family, but is often justified on the grounds of equity of access to hospice beds.

Aims: To explore process of transfer from hospice to NH and evaluate survival times within the NH setting.

Methods: A casenote review of patients discharged from NH, from a 22-bedded hospice in England, with follow-up established to follow patient progress or date of death. Over a 3 year period, 28 hospice inpatients were transferred to a NH, with notes available for 22.

Results: 16% had been mentioned prior to hospice admission. In the majority of cases NH was brought up by hospice staff (55%), though discussion was also initiated by patients (n=5), family (n=6), or community team (n=1). NH was first broached an average of 18 days (1-61) after hospice admission. Response to the suggestion of NH was positive in 46% (n=10), with a clear aversion to the idea in 23%. This group had a mean hospice stay of 43 days (14-93), compared to a unit average of 16 days. Of the 28 patients discharged to NH, 23 died in their NH and 5 are still living in the NH. The latter 5 patients living in a NH at the end of the study had stays of 1, 16, 30, 40 and 380 days respectively. Length of survival within the NH ranged from 1-3weeks (3/23) to over 6months (3/23), with 9% surviving 3-6weeks, 26% 6-12weeks and 26% 12weeks-6months.

Conclusion: Most hospice patients discharged to a NH survive longer than 3weeks (87%) and many considerably longer than anticipated. The negative response to the suggestion of NH may be less common than feared by staff. Further information is required to explore quality of life after discharge and palliative care in NH. How could we consider the patient to whom the idea of NH is introduced, but who deteriorates before transfer.

Abstract number: P1-266
Abstract type: Poster

Continuous Sedation until Death and Physician-assisted Death: Different or Equivalent? A Focus Group Study in Nursing Homes, Flanders, Belgium

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Introduction: Continuous Sedation until Death (CSD), the act of reducing or removing the consciousness of an incurably ill patient until death, has become a controversial topic of which CSD is meant to be equivalent to Physician-Assisted Death (PAD), or that CSD is frequently misused to perform slow euthanasia, despite the fact that qualitative research stresses the distinction between these two practices. Given the increasing incidence rate of CSD in nursing homes in Flanders (Belgium), together with the low incidence of PAD in this setting, it is interesting to examine whether and to what extent nursing home clinicians consider these two practices to be different or equivalent.

Methods: Six focus groups were conducted including 10 physicians, 24 nurses, and 14 care assistants working in either public or Catholic care homes of varying size. All discussions were transcribed and subsequently analyzed using a thematic content approach.

Results: For some clinicians, the distinction between CSD and PAD is clear, whereas others consider CSD a form of euthanasia. Another group takes a stand between these two and considers CSD as a grey area between pain relief and ending life. The underlying arguments for these perspectives refer to the following themes: intention, dosage of sedative drugs, unconsciousness, and the pace of the dying process. Generally, CSD is considered easier to deal with emotionally, compared with PAD, since it results in a more gradual process of dying.

Discussion: This study highlights the lack of agreement among nursing home clinicians regarding the distinction between CSD and PAD. The opposing and frequently inconsistent arguments of clinicians used to claim a difference or equivalence between the two practices are presented. The latter demonstrate that the framework of CSD - as proposed in the guidelines - is prone to abuse.

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Abstract number: P1-267
Abstract type: Poster

Vulnerability to End of Life in Advanced Cancer Patients

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Background: Vulnerability is a universal human condition. Feeling vulnerable comes as a result of being at risk of physical, psychological or emotional harm. At the end of life, everyone is vulnerable. We all face mortality and thus are susceptible to the experience of vulnerability. Advanced cancer and all that surrounds it, has a great potential to become threatening agent and highlighting the vulnerability of the patient and family.

Objective: To reflect on the vulnerability in cancer patients at the end of life from different aspects such as spirituality, suffering, emotional burden of caregivers, place of death and thus the ethical implications of the decisions and actions of the palliative care team.

Method: Review of the literature on the subject, with particular attention to those qualitative studies that analyze the narratives of patients and professionals.

Conclusions: Spiritual vulnerability is a need of the patient should be assessed. The dying process can not be understood solely as a clinical problem, and one of the goals of palliative care is to address biological problems, but also address the crisis of spiritual experience. Understanding the patient’s end of life in the perspective of the main elements above mentioned will be the reflection that we will show at the end of the seminar and will be complemented by the case study.

Abstract number: P1-268
Abstract type: Poster

Advance Care Planning (ACP) - What Do Portuguese Palliative Care Patients Think?

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Background: Over the last years, there has been an increasing development of Portuguese palliative care teams in the hospital setting, but we cannot expect that they can be involved with every patient who needs them. Since last august there is an advance care law in Portugal, but there are many people that don’t know how the meaning of it. As palliative care professionals, we believe people must be aware of all the implications of having an advance care plan.

Objective: To identify the lack of knowledge about ACP and to know what are the advance care wishes people claims.

Method: All the patients are in palliative care day clinic of a Portuguese cancer hospital.

Methods: Patients were asked if they had an ACP and what were their wishes when they formalised it. We used a questionnaire.

Conclusion: Most of the patients haven’t thought about their ACP. Portuguese healthcare professionals must inform and be available to answer patients concerns about most end of life care. It should also be a political and media role.

Abstract number: P1-269
Abstract type: Poster

MORECare Capacity: Mental Capacity and Processes of Consent for Research on End-of-Life Care

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Aims: To undertake a meta-synthesis of the research involving individuals with impaired capacity examining the clinical experienced and solutions used to manage processes of consent.

Methods: Systematic literature appraisal using the databases MEDLINE, EMBASE, CINAHL, PsycINFO and the Cochrane Library (from 2000 until September 2012). Search terms included the combination of consent and capacity (and synonyms) within these three domains - palliative care, mental health and accident and emergency. Selection criteria: primary research concerning adults with compromised capacity to consent processes of consent in research. Database searches were supplemented with a short-semi structured email survey to leading national and international researchers (n=317) to capture but of view/ best practice.

Results: 9,916 references were identified from the literature search, 107 were included for full paper searches were invited to participate in the grey literature survey, of the respondents 61% had undertaken research involving adults with compromised capacity with consent being the most common approach used, predominantly in mental health research.

Conclusion: The meta-synthesis provides guidance on key challenges and solutions to involving those at the end of life in research. However, there is a need for more research into consent processes and the ethical implications of these practices.

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Abstract number: P1-270
Abstract type: Poster

The Ethical Climate in European ICUs. Results from the Appropriacy Study

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Aims: The ICU generates stress for clinicians both because of the high patient mortality and because moral dilemmas are daily. The ethical climate can influence the building of the organizational conditions and practices that affect the way difficult patient care problems are discussed and decided. The aim is to determine the perceptions of the ethical climate in perceived ethical climates in European ICUs as well as its relation to perceptions of inappropriateness of care and intention to withdraw.

Methods: A single-day cross-sectional evaluation of perceptions of inappropriate care among 1993 ICU nurses and physicians providing bedside care to adult ICU patients in 10 European countries.

A 7-item questionnaire was used to assess the (perceived) ethical climate. Factorial analysis was used to reduce 7 dimensions.

Results: Factor analysis with varimax rotation resulted in a two-factor solution: the first factor concerns 4 items dealing with ethical dilemmas (do clinicians talk about feelings and opinions); the second item (30% of variance) concerns 3 items dealing with decision-making (is there bedside interdisciplinary decision-
Conclusion: Patients who are older and not English-speaking tend to be unaware of diagnosis or prognosis and hence will be excluded from making decisions regarding their own care often because they do not understand that their medical condition would reduce wellbeing and may even hasten death. Nonetheless, a higher percentage of patients who were aware of diagnosis or prognosis were able to die at home, which is often viewed as a goal of end of life care. Hence, it may be culturally appropriate for some patients not to be involved in medical decision-making. Providing palliative care in such circumstances is challenging but is possible.

Family & Care Givers

Abstract number: P1-273
Abstract type: Poster

Distress in Cancer Patients: View of Family Members

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Aims: The objective was to verify the opinion of family members about distress on cancer patients and the factors associated with it.

Methods: A cross-sectional study was conducted from June to August of 2012 through interviews with 140 individuals with at least 6 years of schooling who were family members of cancer patients. The Distress: The Thermostat: was used. The ANOVA F tests for linear regression and chi-square tests were used.

Results: Most family members were female (82.9%), married (50%), aged between 30 and 49 (55%), with a mean schooling of 10.5 y (SD = 3.3) and a family income of $ 500 to 700 (50%). Then types of cancer were breast cancer (18.6%), colon (9.3%), uterine/ovarian (8.5%), prostate (8.5%) and leukemia/lymphoma (8.5%). Sixty-five percent of patients were considered as having a family history of cancer. The complications faced were pain (83.5%), nausea and vomiting (82.4%), sadness (74.7%), fatigue (80.5%), pain (65.5%), sleep disturbance (63.7%), fear (58.2%), or without health insurance (57.1%), problems with eating (53.8%) and appearance (52.7%). The regression model showed that the risk was associated (p<0.05) with the distress of the patient's care in the health institution, work or school attendance, depression, fear, nervousness, sadness, worry, loss of interest in usual activities, appearance, fatigue, swelling, and difficulty sleeping.

Conclusion: The opinion of relatives about the distress of patients is poorly considered in the routine assessment but can be of great help in minimizing the suffering of patients. A family which is well-informed about how to assess distress and prevent distress and stimuli can use actions to control distress and can contribute to improving the quality of life of patients with cancer.

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We have found significant correlations between the PSQI score and “hours spent caregiving/day” (r=0.39), the PSQI score and dyspnea of the patient (r=0.34), the PSQI score and “attending the patient at night” (r=0.39), and anxiety of the patient and “attending the patients at night” (r=0.32).

In our study, there was no relationship between the ZBI and the Occurrence of the disease.

Conclusion: Most of carers have bad sleep quality, which is similarly high for all caregivers.

It appears there is a certain correlation between the situation of patients and the sleep quality of caregivers; although this fact should be proved by some prospective research.

We can’t confirm in our sample there is relationship between the sleep disturbances and the caregiver burden.

Abstract number: P1-277
Abstract type: Poster

Introduction of a Schwartz Round at a UK Hospice: Taking Time to Be Human

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Aim: To present the experience of implementing Schwartz Centre Rounds at a UK hospice.

Method: Schwartz Centre Rounds began in the USA in the 1990s and were introduced in hospitals in the UK in 2009. The Rounds offer a chance to talk openly and honestly about situations experienced in the course of work that challenges traditional thinking or working practices.

Schwartz Centre Rounds start with 3 or 4 people giving a short presentation about an experience followed by an open discussion. The facilitators offer their reflections or talk to similar experiences.

The facilitator of the Rounds is a project sponsored by Kings Fund, who provide mentor support for the first year. A Schwartz steering group was set up with representatives from across the organisation. The facilitator is the Head of Psychosocial and Spiritual Care, supported by an administrator, with 2 consultants sharing the clinical lead role.

The Schwartz Centre Rounds were opened to the wider hospice community: all paid staff, volunteers, primary care colleagues and hospital palliative care teams.

Results: The Schwartz Centre Round was held at the hospice in May 2012, and to date we have had 4 rounds. The mean attendance has been 43, min 35 and max 56. 128 evaluations have been collected and collated using Survey Monkey. 103 (80.5%) felt the round was relevant to their work, 113 (88.3%) gained insight into how colleagues thought/feel in caring for patients, 121 (94.5%) rated the round as good, excellent or exceptional, and 100 (78.1%) were keen to attend another Schwartz Centre Round.

Conclusion: The introduction of the Schwartz Centre Rounds has been very positively evaluated. Over time we hope they will improve morale and practice across the service.

Abstract number: P1-278
Abstract type: Poster

Family Carer Perspectives of Quality of End of Life Care for Dementia

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Aims: There is little work investigating family experiences of end of life care (EOLC) for people with dementia. Much of the quality of care (QOC) literature is focussed on or developed for the perspective of professionals. Family carers of persons with dementia, in particular often play a crucial role in their care, sometimes becoming experts through experience. This study aimed to develop an understanding of QOC at the end of life for people with dementia from the perspective of family members.

Methods: The research team interviewed using a topic guide were conducted with 20 family members of people with dementia. Family members were either recently bereaved or currently caring for someone who was dying from dementia. They were recruited through purposive sampling from carer networks of UK voluntary sector groups. Interviews were subject to thematic framework analysis.

Results: The interviews highlight current weaknesses of EOLC for dementia including different health and social care systems to navigate, with many families left to guide themselves. Key components of quality from their perspective included maintaining the dignity of the person with dementia and the inclusion of family members in decision making and subsequent care. Finally, the interviews show the complexity of when palliative or end of life care should begin for people with dementia, with family members talking about end of life care as a prolonged period at various stages of the disease.

Conclusion: Family perspectives of QOC focus on the interactions and relationships of the patient, family and professional. Focusing on developing the trust of relationships is important for providing high quality care influencing both the structures and processes of care. This study emphasized the importance of including family members within EOLC for dementia and the value of using family experiences.

Funding: 7th framework program European Commission

Abstract number: P1-279
Abstract type: Poster

What Concerns the Family Caregivers of Egyptian Palliative Care Patients with Advanced Cancer

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Introduction: Palliative care aims at improving the quality of life of patients with life-threatening illnesses and their families. The Egyptian Cancer Society offered an advanced cancer care program in 2010 for patients and families. The Schwartz Centre Rounds are held with 3 or 4 people giving a short presentation about an experience followed by an open discussion.

Methods: The study included 47 family caregivers of advanced cancer patients referred to an Egyptian cancer center-based palliative medicine unit. Caregivers were asked to enumerate what concerns them most about their related patient.

Results: The median age of related patients was 55 years, 62% were females and the majority (94%) was married. Forty-six (98%) of interviewed family caregivers at least one concern and the median number of concerning issues per caregiver was 2. A total of 23 issues were identified. The most common concerns were uncontrolled pain (80%), weakness/fatigue (23%), lack of appetite/mobility to eat (15%), vomiting (15%), skin lesions (11%) and lower limb edema (9%).

Conclusion: Concerns related to their patient, uncontrolled pain is the major concern for Egyptian family caregivers. There is a need to overcome barriers to cancer pain control in Egypt to relieve suffering of advanced cancer patients and their families. Other uncontrolled symptoms and advanced cancer-related changes that limit the functional and social well-being were significantly high proportion of caregivers. Research is mandatory to assess further the needs of Egyptian family caregivers and to develop culturally sensitive palliative care models that effectively incorporate them into the care of their related patients.

Abstract number: P1-280
Abstract type: Poster

The Challenges of Providing Carers' Support for Palliative Care Patients in a Tertiary Cancer Centre

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Background: Carers play a central role in providing support to patients. However, many carers do not experience a cohesive integrated system of social support. Caring for someone who is dying can cause a significant level of stress and impact on both physical and psychological health. Providing carers with adequate information and additional support at appropriate times may help to prevent hospital admissions. Optimal input for carers will depend on a comprehensive assessment of the situation and individual needs which can be challenging, particularly in a tertiary cancer centre which cares a population of 2.3 million, caring for over 7000 new patients per year and includes a large number of different healthcare organisations.

Aims: To develop a practical method of assessing the needs of carers. To develop a directory of information for carers which could be used across a wide geographical area.

Method: A professional group was set up to establish the baseline needs of carers. The assessment and documentation of carers’ concerns and needs was evaluated using the documentation recorded on the Trust’s electronic system. Research was used to identify if any information already available for carers in the region.

Results: A directory of information, support and advice for carers has been produced with support from the local Cancer Network. The directory includes advice on carers’ assessment, advice on respite care, information on social services, national support organisations and charities for carers. There is a core section applicable to all and separate sections dependent on location.

Abstract number: P1-281
Abstract type: Poster

How Well Do People with Dementia and their Family Carers Agree on Preferences for Life-Sustaining Treatments at End of Life? A Pilot Study

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Aims: Advance Care Planning may support the consideration of the wishes and preferences of people with dementia (PwD) when making end of life care decisions. However after the PwD loses capacity, it is often left to a family carer to indicate what these might have been. We will explore how well carers and their advanced cancer treatment preferences for PwD would move and the accuracy of proxy decisions is unclear.

Design: Cross sectional study using interviews with PwD and their carers in two NHS Trusts in the UK. PwD had an MMSE range of 20, mental capacity and an identified family carer. Carers were next of kin or ‘key decision maker’.

The Multiple Sources Supporting Preferences questionnaire (LMSPQ) with 3 health scenarios and 3 treatment options was used and levels of agreement calculated. PwD identified their preferences for health care scenarios and carers predicted what the preferences of the PwD would be.

Analysis: Descriptive statistics and kappa coefficient (κ) for agreement.

Results: Twenty five dyads (25 PwD & 25 carers) were interviewed using the LMSPQ. The mean age of PwD was 86.2 ± 1.6, range 69-93; Carer-66, range 47-90. MMSE of PwD (Mean 25.2, range 20-29), Gender PWD (M=12; F=13), Carer (M=5, F=20). A wide range of ethnic backgrounds was represented and levels of education. Most agreement was found on rating current health state on the LMSPQ. Of all health scenarios, lowest agreement was found for resuscitation and tube feeding had the lowest levels of agreement in treatment choices. Scenario 2 (stroke and coma) showed low agreement (κ. 332; P=0.032). Scenario3 (advanced cancer) showed moderate agreement (κ. 478; P=0.005) treatment issues.

Conclusions: Whilst this pilot is underpowered it suggests that carers may not be able to consistently predict the treatment preferences for PwD about to become distressed by discussing these issues. We will now extend to a full study with 100 dyads and also examine contextual factors that influence agreement.

Abstract number: P1-282
Abstract type: Poster

Carers of People with Advanced Dementia: Their Experiences at the End of Life

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Aim: To test the feasibility of recruiting carers of people with advanced dementia, the acceptability of the study, and to explore their health and social care needs at the end of life and into bereavement. Previous research shows that carers of people with advanced dementia experience a significant care burden, mental and physical poor health and anticipatory grief.

Design: Pilot longitudinal cohort study.

Method: Carers of people with advanced dementia (Functional Assessment Stage score 4/6) were recruited from 2 NHS hospitals in London, The Zint Care Burden (ZCB) Brief COPE, Hospital Anxiety and Depression Scale (HADS), Inventory of Complicated Grief - pre loss (ICG), the SF-12 and the Satisfaction of Care at the End of Life Questionnaire (SOWLCQ) were used at baseline assessment and repeated monthly.

Findings: 22 carers were approached and 16 recruited (73%). The mean age was 63 (range 46-80), 75% female, 36% married and 82% a child of the person with dementia. Mean ZCB score was 16.79 (range 4-86), On the COPE (ZCB-2.8) the most common adaptive strategies were acceptance and problem solving.
Background: Family caregivers are central in palliative care, but they often report feeling insufficiently prepared to handle the caregiving role. Preparedness has proved to be a powerful variable that may protect family caregiver wellbeing. Preparedness refers to how ready family caregivers perceive they are for the tasks and demands of the caregiving role. Aim: The aim of this study was to explore factors associated with preparedness, and further to investigate whether preparedness is associated with caregiver outcomes.

Design: This was a correlative study using a cross-sectional design.

Setting/participants: The study took place in three specialist palliative care units and one hematology unit. 125 family caregivers participated.

Result: Being female and cohabiting with the patient were significantly associated with a higher level of preparedness. The relationship to the patient was significantly associated with preparedness, while social support, place for care, time since diagnosis, and age of the patients showed no association.

Preparedness was significantly associated with higher levels of hope and reward and with a lower level of anxiety. In contrast, preparedness was not associated with depression.

Conclusion/Implications: Preparedness for caregiving seems to be an important protective variable for family caregivers in the unique situation when the patient is severely ill, close to death. Family caregivers with higher preparedness had higher levels of hope and caregiver rewards, and lower levels of anxiety. These effects of preparedness supported the inclusion of preparedness in support models for family caregivers in palliative care. We argue that improvements of caregiver preparedness to provide care as well as early psycho-educational interventions are vital to foster positive caregiver responses to the challenges of their role.

Abstract number: P1-284
Abstract type: Poster

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

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Purpose: This randomised controlled trial tested the impact of a brief psycho-educational intervention given to family caregivers of home based palliative care patients. The aim of the study was to determine the psychological benefits of the intervention.

Methods: A three arm randomised controlled trial compared the impact of three levels of intervention (1) face to face intervention between 2 visits vs. (2) telephone support vs. (3) control group. Data were collected at baseline and four weeks. Data were collected on anxiety, depression and quality of life.

Results: 298 caregivers participated, 148 were in the control condition, 93 in Intervention 1 (1 visit), and 93 in Intervention 2 (2 visits). Relative to participants in the control group, the psychological wellbeing of participants in the intervention condition improved by a small amount but not significantly. No significant reduction in unmet needs or improvements in preparedness were observed among the different intervention groups. However, those in the intervention group had significantly higher levels of quality of life.

Conclusion: The intervention demonstrated significant improvements in participants’ levels of preparedness and competence for Intervention 2.

Abstract number: P1-285
Abstract type: Poster

A Multiple Nation Originality “A Challenge in Managing a Child with HIV/AIDS”

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Methods: The aim of the research was to learn about the experiences and challenges of managing HIV positive children within the home. A total of 130 respondents were recruited using a chain referral method.

Results: There are a lot of Challenges in managing an HIV child with multi-national originity. A child with multi national qualities refers to offspring of parents of different races. The child has grown up in different cultures and these cultural differences have led to many challenges. Most challenges are legal, financial and educational. Language barriers were also considered important. The child has been exposed to different forms of the disease in different countries.

Conclusion/Implications: This research adds to accumulating body of evidence demonstrating that relatively short psycho-educational interventions can enable family caregivers to feel more prepared and competent in their role of providing care. It is required to determine the longer term outcomes of such interventions.

Abstract number: P1-286
Abstract type: Poster

Exploration of Opioids for Terminal Cancer Patients: The Bereaved Family Members’ Experiences and Recommendations

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Background: Palliative care is expected to incorporate comprehensive support for patients with life-threatening illness and their family caregivers because many caregivers suffer psychological morbidity. However, systematically implemented evidence based psychological support initiatives are lacking.

Aim: To prepare caregivers for the role of supporting a patient with advanced cancer receiving home based palliative care by offering a one to one psycho-educational intervention. We hypothesised that primary family caregivers who participated in the intervention would report decreased psychological distress (primary outcome), fewer unmet needs and increased levels of perceived preparedness, as competence, and positive emotions.

Methods: A three arm randomised controlled trial compared the impact of three levels of intervention (1) face to face intervention vs. (2) telephone support vs. (3) control group. Data were collected at baseline and four weeks. Data were collected on anxiety, depression and quality of life.

Results: 298 caregivers participated, 148 were in the control condition, 93 in Intervention 1 (1 visit), and 93 in Intervention 2 (2 visits). Relative to participants in the control group, the psychological wellbeing of participants in the intervention condition improved by a small amount but not significantly. No significant reduction in unmet needs or improvements in preparedness were observed among the different intervention groups. However, those in the intervention group had significantly higher levels of quality of life.

Conclusion: The intervention demonstrated significant improvements in participants’ levels of preparedness and competence for Intervention 2.

Abstract number: P1-287
Abstract type: Poster

Patient with Schizophrenia: Coping with Cancer - Case Presentation

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Introduction: Schizophrenia is a severe, lifelong mental disorder with different symptoms. Physical health problems in patients with schizophrenia are common, including cancer too. Incidence of cancer in patients with schizophrenia is same as in other population (data from different studies). But, coping with cancer illness in patients with schizophrenia opens a lot of care in a biological, existential, ethic, human, social.

Case: Mr. M. is 47 years old single woman, living in her parents home. The first episode of schizophrenia occurred at age of 23 she was student of medicine. Since then, she has had a many relapses and was hospitalized many times on psychiatric clinic. During that time, she worked just a few months. Permanently she thoughts about her self as a student of medicine and never moving forward. In her last staying in psychiatric clinic, medical stuff discovered breast cancer and immediately referred her to oncological clinic. It was advanced breast cancer with bone and brain metastases. M. I. experiences pain, becomes restless, verbal communication is poor, irritable. While team oncologist discussed about treatment, they’ve let her go home for a month, because “she is non cooperative patient”. She suffered a lot. Small family background: in same home lives 3 generation of women. Grandmother, 91 year old lady, blind, lonely. Mother, 72 years caring for husband in bed after hard brain stroke (dying zone aneurysm). While she is exhausted physically and emotionally. Young sister, works and takes care of the family finances.

Conclusion: M. I. did not understand their primary illness or cancer. Schizophrenia complicated coping with cancer. M. I. has got no capacity for coping with cancer. With low cognitive ability, increase problem focused coping and decrease quality of life. In this case the big burden was on the family. Support from institutions was poor. Both patient and family suffered much.


Abstract number: P-290
Abstract type: Poster

**Knowledge of the Sleep of Family Caregivers to Patients in Hospice:**

 objetivo: El objetivo fue examinar la viabilidad de un estudio de sueño de familiares. El estudio del cuidador parece ser la relación entre la pérdida de sueño y otros familiares. Los resultados de esta investigación se deben a una revisión bibliográfica de casos de tratamiento.

**DOEs Health Status Affect Perceptions of Factors Influencing Dignity at the End of Life?**

**Aims:**

To investigate whether health status affect the perceptions of factors influencing personal dignity at the end of life, and the relationship between those perceptions and socio-demographic and environmental factors.

**Methods:**

Data were collected within the framework of an "Advance Directives" cohort study. The present study focused on the subsample (N=218) of persons who completed the Patient Dignity Inventory. Health status groups were defined by use of the EGOS-items combined with a question that asked the respondents whether they had an illness. Descriptive statistics and logistic regression analyses were used.

**Results:**

Limited differences were found when comparing how people in good health and people with a poor health status perceive factors important in maintaining dignity for patients reaching the end of life. Three physical items on symptoms, roles and routines, were significantly more often considered as important by people with a poor health status. Independent of the setting and having a belief or religion that is important to one's life were found to be determinants regarding the understanding of factors influential to dignity.

**Conclusion:** Health status seems only to affect the perceptions on physical factors maintaining dignity at the end of life. Significant change in the understanding of dignity will not substantially change as health status changes.

**Medical Sociology**

**Delevitch H., Vandersmissen J.**

**Objectives:**

To understand the experiences of patients living alone who undergo cancer treatment. This research has implications for health care providers in primary care, who have to be attentive to the different experiences of living alone and the influence of those on their experience and adjustment to cancer treatment.

**Methods:**

Using qualitative methods, a purposeful sample of 32 patients living alone and undergoing cancer treatment were interviewed, using a semi-structured guide. Interviews were audiotaped and transcribed verbatim. Analysis was conducted using grounded theory techniques and, open, axial and selective coding was performed.

**Results:**

Finding that living alone was experienced by cancer patients in two ways: as a lack of specific social support characteristics, but also as a condition from which they gain. Consequently, living alone was experienced respectively as a threat or as a resource for their adjustment to cancer treatment. Both experiences made that staying independent was the key goal during their cancer treatment, this out of necessity or out of virtue. The length of living alone and the way they became to live alone had an influence on those interactions.

**Conclusion:** The study has provided qualitative insight into the experiences of patients living alone who undergo cancer treatment. This research has implications for health care providers in primary care, who have to be attentive to the different experiences of living alone and the influence of those on their experience and adjustment to cancer treatment.

**Abstract number:** P-294
**Abstract type:** Poster
Introduction: Clinical and social management of foreign patients may be different and more complex than that of native ones. Foreign patients refer to patients not born in Spain.

Aims: To describe foreign patients features admitted to a PCU.

Methods:

1. Descriptive and retrospective study. All foreign patients admitted consecutively to a PCU from January 2008 to October 2012 were included.

2. We conducted a care model study to make a reliable analysis of the differences, matched for age, sex and type of disease/tumor site. The variables are presented in the results section.

Results:

1. Of the 1,571 patients admitted during the study period, 72(45%) were foreign. 450.21 years men and 213(2.5%) women, mean age, 60.6±16.2 years, 60.9% had a cancer disease and the most common cancer sites were: lung (16.222%), genital (15.2%) gastrointestinal (70.7%). 27 different nationalities were observed; the most common being Moronac (13.18%), and French (8.11%). Geographic clustering: Asia (22.30%), Latin America 21.29%, Africa (16.22%), Asia 19.12%, U.S. 4.5%). Discharge destination: deceased 58.7%, home 11.8%, other centers 55.8%. The average stay was 20.7±20.4 days.

2. Of the 72 foreign patients matched and different factors have a significant presence of primary caregiver (64.5% vs. 90.3% native vs. foreign patients, P=0.002), social intervention (61.3% vs. 40.3%, P = 0.04), Electronic referrals (79.2% of foreign vs. 96.8% natives, P = 0.003). No difference was found in discharge destination, use of opiod, psychiatric evaluation. Communication difficulties: 72(29.2%) ethnic minority patients were predominantly male, with a mean age of 60 years, of several nationalities, mainly European and South American. In the care of foreign patients requested further social intervention, fewer foreign patients had a primary caregiver, and they used less psychotropics drugs.

Conclusions: The results section.

Acknowledgements: We gratefully acknowledge the help of all the professionals who contributed. A systematic search of the use of D* in PC literature resulted in 668 references. The corresponding abstracts were analysed regarding the context in which D* was mentioned and, whether D* was a major topic contributing significantly to the article’s content.

Poster sessions

Poster sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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Organisation of Services

Abstract number: P1-301
Abstract type: Poster

First Five Year Experiences of a Tertiary Medical University in Provision of Palliative Care in Bangladesh

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Despite World Health Organisation reiteration of importance of palliative care at all stages of disease, services are scarce patchy and inconsistent. Bangladesh is world’s eighth most populous country with a population of 146 million, two thirds live in rural and one third in urban areas. Adult literacy rate is 54%. Per capita annual health expenditure is US $ 12.5. The experiences of first five year of a tertiary medical university are described in this paper. A retrospective review of electronic database case notes for all registered patients was undertaken. The data were collected at the outpatient clinic, during first consultation. One thousand and fifty patients with mean age 50 years, diagnosed with incurable cancer were seen during a period of 51 months (October 2007 to December 2011). Most of the patients were from middle class socioeconomic group (30%), already knew about their disease status and prognosis (60%) referred from other disciplines formed the majority group (57%) of this population. All of them had been registered patients was undertaken. The data were collected

Abstract number: P1-303
Abstract type: Poster

Developing and Implementing a Cancer Specific Model of Advance Care Planning in an Australian Cancer Centre - Lessons from Practice

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Background: Despite increasing evidence that Advance Care Planning (ACP) can improve end-of-life care, the majority of cancer patients do not engage in this initiative. The development of more disease specific ACP programmes, step by step strategies and interventions to trajectories and complexities specific to cancer patients, may lead to improved outcomes. A multifaceted programme of service development, education, and research was identified as a requirement to meet specific organisational needs as well as national and accreditation requirements on ACP in Australia.

Results: We will present the successes and challenges of various interventions undertaken including:
1) Electronic embedding of Health information services to ensure visibility of information and to allow for a more dynamic system to document ongoing conversations. 
2) Design of ACP documents to reflect the complex nature of decision making in the cancer population, 
3) Design of appropriate information materials and interventions to allow for healthcare decisions to be documented throughout the cancer trajectory, 
4) Methods to identify and target learning needs for staff in a cancer centre, 
5) Policy development and identification of key performance indicators for the cancer populations, 
6) Utilisation of a comprehensive research programme to inform and evaluate the above strategies.

Conclusions: This paper will report on data from baseline interviews with community members and health care professionals, in relation to the following areas:
• Community perspectives of ACP, good practice from neighbouring countries & international experiences.
• Educational needs of health professionals in relation to minority health, illness and death practices.
• Views on how these barriers could be addressed and palliative care could be made more accessible.

Implications: We will provide an evaluation of the success of the above strategies.

Abstract number: P1-305
Abstract type: Poster

Pilot Palliative Care Projects in Armenia: Results of First Year Operations

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Purpose: Armenia is in need in Armenia. Four pilot projects were initiated in 2011 with support from the Global Fund; the first time GF has supported palliative care development not restricted to HIV, TB, or Malaria. The aim of this project was to demonstrate that palliative care could be introduced into the national health care system and to measure its impact on the care and cost of care for patients with life threatening illness.

Methods: This project used a program evaluation framework to measure results. All 4 sites used the following indicators: EQ-5D, 10-point pain scale, Hospital Anxiety & Depression Scale (HADS), Kamofsky Performance Status (KPS), & neuropsychiatric pain screening tool (NPST). The HADS & NPST were used on admission for screening & care planning. Results for pain, quality of life, and KPS were compared to admission scores. Seventy-three interventions were held.

Results: 132 patients were admitted, 70 died, it were discharged and 54 remained on service. Average age 59.63 including 9 children. 78.5% had a cancer diagnosis. Mean length of service was 64 days median 37. All sites provided home care (962 visits), inpatient care (25 admissions), outpatient clinic (1388 visits), and emergency calls. Over half of patients had anxiety & depression. Avg pain score on admission was 5.69 and 30.3% had neuropsychiatric pain. Mean post admission pain hospital costs decreased at all sites but ranged from -0.05 to -2.5. Quality of life improved for pain, depression & anxiety not for activity, anxiety & self-care. Fewer referrals were held.

Conclusions: Palliative care was successfully introduced into the Armenian healthcare system along with standardized care plans & service. Plan for expansion & outcome control results were limited by lack of oral morphine. Methadone was introduced along with special training late completion of both, one in 6 months, the other in 4 months. Plan was modified to allow for the institution of a comprehensive government policy to develop PC in Armenia. In order to operationalize the strategy & action plan support is being provided to the Ministry of Health (MoH) to develop a model of PC delivery appropriate to the circumstances & resource constraints of Armenia.

Abstract number: P1-304
Abstract type: Poster

Development of a Model of Service Delivery for Palliative Care in the Republic of Serbia

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1Development of Palliative Care Services in the Republic of Serbia, Belgrade, Serbia; 2Oxford Policy Management, Oxford, United Kingdom

Aims: A national palliative care (PC) strategy was passed by the government of the Republic of Serbia in 2009 & set out a comprehensive government policy to develop PC in Serbia. In order to operationalize the strategy & action plan support is being provided to the Ministry of Health (MoH) to develop a model of PC delivery appropriate to the circumstances & resource constraints of Serbia.

Methods: A model of care was developed based on the requirements set out in the national strategy. Through consultation with existing healthcare providers & policy makers a number of areas external to the model of care were identified including assessment of workload, operational procedures, quality standards, referral protocols, assessment of human & other resource inputs & potential performance indicators. Key proposals were designed using available Serbian practice & experience complemented with good practice from neighbouring countries & international PC. These were tested & amended through a process of participatory study with existing healthcare institutions.

Results: A detailed specification of the model of PC delivery including the resources & organisational requirements at the different levels of health & social care delivery.

Conclusion: The development of the model of PC delivery which translates policy into practical guidance at each level of the healthcare system is a vital component in operationalising a PC strategy & cooperation between separate government structures (health & social care) & the role of the non-public sector in provision remain to be developed.

This work is funded through the EU project “The Development of PC in the Republic of Serbia” (EuropeAid/129769/C/SER/RS)
The Quality of Professional Life and Means of Support for the Palliative Care Staff

Introduction: Working in palliative care can lead to emotional satisfaction or compassion fatigue and burnout. The purpose of this study was to determine the factors that intervene and identify the needs of palliative care professionals working in palliative care in Romania.

Method: A survey was conducted among 105 professionals working in palliative care, oncology, and oncopediatric wards from 4 cities in Romania. The professionals were handed a questionnaire with open-ended and multiple choice questions from 01.07 until 30.07.2012. A sample of 148 subjects was selected, 104 returned the completed questionnaires, 94 were valid. Data were included in an Excel database and analyzed with Epi Info.

Results: Respondents were: nurses 20%, doctors 23%, in 17% social workers, 5% psychologists, 4% and spiritual counselors. 26% consider themselves frequently and 10% excessively physically and emotionally as a result of their professional activity and 74% rarely. We found an association between distress factors and professional burnout as follows: lassitude-risk ratio (RR) of 4,08, yluy-fear factor (SPCF) of 1,20, anxiety-risk RR of 4,97, 18,69, cynism-risk RR of 4,18, 5,96, lack-of motivation-risk RR of 4,68, 4,6 and postponement of work related duties-risk RR in the last year. In 24% of the respondents, we found significant support from their families, 76% from colleagues, 31% through spiritual counseling, 20% from their managers. Conclusion: Our data indicate that there is a significant association between the physical, emotional, personal, professional distress factors and the risk of compassion fatigue, the need to educate the staff in recognizing these factors.

Keywords: Compassion fatigue, burnout, distress indicators, support.

The Integration of Palliative Care (PC) into Two Intensive Care Units (ICU) in a Community Hospital

Wolfer EL, Brophy N, Morse K, Effren L.

SNCA, Palliative Care, Oceanside, NY, United States

A majority of Americans die in healthcare facilities. More than 50% of these individuals spend their last days in an ICU. This study shows that a large number of decessants have had poorly managed symptoms, ignored treatment preferences and poor communication with clinicians.

South Nassau Communities Hospital (SNCH) has 406 beds including a 12 bed Medical-Surgical ICU and a 10 bed Cardiac ICU. Diagnostic services include MRI, CT, PET and 131 I. Audits show that in 18 months 68.9 day average length of stay. Eighty patients received CPR only. One patient survived. Mortality approaches 30%. SNCH has a Mobile Palliative Care Consultation Team (PCTT) consisting of Hospice and PC physician, an Advanced Practice Nurse in PC and a PC Social Worker. Chaplains and Ancillary Services provide expertise on a voluntary basis. High quality ICU is a PC anticipates standard. Stakeholders believe key attributes of this standard include:

1. Comprehensive communications,
2. Decision making on patient/family centered preferences,
3. Care maintaining comfort, dignity and personhood,
4. Family choices of access to patients,
5. Interdisciplinary team (IDT) support,

The Improving Palliative Care in the ICU (IPAL-ICU) project was an initiative co-sponsored by the National Institutes of Health (NIH) and the Center to Advance PC (CAPC). The project included resources, tools, evidence and expertise to all ICU clinicians.

IPAL-ICU was used to be a guide for the SNCH PCTT. We have the following goal: "Improving Specialist Palliative Care consultations to any ICU patient/family with PC needs. Initial steps include:

1. Take leadership role in an IPAL-ICU working group,
2. Participating in ICU IDT meetings,
3. Enhancing opportunities for team work promoting integration across the ICU matrix,
4. Define work processes especially family meetings,
5. Education to ICU clinicians,
6. Develop Performance Improvement projects,
7. Maximal utilization IPAL-ICU resources.

Poster sessions

Poster sessions

Poster number: P1-306
Poster type: Author
The Quality of Professional Life and Means of Support for the Palliative Care Staff

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3. Enhancing opportunities for team work promoting integration across the ICU matrix,
4. Define work processes especially family meetings,
5. Education to ICU clinicians,
6. Develop Performance Improvement projects,
7. Maximal utilization IPAL-ICU resources.
Abstract number: P-312

Abstract type: Poster

Strategy to Improve Palliative Care Delivery at Beginning of Life Care Setting: Continuity of Care and Regional Resource Coordination: Madrid Regional Palliative Care Observatory


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Introduction, national, regional, local standards guide Palliative Care (PC) development. Implementation and outcomes evaluation is an important albeit complex process. Systems to access clinical, administrative and managerial data for analysis and presentation are needed. Aims: To follow up regional PC activity with a functional framework evaluating progress and available services supported by an electronic system. To reliably inform strategic planning.

Method: Three phases outlined this project: Definition (Working Group for Outcome Indicators and Functional description) and Progress (validation and deployment). Electronic system: including documentation, implementation and training resulted in new tools: to access clinical records, info PAL, and merge data. The venture offers automatic data collection.

Results: A new structure resulted. PC integral management board combining input pathways, clinical and non clinical exchange platform and output pathways. Its human-technical characteristics are designed to facilitate data use and operationalization for: consultation, presentation and update; information flow and bundling by clinical, functional, use and procedure category to reach user; minimum manual interactions, data and information presentation relevant to user levels. The Regional Observatory holds PC clinical records, and provides it available to professionals, managers and policy makers; with necessary records for continuity of care such as available regional PC bed, mortality, multiple agreed plans, preferred place of care and death. 24h a day.

Conclusions: The Observatory uses modern technology to change the face of PC provision simplifying processes. Its social and professional impact potential contributes to patient care. Professional resource use and managerial adjustment to clinical activity and needs.

Abstract number: P-313

Abstract type: Poster

The Changing Face of Hospice Care

Craus, A.A., Medcalf, C.V., Kelly-F.G., Finney, D.M., Murphy, M.M.

Marymount Hospice, Liverpool, England, University College Cork, Cork, Ireland

Background: Palliative Care is a growing and evolving specialty. In Ireland, over 6,000 people utilised hospice services in 2009. This is predicted to increase to 16,000 people by 2020 (HESE, 2009). Improving access has been shown to increase the proportion of cancer deaths that occur in hospices. Ease of access therefore has the potential to impact patients’ preferences with regard to place of death. The balance between malignant and non-malignant diagnoses is also shifting. Service developments, in conjunction with society’s changing perceptions and a shifting disease burden, suggest that the characteristics of hospice populations may be changing. One year ago, Marymount Hospice relocated to a purpose built facility with significantly improved patient accommodation facilities. This was actively published to increase awareness and promote acceptance of the facilities. Objectives: To determine the demographics and patient characteristics of a hospice population over a two year period. To compare this data prior to and after a geographical reorganization.

Methods: A retrospective cohort study will be employed. ICAPE was used to collect demographics, length of stay, admitting institution and diagnosis. Death and diagnosis and status of active disease modifying treatment will be obtained from discharge documentation. Period One, September 2010 to August 2011 will be compared with Period Two, September 2011 to August 2012. Data will be entered in Excel and analysed using SPSS 12.0.

Results: Data collection is ongoing.

Conclusions: Observational data suggests that the complexity of patients admitted to the specialist inpatient unit is changing weighting towards a younger, rural population and an increase in number of people on active treatment. These changes will have service and staff implications. A study exploring the current and future needs of patients will be undertaken.

Abstract number: P-314

Abstract type: Poster

Making End of Life Care Services More Accessible to Patients and Carers
de Leuw, W.E., Stevens A.

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Aim: To increase the choice and accessibility of end of life care services for patients and carers.

Method: Building on a previous demonstration of experience in delivering end of life care services from a central hospice base to a patient population of 500,000 over a semi-rural geographical area of over 700 square miles a new model of service delivery was developed. This was driven by recognising that patients are living longer with life threatening conditions, the adverse impact this has on having both them and their carers, challenges the established paternalistic model of the hospice i.e. deciding who would be included in the care and that some people do not need, or want the intensive and costly specialist interventions traditionally on offer e.g. one to one with a Clinical Nurse Specialist in the home. The Outreach model has therefore been developed.

The new service delivery model, formed from the results of focus group interviews with existing patients and carers, members of the public and the local health and social care providers in the hospice catchment area, is based on the principles of offering “more for more” and delivering “lighter touch” services which will complement the specialist palliative care interventions already on offer.

Results: The new services are delivered in the local community in centres and satellites that also offer a drop in facility. To date one new larger “Outreach” and three smaller Outreach satellites have opened. The Outreach Centres offers a drop in cafe for information and advice to anyone affected by a life threatening condition. This is facilitated by volunteers. There are also facilities for trialling drop in “wellbeing workshops” as well as running existing patient and carer groups and establishing a base for three of the hospice outreach teams. The satellite centres have allowed hospice services to be taken closer to patient’s communities, working in collaboration with local health and social care providers in each area.

Abstract number: P-315

Abstract type: Poster

Maintaining the Momentum: Sustaining the Gold Standards Framework in an Acute Hospital Trust

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Background: The challenge hospice had along the way included the hospital is a ripe environment to embrace the Gold Standards Framework in an acute hospital Trust. To increase the choice and accessibility of end of life care services for patients and carers.

Aim: To prepare the acute hospital & develop the workforce to be able to consistently provide high quality End of Life (EoL) care, by implementation of the Department of Health’s Route to Success for Acute Hospitals programme, reviewing and measuring against care standards from the five key enablers, establishing baseline measurements & inclination for change. The five key enablers suggested are: Liverpool Care Pathway, Advance Care Planning, Rapid End of Life Transfers, End of Life Locality Based Registers, AMBER Care Bundle. The hospital already has potentially powerful levers such as a well embedded Strategy Group, newly created Transform Facilitator and high profile Palliative Care Team.

Method: Audit of current use of EoL tools within the hospital to ascertain effectiveness & productivity, demonstrating continued momentum for change.

Results: End of Life register located within the hospital has increased from 2010/11 to 2011/12, with 30% of all registrations originating from the acute hospital, 30% of acute cancer registrations and the other two thirds being notified by primary care.

Liverpool Care Pathway usage in hospital has increased from 47% of all hospital deaths to 55% (national average 37%) Rapid End of Life Transfers increased from 26 in 2010/11 to 72 in 2011/12

Advance Care Planning is still in its infancy, but raised awareness though staff training sessions & a public awareness campaign have increased the profile & recognition of the value of this tool. An information pack demonstrating ways to document preferences is available throughout the Trust

AMBER Care Bundle implementation is planned for early 2013 & figures for this will be available.

Conclusions: With three of the five key enablers already successfully implemented in the hospital, & preparation firmly underway for the use of the other two, it would appear the hospital is a ripe environment to utilise the programme, & prepared to build upon established success.

Abstract number: P-317

Abstract type: Poster

Challenges when Opening a Hospice Casa Speranza Branch in Bucharest the Capital City of Romania

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Hospice Casa Speranza is the Palliative Care pioneering organisation in Romania. The idea of opening a new Hospice branch came as a response to the great need for palliative care in Bucharest. On planning our work we encountered challenges and barrier from the local communities and the authorities. The challenges hospice had along the way included the hospital is a ripe environment to embrace the gold standards framework in an acute hospital Trust.
hospices, advocating to the public authorities, respect the particularities (in-patient, out-patient units, day centre etc.) of a hospice building and services provided by this institution.

Considering the lack of education in the multiple communities regarding the hospice philosophy and palliative care concept, we've lobbied throughout numerous meetings with companies’ representative, communities’ leaders, volunteers in order to raise awareness on the importance of holistic hospice care and of raising funds for building the palliative care facility. One important aspect of hospice care is the team involved and recruitment of skilled and well trained clinical staff is based on developing relationships based on trust and respect with other health-care professionals, in order to promote the concept and implement total care, for all the patients who need it.

Opening of a new Hospice CS branch in Bucharest will integrate care services for people who are referred by patient care team to over 2000, the number of medical professionals that provide quality palliative care services to incurable ill patients. The following palliative care services will be provided: homecare teams, in-patient units, hospital teams, day centers, out-patient clinics, all of them both for adults and children, and educational center for children.

Keywords: Planning, challenges, hospice, cultural considerations and legal context.

Abstract number: P1-318
Abstract type: Poster

Evaluation of a Macmillan Health Care Support Worker Project Designed to Support Care of Patients in the Community with Palliative Care Needs
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Aims: This study reports a descriptive service evaluation of a new role, the Macmillan Health Care Support Worker in one in a Scottish CHC Board. The study aimed to allow local support to patients and their families and be part of the team delivering high quality practical care to patients in the community with severe ill health needs, other than palliative care or palliative care needs, therefore, allowing more patients to be supported at home during periods of difficulty and allowing those to die at home as planned.

Results: The study was a mixed methods evaluation incorporating a systematic literature review, interviews, participation observation and audit data. The overall design of the evaluation was carried out in liaison with the funders and in particular with local managers and staff of NHS Forth Valley.

Conclusions: We make several recommendations based on the findings particularly in relation to mandatory training and in particular with local managers and staff of NHS Forth Valley.

Abstract number: P1-319
Abstract type: Poster

Integrating Palliative Care in Lung Cancer: An Early Feasibility Study
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Aims: Having a diagnosis of lung cancer has been associated with increased physical and psychological distress when compared to other cancer types of cancer. The aim of this preliminary feasibility study was to evaluate the feasibility of conducting an effectiveness trial of early access to palliative care services through an integrated outpatient model in a Scottish population. The specific objectives of this study were to evaluate the number of eligible participants, the willingness of participants to participate in a randomised controlled trial; the data collection plan, the response rates to the trial recruitment pack, as well as, the adherence/ compliance rates. Newly diagnosed patients with lung cancer receiving palliative intent or best supportive care treatment were recruited over a five month period from one outpatient clinic in Scotland. They were offered a discussion with a palliative medicine consultant at two time points (baseline and 12 weeks later). Prior to each review they filled in three questionnaires: the Functional Assessment of Cancer Therapy-Lung scale (FACT-L), the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS). During this period, interviews were also conducted with patients to explore their experiences of being involved in the study. Major reasons for low recruitment recorded were patients' observations that they did not want extra hospital visits. However, qualitative data indicated that patients found this extra layer of supportive care useful in identifying and managing their symptoms and enabling future planning. Taking into consideration findings from this feasibility study, further testing is needed for early access to palliative care services for patients with lung cancer to be integrated in routine practice.

Abstract number: P1-320
Abstract type: Poster

Work is an Important - and Neglected - Issue in End-of-Life Cancer Care
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Aim: The importance of enabling people with cancer to work in remission is widely accepted. However, the role of employment and the cancers of the brain and lung is underexplored. This study aimed to identify the factors that allowed people with cancer to work in remission, and to understand patients’ perspectives on employment.

Methods: A Realistic Evaluation was used to develop exploratory accounts of what works in cancer VR. Data sources included:
- interviews and focus groups with service providers (n=22);
- patient case records and final reports; and
- interviews with service users (n=25).

Key findings:
- More people were being referred to VR for the first time.
- Work was often a topic on the palliative care agenda.
- Patients identified a range of supports needed to return to work.
- Trust between professionals, associations, population and other local authorities can overcome challenges and establish PC in this paper we present the way of starting and establishing outpatient PC in Istria County.

Results:
- Development of PC in Istria was passing through three periods: in the beginning period we formed the trained and supported by District Nurses. The overall aim of the study was to evaluate the role of the Macmillan Health Care Support Worker in one NHS board area in Scotland.

Abstract number: P1-322
Abstract type: Poster

Organisation of Community Palliative Care Service in Istrian County
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Background: Palliative care (PC) in countries where there is no national strategy for PC is a challenge for health care professionals and the community. Close cooperation and trust between professionals, associations, population and the local authorities can overcome challenges and establish PC. In this paper we present the way of starting and establishing outpatient PC in Istria County.

Aim: The importance of enabling people with cancer to work in remission is widely accepted. However, the role of employment and the cancers of the brain and lung is underexplored. This study aimed to identify the factors that allowed people with cancer to work in remission, and to understand patients’ perspectives on employment.

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- Development of PC in Istria was passing through three periods: in the beginning period we formed the trained and supported by District Nurses. The overall aim of the study was to evaluate the role of the Macmillan Health Care Support Worker in one NHS board area in Scotland.

Abstract number: P1-323
Abstract type: Poster

Evaluating the Need for and Challenges of Providing Community Based and Inpatient Palliative Care for Homeless People in the UK
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Introduction/aims: In the UK the average age of death of a homeless person (HP) in the UK is 47 years. Complex care needs are usual in this population due to addiction, multi-morbidity, and psychosocial issues. We discuss these and reflect on our experience of caring for this group of patients, with discussion of a case admitted to our SFU. We also assess the prevalence of SPC needs in the homeless.

Methods: 47 consecutive homeless patients admitted to a 13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

Poster sessions
London hospital were supervised by a multidisciplinary team for homeless persons. Experience of accessing health and social services was discussed with each patient. In addition we discussed our experience of caring for a homeless person in our SPCU.

Results: Of the 47 patients assessed, 3 had uncontrolled symptoms warranting SPC input. None had contact with SPC services. These patients cited additive behaviours, personal characteristics, healthcare professionals, transient place of stay and lack of information about services to barriers to receiving required care. Our experience of caring for a HP with multiple addictive, medical and social needs in our SPCU highlights the challenges of meeting complex needs and maintaining a safe and therapeutic environment for all patients.

Conclusions: The prevalence of persons requiring SPC input is disproportionately high in the homeless population. They may benefit from Open Access. Ecological complex health needs take priority. A hospital homeless team may promote identification and appropriate management. Homelessness is a direct barrier to accessing SPC. Caring for a HP in a SPCU is a unique challenge. It requires a flexible team approach and consistent communication. Further investigation of the HP's needs of homeless people would help to develop services that provide for them.

Abstract number: P1-324
Abstract type: Poster

Retroactive Survey Evaluating “Open Access” Hospice Admissions for Palliative Patients at Risk of a Crisis at Home

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Aims: Palliative patients at risk of an imminent and anticipated crisis at home, were offered “open access” (OA), an urgent, hospice admission pathway triggered by patients, relatives or health professionals. It aims to enable patients to stay at home for longer, reassured that rapid hospice admission for the anticipated crisis is available 24 hours a day as an alternative to hospital attendance. Pre-assessment means further medical review is not required on admission and instead admission is nurse led, especially relevant when the crisis occurred at night. The aims of the paper are summarised. A retrospective survey was undertaken to assess indications for OA admission.

Methods: A retrospective survey of the electronic records of patients offered OA from 1st July 2011 to 30th June 2012. Results: Over this period, 12 patients were offered OA. Mean age was 64.3 years and 9 (75%) patients had a cancer diagnosis. The indications for offering OA were:

- Threat of haemorrhage (5 patients, 42%)
- End of life care (5 patients, 25%)
- Breathlessness (1 patient, 8%)
- Patient care declined by 10 in 11 offers of OA
- 5 of 12 (42%) patients were admitted to the hospice under OA, 2 admissions occurred out of hours, 1 of which was nurse led admission. Following OA offer to admission was 3 days (mean 5.3 days). 4 patients died during admission. Of patients not admitted under OA, 6 died at home or nursing home in 1 haematology admission.

Conclusions: Our survey suggests open access hospice admissions can help manage anticipated end of life crises in the home as an alternative to hospital admissions which does not impact on hospital out of hours medical staffing. Further evaluation is required to assess the benefits for patients and families.

Abstract number: P1-325
Abstract type: Poster

Presentation of a Network Model and Program of Excellence Palliative Care

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Aims: A network model of excellence palliative care, with a multidisciplinary palliative care team (EMPCT) as a central element, has been in operation since summer 1998. A national guide of norms and standards published in 2011 provides a model for palliative care which is similar to our network model, on the basis of providing access to palliative care support wherever the patient and the family are.

Methods: The model sets the standard for palliative care ensuring the patient receives appropriate information.

- a) that patients always have access to the necessary contact data;
- b) that palliative care is given within dynamic and flexible systems across competency levels with clear-cut responsibilities,
- c) to establish better routines for patients in hospital and primary care,
- d) to better communication between hospitals an primary care,
- e) that services are based on holistic and interdisciplinary thinking,
- f) that treatment and care is provided at home or as close to home as possible,
- g) that the organization promotes further development of clinical practice and research in the field.

Results: A patient associated with EMPCT has:

- a) continual association
- b) called Open contact “Open return” to a special unit at the hospital
- c) contact-nurses at the hospital and in primary care,
- d) the EMPCTs are part of the treatment at the hospital and at home
- e) access to contact to EMPCT and the hospital unit when necessary
- f) a form is send to all involved partners with information of the exact type of admission to EMPCT e.g. a network of nurses with special interest in palliative care

Conclusion: The organizational model enables EMPCTs to offer services to patients and their families, hospitals, as well as primary care professionals throughout our area. The central element of the model is that basic care levels have the necessary knowledge of common conditions in palliative care.

Abstract number: P1-326
Abstract type: Poster

An Evaluation of an Integrated Specialist Nurse Led Palliative Care Clinic within a General Practice Setting

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Research aims: A community nurse led palliative care clinic was introduced at a GP (General Practitioner) practice in the United Kingdom (UK) in April 2012. Whereas previously CNS (Clinical Nurse Specialists) nurses would support their patients by home visits, the fortnightly clinic at the GP practice has now been introduced as an additional complementary resource to consolidate the local primary care/specialist palliative care approach for this patient group. This study evaluates implementation processes and the impacts of the clinic on patient experiences and practices, uptake of palliative services and the management and delivery of palliative care by the GP surgery and CNS team.

Study design and methods: Baseline interviews with GPs (n=5) and the CNS team (n=4) were carried out prior to the set up of the clinics in February 2012. Patient interviews (5-12) and follow up interviews with GPs (6-10) and CNS (4-6) are to be carried out in November 2012. Patient interviews will be analysed using Interpretive Phenomenological Analysis (IPA) methodology, interviews with health professionals will be analysed using Framework Analysis. The evaluation will also report on quantitative data from the palliative care register and patient tracking.

Results: Data collection has suggested some weaknesses at the GP surgery in terms of referral and communication practices, especially for non cancer patients.

Conclusion: Conclusions will be drawn on the effectiveness of the clinic and implications identified for palliative care provision in primary setting.

Abstract number: P1-327
Abstract type: Poster

Development of Out-patient Specialised Palliative Care

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Patients in terminal care often want to stay in familiar surroundings. If they suffer from symptoms like pain or shortness of breath from vomiting or bleeding wounds, family members and emergency doctors alike tend to recommend hospital admission, even if the patient should be dying.

The team of the palliative care ward analyzed which serious illness managed at home, looking at the patient himself as his next of kin, asking the General Practitioner and the nurse.

The report describes the development of the project “Brückenteam” from its analyses and dialogues with insurances to the evaluation over two years until today where we work as a regular team taking care of critically ill patients.

Abstract number: P1-328
Abstract type: Poster

Psychological Empowerment and Self-perceived Effectiveness on Health Professionals Providing Palliative Care in Home Setting

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Introduction: The literature emphasizes that empowerment is an important component of individual, team and organizational effectiveness. Health professionals are key players in providing quality patient care. Empowerment involves a personal sense of control in the workplace as manifested in four beliefs about the person: relationship, meaning, competence, self-determination, and impact. Self-perceived effectiveness is defined as the degree to which professionals perceive that they fully or exceed work role expectations when providing quality patient care. Aim: To analyze the relationship between psychological empowerment and self-perceived effectiveness. Method: A descriptive, cross-sectional, correlational survey was used to measure the major study variables. In the study, the Self-perceived Effectiveness Scale allowed professionals to compare themselves with an “ideal professional”. Scales revealed adequate psychometric properties. Results: A series of multiple regression analyses tested the model hypothesized. The results suggested that levels of psychological empowerment resulted in higher levels of self-perceived effectiveness (β=.81, p < .001) in the workplace. The model accounted for 75% of the variance. Conclusion: Health professionals are key players delivering quality patient care. Empowerment in the workplace is an important predictor of professional effectiveness in providing palliative home care services. Organizations should develop programs to assess and put in place empowering structures and practices that engage professionals to attain a personal sense of control in the workplace.

Abstract number: P1-329
Abstract type: Poster

Building a Palliative Care Consultation Service in Long Term Care Facilities: Strategy, Business Model and Outcomes

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Aims: Long term care facilities (LTCFs) in the U.S. have begun palliative care programs for patients not eligible for hospice. Some LTCFs have a full time nurse and others contract with hospice and palliative care programs for palliative care consult services (PCCS). In 2009 our hospice and palliative care (HPC) program established a PCCS for LTCFs led by a nurse practitioner (NP). The aims of this study are: 1) to describe the process for establishing, growing and funding a PCCS in LTCFs; 2) profile PCCS patients, interventions and outcomes; and 3) present LTCF staff perceptions of PCCS services.

Methods: This is a descriptive study of the establishment and growth of HPC LTCF partnership. The PCCS maintains an Excel database of 600 patients, interventions and outcomes to date. LTCF staff members were surveyed for perceptions of the scope and quality of the PCCS in their facilities.

Results: Working with a steering group and informal network of LTCF’s, protocols were developed and four candidate facilities chosen. PCCS referrals grew by 32% the first year and 40% the third year following the hiring of an NP. Average increase in patient enrolments by a mean of 50 per year. PCCS patients with do not resuscitate (DNR) orders had higher rates of hospice enrollment and lower rates of re-hospitalization. PCCS patients with symptom control were effective 66.7% to 100% of the time. LTCF staff reports that palliative care is most helpful for pain management (91%), social/emotional issues (86%), and establishing goals of care (94%).
Conclusions: In 2012 already within the medium-term project this team established a palliative care initiative in cooperation with penal institutions. In January 2012 a nongovernmental health organization began a palliative care project in Temirtau, Kazakhstan, which was conducted in 2012 and published in EJPC. Its main objective was to characterize the meaning of life among the convicted.

Methods: An initial survey among the sentenced in Gdansk was conducted in 2012 and published in EJPC. Its main objective was to characterize the meaning of life among the convicted.

Results: The survey included 747 respondents aged 18-60 years. The majority of participants were male (71%) and had a low level of education (42%). Most respondents were unemployed (79%) and had a history of criminal activity (78%). Among the respondents, 34% reported a history of substance use, and 24% reported a history of suicide attempts. The majority of participants reported feeling lonely (75%), anxious (72%), and depressed (69%). The majority of participants reported a lack of support from family and friends (81%). The majority of participants reported a lack of hope (75%) and a lack of motivation (78%). The majority of participants reported feeling isolated (65%) and feeling stigmatized (62%). The majority of participants reported feeling stigmatized (62%).

Conclusions: The results of the survey suggest that the convicted have a high level of meaning of life. A qualitative analysis of the data suggests that experiences of hospice volunteering may affect the nature of understanding the meaning of life among the convicted. The study has implications for the development of palliative care in penal institutions.
Individualised, Community-based, End-of-Life Care Reduces Hospital Use, but at what Cost?

Abstract number: P1-336
Abstract type: Poster

Background: To find the financial impact on patients referred to hospice care and support for families from a rural hospital, with a limited level of specialist palliative care available.

Methods: A total of 102 referrals were admitted between 2007-2011 with 74 being discharged home (DH), 24 inpatient (IP) and 4 referrals were reviewed after 24 hours of admission.

Aim: To calculate the inpatient cost and cost savings for DH patients, in order to determine the potential benefits and cost-effectiveness of palliative and end of life care.

Finding: DH patients saved 13 days of hospital costs compared to IP patients.

Conclusions: This is a significant cost-savings and could be used to reinvest in other community care services.

Presentation: Table 1

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<th>Type of Care</th>
<th>Mean Cost DH</th>
<th>Mean Cost IP</th>
<th>Cost Savings</th>
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</table>

Poster sessions

Presentation of Experiences Made by a Palliative Team in a Project Conducted in Order to Increase Competence by and Cooperation with the Regional Health Service (RHS)

Saeter L.F., Westad B.
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Aims: Palliative team at a local hospital wanted to intensify their outreach work towards the RHS in order to increase cooperation within palliation. The project was funded by the hospital.

Methods: 1. Ambulant service to patient’s home, together with the RHS

2. Outpatients clinic consultations during which RHS
Abstract number: P1-342
Abstract type: Poster

Results of a Delphi-analysis of Palliative Care in German Nursing Homes

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Aims: Based on the results of a series of differently designed model projects in North-Rhine-Westphalia a framework programme of palliative care was developed with a remit of NRW. The Delphi method was used to find a consensus on the overall mean agreement of the revised theses was 8.43. After the second round (n=51) this was again presented for consensus rating.

Methods: A total of 129 experts and additionally a group of caregivers were sent out an initial questionnaire was sent in February and March 2012. An interquartile range (IQR, measure of statistical dispersion) of 2 was introduced as criterion to separate experts into high and low IQR classes with an IQR≥3 were revised. In the second round these revised theses as well as the theses with an IQR≤2 were again presented for consensus rating.

Results: In the first round of the Delphi process 88 participants answered the questionnaires. For all 21 theses an IQR≤3 was found. After the second round (n=51) this was found for nine theses only, and out of these only three theses had an IQR ≥ 3. After the first round the mean agreement of all theses was 8.37 and after the second round the overall mean agreement of the revised theses was 8.43.

Conclusion: A high consensus and a high consent for the theses is obvious. However, differences between health and care insurance providers and the medical service for the health insurance funds (MDK, Medizinischer Dienst der Krankenkassen) on the one side and the other groups (project leaders, home leaders, scientists, caretakers) on the other side were explicit.

Abstract number: P1-343
Abstract type: Poster

Conclusions of Monitoring and Evaluating Two Different Projects, which illustrate Different Models of Palliative Home Care, Funded by the German Cancer Aid (DKH)

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Aims: The objective was an improvement of the ambulant care of palliative patients in Germany. The DKH funded twelve regional projects in different models. Study design and methods: the funded projects documented all patients using WHO (Hospital and Palliative Care Evaluation) and EAPCN (Excellence Project Documentation system for palliative patients, German version of EAS) and the Barthel index. Project § were ranged from 18 hymns to March until 2012. In a final meeting from the project managers presented each project in short form, the final statistical analysis of the program was shown and future demands and problems were discussed.

Results: Data of 3.239 patients were analyzed. In total 85.6% of the patients died. Of these, 51.4% were female, 1.9% were younger than 40 years, 21.9% older than 80 years. The most important problems were weakness (70.7%), no appetite (52.9%), fear (52.2%), the need for help with the daily activities (64.8%), family problems (37.0%), pain (35.8%), organisational problems (28.9%), tension (27.1%) and anxiety (25%). When patients died. The place of dying was at home in 50.4%, care home in 19.2%, palliative care ward in 16.0%, hospital in 9.8% and inpatient hospice in 8.9%. All projects implemented a network of close collaboration between primary care providers, social support, ambulant and inpatient specialized services. The place isn't very spacious and this fact helps them; more than 4 people would already be an institution. (NTNU, Trondheim, Norway. 2Department of Oncology, St. Olavs Hospital, Trondheim University Hospital, Trondheim, Norway. 3Scientific Institute for the Quality of Healthcare (IQ) HealthCare, Radboud University Nijmegen Medical Centre (RijnMC), Nijmegen, Netherlands. 4Regional Centre of Excellence for Palliative Care, Haukeland University Hospital, Bergen, Norway. 5National Centre of Excellence in Palliative Care, Oslo University Hospital, Oslo, Norway. Contact address: ragni.sommerbakk@ntnu.no

Background: Implementation of change is challenging, in health care settings in general and in palliative care (PC) settings specifically. In order to plan a successful quality improvement project, it is essential to have knowledge about what makes such projects fail or succeed. Aim: The aim of this review was to identify factors that may act as barriers or facilitators for strategies to improve PC in cancer and dementia settings.

Methods: Systematic, electronic literature searches were done in the Medline, CINAHL, BNI, and PsyCINFO databases. The searches revealed 1579 articles. 144 articles were retained after screening of abstracts according to a checklist. Exclusion criteria: no abstract available, no barriers or facilitators described, not directed at the organization of PC for patients with cancer or dementia, not directed at health care professionals, and pediatric setting. Full-text papers were independently examined by two researchers.

Conclusion: It is important to anticipate potentially problematic issues when planning improvement projects. The factors reported here should be considered when attempting to change organizations that provide PC. This review was conducted as part of the EU funded IMPACT project (Implementation of quality indicators in Palliative Care Study).

Poster sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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Abstract number: P1-347
Abstract type: Poster

Palliative Care for Cancer Patients in the Emergency Department in Iran

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There is only one public hospital in Iran that provides palliative care services to the cancer patients, who are admitted to the Emergency Department (ED). Between 33%-46% of admissions in the ED are advanced or end-stage cancer patients. For this number of admissions there are only 10 beds available in the ED for their daily needs. They normally stay in emergency for days for management of their symptoms (commonly pain and respiration distress) or for terminal care. Barriers for delivering palliative care services in the ED: - Traditional attitude among the ED staff that practice life-saving approaches for every patient regardless of their disease. - Ambiguous medical rules to protect the ED staff from legal action against them if they refuse to provide futile treatments to satisfy the patients’ family with unrealistic expectations. Lack of knowledge about palliative care philosophy regarding the better symptom management and terminal care. - Insufficient number of palliative care teams, community care services and hospices as compared to the number of patients who need them. - To completely escalate rate as a failure of the healthcare system even for advanced, incurable cancer patients. Some suggestions: - Look at palliative care as a necessity in the national healthcare system that should be addressed urgently. - Integration of the basic concept of palliative medicine in educational curriculum of all medical fields and specialties particularly the emergency medicine. - Creation of community care services as a priority. - All the emergency department visit by palliative care team with active involvement when it is possible to symptom control, decision-making and future planning. Referring advanced cancer patients to the palliative medicine clinic after discharging them from the ED.

Abstract number: P1-348
Abstract type: Poster

Organising a Children’s Palliative Care Program in a Developing Country

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Aim: To organise a Children’s Palliative Care Program in a developing country.

Background: Children’s Palliative Care is still not recognised in many countries. Though the need is enormous, there is no policy or strategic planning to provide the services.

Methods: The project has been started with National and International Collaborations and mentorship. The aim is to address needs of children with life limiting conditions i.e. HIV/AIDS, Cancer, Thalassemia, Neurological disorders and to improve the quality of life of the children and their caregivers. It becomes more essential where poverty, illiteracy, superstitions, beliefs, gender differences and social stigma is prevalent in the society. The project is trying to bridge the gaps and overcome the challenges in implementing the Children’s Palliative Care Program in three different models. The two sites have already been started, one being at the Paediatric HIV unit at the Urban Public Hospital and the other at a Primary Health Care set up in a remote tribal rural area.

The important elements of the project are: a) Advocacy for Children’s Palliative Care by adoption of Paediatric Palliative Care Policy by the Government b) Education & Training: Awareness to Doctors, Nurses, Social Workers, Volunteers and NGOs in Knowledge, attitude and skill to deliver supportive care to children and to integrate Palliative Care into undergraduate and post graduate Medical, nurses/social work training curriculum c) Availability to pain relieving medication like Morphine & Emopodil d) Empowerment of the patient and families to improve their Quality of Life

Conclusion: Though there are many challenges in organising a Children’s Palliative Care Centre in a developing country, sensitisation of Health Care Professionals and advocacy with the Policy makers make a difference in the scenario.

Abstract number: P1-349
Abstract type: Poster

Development of a Fatigue, Anxiety and Breathlessness (FAB) Clinic for Palliative Patients

Bakcn L, Dawes F, Thomas J, Plant A, Wells S
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Aims and background: The development of a fatigue, anxiety and breathlessness clinic evolved from multi-disciplinary discussion on end of life issues between the Oncology (OT) and Physiotherapy led clinics. There was recognition of the need for a more holistic approach to these three inter-related symptoms. The aims were to: 1) develop a multi-disciplinary (MDT) clinic (Doctor, Specialist Palliative Care Nurse, OT and Physiotherapist), to help people with palliative care needs cope with their symptoms and enjoy a better quality of life. Spousess/carers were invited to participate within the clinic to gain peer support, information and advice.

Method: We developed a clinic consisting of 2 weekly 2 hour sessions over a 4 week rolling programme. Suitability criteria for clinic attendance were agreed. Following an initial introduction and assessment, we focus on a different symptom each week within a small, intimate group of four patients plus carers. Weekly symptom diaries and post clinic assessments are also completed. The clinic is reviewed and modified by the MDT on a regular basis.

Results: More than 300 patients have been referred over 6 years, with both cancer and non-cancer diagnoses. Qualitative feedback from patients and carers shows evidence of improved symptom control, access to peer and emotional support, and earlier introduction to the hospice. Quantitative data, collected through validated assessment tools, shows significant improvements in all 3 symptoms and a positive impact on quality of life for many patients.

Conclusion: Attendance at a multi-disciplinary, small group clinic can empower patients and carers to positively manage symptoms of fatigue, anxiety and breathlessness. The FAB Clinic is receiving increasing numbers of referrals for non-cancer patients who have suffered a severe life limiting illness.

Policy

Abstract number: P1-350
Abstract type: Poster

Is it Enough or Not Enough Staff Power of Medical Rehabilitation Professionals in Palliative Care Team at Cancer Institute in Japan?

Abe PK
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Objective: To investigate staffing about medical rehabilitation professionals in palliative care team (PCT) in Japanese regional cancer institute.

Study design and methods: To collect data about staffing of medical rehabilitation staffs in PCT each institutes connected by internet on the end of April 2012. Then analysed collecting data statistically.

Results: Three hundred ninety-three regional cancer institute were found out by the survey. The size of institute was:

1. Under five hundred beds: 208 (52.9%),
2. Over five hundred to one thousand beds: 164 (41.7%),
3. One over thousand beds: 21 (5.3%).

Number of doctors: 308 (100% of all), Nurses: 392 (99.8%), Pharmacists: 378 (96.5%), Medical social workers: 316 (80.4%), Dietitians: 260 (66.2%), Physical therapists: 231 (58.8%), Clinical psychologists: 214 (54.3%), and Nutritionists (Osteo): 260 (66.2%).

Conclusions:

This is a first national wide survey about staffing of medical rehabilitation professionals in PCT in regional cancer institute. The numbers of medical rehabilitation staffs (231) are almost equal who are staffing in PCT in Japanese regional cancer institute. The numbers of medical rehabilitation staffs in PCT each institutes are almost equal who are staffing in PCT in Japanese regional cancer institute. The numbers of medical rehabilitation staffs in PCT each institutes are almost equal who are staffing in PCT in Japanese regional cancer institute. The numbers of medical rehabilitation staffs in PCT each institutes are almost equal who are staffing in PCT in Japanese regional cancer institute.

Policy

Abstract number: P1-351
Abstract type: Poster

Fitting in. What is the Priority? International Standards or Local Needs?

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Current trends including palliative care programs- go towards globalization, led by external peer review, international standards and adherence with national and international standards and norms. A conflict might ensue for policy makers when these contradict the demands of local populations who offer support with effort, time and resources.

Aims: To raise awareness to the fact that International standards might be only applicable when they set minimum norms but not so good for maximums in certain areas. To evaluate process, sustainability and impact of programs for the population in terms of intended and achieved outcomes and perceived quality of care for those unwilling to leave their beloved island to be cared for, to die or even wait to accompany a loved one in their last journey beyond the water.

Method: Stratified application of WHO, IAHPC AECOP guidelines to the situation in each country, sensitisation of Health Care Professionals and from whom the possibility to offer guidelines to incorporate palliative care services in different settings. None of the recommendations analyzed took into consideration standards setting and delivering maximums. Such lack of extremes inclusion make them impractical to implement strategic planning of advanced societies experienced in the provision of palliative care. Conclusions: Individualized care should be applied to programs and units want to offer compassion and care to its population even within the defined maximums to international standards and norms. Trying to comply with widely accepted standards might keep these organizations from helping their populations achieve their wishes under a modified versions incorporating their needs are used.

Abstract number: P1-352
Abstract type: Poster

Opinions of University Hospital Health Care Professionals on Existity of Palliative Care Consultation Practices; Single Centre Survey May Serve as a Model for Palliative Care Consultation Team Start up

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Background: In the Netherlands, the acknowledgement of palliative care as specialized care is a relatively new phenomenon. In November 2011, at Leiden University Medical Centre (LUMC), a fully equipped palliative care consultation team (PCT) was started to improve care. Until then, palliative care was provided on an ad hoc basis, without proper education, knowledge or specialized protocols. To obtain baseline information on existing practices, shortcomings and needs, an internet survey was sent to all LUMC health care professionals.

Methods: 400 medical doctors and 1200 nurses received a survey containing 30 questions on prevalence of palliative patients, symptoms, discharge, euthanasia, palliative sedation, use of guidelines, and experienced problems and deficits.

Results: 19% responded, representing 75% of all LUMC departments. Prevalence of palliative patients seen by the respondents was low, only 44% considered > 10% of their total in a palliative phase. 80% were cancer patients. Nurses observed more symptoms compared to doctors (median 6 and resp.). Deficits were seen in communication problems regarding timing and communication of transitions from active treatment to symptom control, and absence of integrated care. Only 56% of respondents was aware of the availability of the PCT’s special experience.

Conclusions: Doctors and nurses in this university hospital university hospital do not very often recognize that patients are in a palliative phase. This may result in underconsumption of PCT consultations. In the LUMC, growing awareness of palliative care maybe enhanced by: 1) regular education on symptom management and...
screens were sent during admission for clinical reasons. For the 74 patients found to be MRSA positive, only 6 (8.1%) successfully completed the eradication protocol, while 46 patients (62.2%) died before its completion. In the remaining MRSA positive patients: 12 were discharged before completing the protocol (16.2%), 7 remained MRSA positive (9.5%) and in the remaining 9 patients the object for non-completion is unclear (1.1%). There was no significant survival difference in the MRSA positive group, while MRSA positive patients had a significantly longer length of stay (33.7 versus 21.5 days, p<0.01) and more infection episodes (p<0.01).

Conclusions: MRSA is prevalent in the SPCU but MRSA eradication success was low. MRSA did not affect survival but was associated with a length of stay and infection episodes. In light of this, identifying high risk groups may help guide policy development.

Revisiting the Definition of Palliative Care: Defining what Palliative Care is About Rather than Specifying an Agenda for its Implementation

Graudal J1

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Palliative care is a young profession with ancient roots. In its struggle for acknowledgment in modern civilization it still faces the process of redefinition and reidentification into the health care system and exposition of its role in society. Contemporary approaches to the definition of Palliative Care, exemplified in the formulas adopted by the World Health Organization, confined the effort to describe its essence with attempts to specify various aspects of its implementation. Thus, alongside the prevention and relief of suffering, the definition states core policies such as the requirement for a team approach, early intervention, etc. Although such an approach is necessary to the implementation of palliative care, they shed no light on the nature of palliative care, and could apply to many other professions.

The proposed approach considers the distinction between the subject matter of Palliative, and the ever changing agenda for its implementation. It focuses on the definition of a field of activity intent on the fulfillment of the WHO triangle for adequate pain management: Policy, Drug authorities in close cooperation with Palliative Care team, regulating the rules of prescribing and administration of formulations can be prescribed; Authorization on prescription of opioids was passed to PCP-s. Usage of conventional agents can be prescribed; Authorization on prescription of opioids became one authorized physicians responsibility; Adoption of the commission for prescribing the opioids, prescription policy; new legislations ensure balance for medical usage of opioids.

Milicevic N.1, Ortegon A.1, Florez S.1, Izquierdo C.1, De Lima L.2

Association for Hospice and Palliative Care, Houston, TX, United States

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Aims: A national palliative care (pc) strategy was passed by the government of the Republic of Serbia in 2009 & set out a comprehensive policy to develop pc in Serbia. Prior to this, pc in Serbia was limited. 3 years on, we review how far we have got and what we have learnt.

Methods: Work to implement a strategy has been supported by the EU. Following a review, this paper highlights progress in implementation along with lessons learnt. Key areas reviewed include: Access to care, public & professional education (undergraduate & continuing education), formation of pc teams/units within the health system, legislative provisions & drug accessibility, research & M&E

Results: Implementation of the national strategy is ongoing with varying amounts of success including: implementation & development of an accredited multi-disciplinary training programme with over 1000 professionals having been trained to date; Pc accepted into the curriculum of the national medical schools & in process of being approved by higher nursing schools; 2 hospitals have opened PC units with more under development; legislative changes made to government to increase access to PC including essential

Poster sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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Poster abstract P1-355: State Policy on Quality Pain Management and Legislative Changes in Georgia

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Background: Quality of pain management highly depends on access to opioids and existence of relevant legislation regulating their usage. This study aimed to assess utilization of these medications. Assessment of the National policy on opioids, basing on WHO document ‘Achieving Balance In National Pain Policy’ performed by the state authorities in close cooperation with Palliative Care team, have resulted in legislative changes, focusing on all angles of WHO guidelines adequate pain management: Policy, Drug availability and Education.

Goals: Introduction of the State Policy on Quality Pain Management and legislative changes undertaken in Georgia since 2006. The ‘Law on Regulation of Legal Use of Narcotics’ (2007) - commitment undertaken by the State for provision of the risk of epidemic scale of opioid use, both in terms of the quantity and forms; Paragraph concerning inevitability of opioid usage for medical reasons was added to the Chapter, reflecting the main principles and regulation field (2012). The language was refined and confusing terminology and expressions were eliminated. The law was enacted and published in the Official Journal of Georgia on the 2nd of October 2012.

Results:

• Stigmatizing term “somatonarcoman” (patient with physical dependence) is removed;
• Removed the term “nosocomial patient” (patient with physical dependence is removed);
• State Health Program from 2011 provides opioids for non-cancer pain patients along with appropriate use

Conclusion: The proposed approach considers the distinction between the subject matter of Palliative, and the ever changing agenda for its implementation. It focuses on the definition of a field of activity intent on the fulfillment of the WHO triangle for adequate pain management: Policy, Drug availability, Education and Authorization on prescription of opioids was passed to PCP-s.

Poster abstract P1-356: Setting Policy for Palliative Care Provision at Sub National Level

Nemra Oib JA.1, Diaz-Veyra P.1, Halgunn Lott M.1, Azarmac Espejo H.1,2

1De Oeste; Head Office, Xalapa, Mexico; 2Association Veracruzana de Cuidados Paliativos, Administrativa, Xalapa, Mexico; 3Companeros, Complementary Therapists Cooridnator, Mexico (95%); and in the remaining 9 patients the object for non-completion is unclear (1.1%). There was no significant survival difference in the MRSA positive group, while MRSA positive patients had a significantly longer length of stay (33.7 versus 21.5 days, p<0.01) and more infection episodes (p<0.01).

Conclusions: MRSA is prevalent in the SPCU but MRSA eradication success was low. MRSA did not affect survival but was associated with a length of stay and infection episodes. In light of this, identifying high risk groups may help guide policy development.

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Graudal J1

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Methods: Work to implement a strategy has been supported by the EU. Following a review, this paper highlights progress in implementation along with lessons learnt. Key areas reviewed include: Access to care, public & professional education (undergraduate & continuing education), formation of pc teams/units within the health system, legislative provisions & drug accessibility, research & M&E

Results: Implementation of the national strategy is ongoing with varying amounts of success including: implementation & development of an accredited multi-disciplinary training programme with over 1000 professionals having been trained to date; Pc accepted into the curriculum of the national medical schools & in process of being approved by higher nursing schools; 2 hospitals have opened PC units with more under development; legislative changes made to government to increase access to PC including essential
medicines, clinical guidelines drafted & under review, work has begun on translating & culturally adapting an outcome scale for Serbia.

Conclusions: Implementing such a strategy on a national scale, takes time, resources & commitment & cannot work without collaboration with partners & the government. The implementation of the National Strategy is moving in the right direction, albeit slowly. PC is further developed in Serbia.

This work is funded through the EU project ‘The Development of Palliative Care in the Republic of Serbia’ (EuropeAid/129769/C/SER/RS)

Abstract number: P1-359
Abstract type: Poster

Costs in Context: Factors Associated with Health Resource Use at the Last of Life Year

Background: Understanding health care spending at the end of life helps to plan services and use funds efficiently.

Aim: To identify factors associated with individual health care costs in the last year of life (LYoL), in different care settings.

Methods: Systematic literature review to elicit health care cost drivers in the LYoL of adults, using a highly sensitive search strategy in EMBASE and Medline (until 8/2012).

Inclusion criteria:
1) Populations with life-limiting or advanced progressive illness

2) Settings.

Inclusion criteria:
1) Populations
2) Settings (in care settings).

Results: 21 studies were included. Factors identified were age: old: reduced overall, but higher home care, nursing home and hospice costs

Socio-economic status: lower hospital, but higher home care, nursing home and hospice costs

Poor functional status, proximity to death, co-morbidities:

Non-white ethnicity: lower overall, but increased hospital and hospice costs

Results:

Driver.

Agreement between different studies assessing each cost driver.

Not without difficulty. It also highlighted the need for further high quality research.

Abstract number: P1-361
Abstract type: Poster

The International Narcotics Regime and Barriers to Access to Essential Medicines

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Fifty years after the formal establishment of the global narcotics control regime, 80% of the world’s population has little or no access to the medicines for the relief of pain and suffering, and global problems related to addiction to narcotic drugs remain unsolved. Yet, the regime commands almost universal adherence to the “international” prohibition of billions in annual funding from the US and other UN member states. UN agencies as well as global NGOs have produced reports detailing barriers to access in low and middle income countries and how these might be overcome. This article identifies the significant barriers within the regime itself and locates the source of the misalignment in the “Dual obligations” imposed on the Parties by the Conventions.

Abstract number: P1-362
Abstract type: Poster

NICE Opioids - A Summary of Guideline CG140

Davies G., Taubert L., Ross J., Pettigrew M., Schmidt-Hansen M., Bennett M., Guideline Development Group for NICE CG140: Development of Opioids in Palliative Care

Aims: The multi-level action research project was laid out in three phases: needs assessment, planning of interventions and implementing actions. Attention was given to three types of interventions: development of palliative care in primary care and its acceptance of specialist palliative care structures; integration and governance of hospice and palliative care plan in Tyrol. Participation was encouraged in the care unit and innovative data collection, needs assessment and evaluation. The action research project offered possibilities to further develop organisational palliative care processes within different care settings. The participating actors developed plans for necessary measures and steps to further implementation of palliative care in the model regions. On policy and management level a steering committee was established, that brought together all representatives of the commissioning agency. At all levels common goals and interests were discussed, strategic decisions and conceptual suggestions were debated. Conclusion: The project process has enabled the local stakeholders to develop a perspective of an adequate regional palliative care culture. It served to develop sustainable partnership, networking processes and establish structures of specialised palliative care services and units. To foster the acceptance of the new palliative care model in the region.

Abstract number: P1-363
Abstract type: Poster

Hospice and Palliative Care in Tyrol, Austria: Development of General and Specialised Palliative Care in the Health Care Systems of Two Model Regions

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Aim: In Austria’s Tyrol a three year research project was undertaken with following objectives: To develop a regional specific economic model for the integration of palliative care; to generate knowledge and foster communication among local actors and stakeholders; to integrate palliative care into the health-care system in the different model regions and to foster implementation of palliative care in the model regions. On policy and management level a steering committee was established, that brought together all representatives of the commissioning agency. At all levels common goals and interests were discussed, strategic decisions and conceptual suggestions were debated. Conclusion: The project process has enabled the local stakeholders to develop a perspective of an adequate regional palliative care culture. It served to develop sustainable partnership, networking processes and establish structures of specialised palliative care services and units. To foster the acceptance of the new palliative care model in the region.

Abstract number: P1-364
Abstract type: Poster


Evans N., Alman B., Velasco Alonso L., Van den Block L., Miccinesi G., Vivanco V.C., Donker G., Bertolla S., Zumaga O., Dellen L., on behalf of EUROPEPAC

EMGO+ Institute, VU University Medical Center, Public Health, Decisions and Health, Copenhagen, Denmark, Public Health, Decisions and Health, Copenhagen, Denmark, Public Health, Decisions and Health, Copenhagen, Denmark, Public Health, Decisions and Health, Copenhagen, Denmark

Aims: Interpretations and misunderstanding have surrounded the use of strong opioids for decades, which has resulted in errors causing under-dosing and avoidable pain or over-dosing and distressing adverse effects. The UK’s National Institute for Health and Clinical Excellence (NICE) developed Guidelines on Opioids in Palliative Care, to offer a consistent approach for the initiation of strong opioids in palliative care.

Methods: Systematic reviews were conducted to consider the best available clinical and economic evidence. No minimal evidence was available, the Guideline Development Group’s experience and opinion of what constitutes good practice was sufficient. A de novo cost-effectiveness analysis was also conducted.

Results: The NICE guideline was issued in May 2012. (1,2,3) A number of key areas were identified, including: effectiveness of palliative care communications; starting strong opioids, management of breakthrough pain and side effects.

Conclusion: NICE is a provider of national guidance on the promotion of good health and NHS organisations aim to comply with guidance as part of clinical governance policy. This guideline takes effect at the point in time when a palliative care patient has moderate to severe pain, which necessitates commencing strong opioid analgesia. For this abstract, a member of the NICE guideline development group will summarize CG-MS recommendations and discuss the implications that the most recent guidance has for palliative care providers and draw parallels to the recent EAPC Guidelines on Opioids in Palliative Care.
Abstract number: P1-368
Abstract type: Poster
Implementation of New Models for Psychosocial Care. Effectiveness of the Programme Comprehensive Care of Patients with Advanced Illnesses in Spain
Gómez Batiste E.1, Matoe D.1, Martínez Muñoz M.1, Buisán M.2, Velasco D.1, de丕scallan V.1
1Custode Institute of Oncology, The Quarcy Observatory / WHO/ICHO, Hospital de Lisboa – Barcelona, Spain, 2La Caixa Foundation, Barcelona, Spain
Introduction: The programme for comprehensive care of patients with advanced illnesses starts in 2008, as an anticipatory planning, with the aim of adding quality and put in value the task of palliative care teams. The programme was implemented in 264 (69%) of the patients active decision control preferences (p≤0.001). There was 182 (47.6%) shared and 81 (21.2%) passive. 345 (92%) treatment preference discussions and surrogate appointment in the last three months of life, including the discussion of treatment preferences and appointment of surrogate decision-maker, for all patients who died using a standardised questionnaire.

Conclusions: In this study did not adhere to a traditional paternalistic decision making model. Patients with older age and those that want to know their diagnosis were more satisfied with the way the decisions were made.

Abstract number: P1-369
Abstract type: Poster
Is Always Palliative Oncology Treatment Permeated with Psychiatric Symptoms?
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4Instituto Cancerologia, Hospital Universitario Marques de Valdecilla, Santander, Spain, 5Hospital Universitario Marques de Valdecilla, Santander, Spain
Objective: To evaluate the levels of hope, anxiety and depression in palliative cancer patients comparing palliative treatment initiation and evolution over the period of a month.

Materials and methods: We conducted a prospective cohort study, evaluating 40 adult patients of both sexes diagnosed with a diagnosis of advanced neoplasia no possibility of cure, which were part of the Palliative Care Programme of the University Hospital Barretos Cancer Hospital (BCH). We used the Socio-Demographic Questionnaire, Beck Hopelessness Scale (BHS), Hospital Anxiety and Depression Scale (HADS) and the Inventory of Coping Strategies, which were applied individually before the first appointment and in the last visit (with support) 30 days.

Results: The scales were tabulated with significance level 0.05.

Conclusion: The program for comprehensive care of patients with advanced illnesses has consolidated innovative, specialized palliative care teams, which have performed effective interventions.

Abstract number: P1-370
Abstract type: Poster
Gender Influence on Coping Strategies in Pediatric Palliative Care Team Members - A Pilot Study
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Introduction: After the death of a child parents nowadays often receive gender specific offers for dealing with grief. This is based on the insight that grief has gender specific issues. Conversely there are no gender specific offers for children’s palliative care. Therefore the aim of this study is to examine the culture of grief and coping among palliative care professionals.

Methods: We conducted a standardized survey among members of ppc, in order to analyze gender specific differences in coping strategies.

Materials and methods: For investigation of coping mechanisms in members of ppc a questionnaire was developed on the basis of Swetz et al. 2009. Further the screening instrument for anxiety and depression (PHQ-9) was used, as well as a validated health utility index and an instrument for measuring optimism/ pessimism. The link was send via email to department heads and questionnaires were completed, 43 by women, 7 by men. The survey involved different specialities like nurses, physicians, social workers, psychologists and pastoral caregivers.
Poster sessions

Results: There were no differences between men and women in age and work experience. Both displayed a comparable distribution regarding leisure time activities involving consumption, remembering of former past or realistic expectations.

Discussion: The results of this pilot study show differences in coping strategies of male and female employees. These insights can be used for optimizing further studies on gender differences in coping strategies with the long term goal of developing support strategies. A limitation of the present study is the strong female overlap.

Abstract number: P1-372
Abstract type: Poster


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Background: As a result of a 2 year research study involving over 34 stakeholders, a new model for breaking bad news to people with intellectual disabilities (ID) was developed and presented at the EAPC Congress in 2011.

Aims: To develop a model accessible to key stakeholders, including family carers and staff in intellectual disability services as well as genetic healthcare and palliative care professionals.

Methods: Around 60 stakeholders were asked an open question about their preferred way of accessing information about worsening health. The results of a 1 day advisory board meeting, a stakeholder feedback conference and via email, in addition, their opinion was sought on preferred terminology.

Results: There was a strong preference among all stakeholder groups (but especially among family carers and support staff) for an individualized and on-line approach to the news model. The wording “guidelines” was adopted as family carers did not like the word “model”, which they associated with a lack of flexibility. Suggestions of different terminology (including “communicating” instead of “breaking” and “significant news” instead of “bad news”) were rejected as being too confusing, with family carers feeling particularly strongly that it should be “breaking bad news”. As a result, a comprehensive website was developed (www.breakingbadnews.org), as well as a handbook in plain English.

Conclusions: The website went live in October 2012. The use and usefulness of the guidelines, website and book will be monitored during the coming year. Initial feedback is positive.

Abstract number: P1-375
Abstract type: Poster

Analysis of Survey on Psycho-oncology Development in Former Eastern Bloc Countries

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Introduction: Psycho-oncology is an interdisciplinary field of medicine. In Europe its development falls in the 1980s, 20th century. However, in some countries of the former Eastern Bloc quite a different situation occurs since psycho-oncology, as generally defined, has just come into existence. Aims: To present the current situation with regards to psycho-oncology development in selected countries of the former Eastern Bloc: Belarus, Kazakhstan, Lithuania, Ukraine.

Materials and methods: The analysis includes data collected based on survey forms filled in by medical staff representing the main cancer hospitals in the countries of the former Eastern Bloc and data on psycho-oncology development provided by medical employees from the specific countries. 120 medical staff were asked to participate in the survey that was conducted in the period from January to March 2012.

Results: A profession most frequently declared by the respondents was a doctor (from 34.8% in Belarus, up to 63.6% in Ukraine) or a psychologist (from 4% in Kazakhstan to 21.8% in Lithuania). 63.6% in Ukraine) or a psychologist (from 4% in Kazakhstan to 21.8% in Lithuania).

Conclusions: Psycho-oncology in the countries analyzed is at its early stage of development except for Lithuania. The main objectives, tasks and principles of psycho-oncology in the selected countries of the former Eastern Bloc are similar to those identified in Poland.

Abstract number: P1-374
Abstract type: Poster

Breaking Bad News: Experiences of Doctors in the Care of Cancer Patients in Mulago National Referral Hospital

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Introduction: Breaking bad news is a routine task done by many health professionals and doctors are often involved in giving bad news. However communicating with distressed patients is one of the most important, yet challenging tasks required of the medical profession. Though much has been written about the way that bad news is delivered, the skills needed and the impact of delivering the news on the recipients, the actual experience of breaking bad news has not been studied.

Aims: To explore doctors' experiences and challenges of breaking bad news to cancer patients to enable future skill development and for support, to improve the doctor-patient communication.

Method: It was a qualitative study which used in-depth semi-structured interviews. Participants: 12 respondents drawn from among Senior House Officer from different department of Medicine, Surgery, Gynaecology and ENT within Mulago National Referral Hospital were interviewed using the briefer mentioned above.

Results: The study findings noted the importance the doctors’ place on breaking bad news. The circumstances which surround the situation of breaking the bad news either hinder or enhance the doctors’ breaking of bad news.

When these were unfavorable the emotions the doctors experienced were overwhelming and stressful.

Conclusion: Breaking bad news fosters strong relationship between the doctor, patient and family which is required for maintaining a level of comfort of care for cancer patients.

Recommendations: There is need to adequately train doctors to equip them with skills and knowledge of breaking of bad news to patients. These skills will equip them to handle the various responses of the patients and family members.

Abstract number: P1-375
Abstract type: Poster

Evaluating the Effect of Advanced Communication Skills Training (ACST) for Doctors by Patient Reported Outcome Measures (PROM) in Hospital Outpatient Clinics: A Feasibility Study

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Background: ASCT is currently being proposed to be mandatory in England for all palliative care clinicians. Strong evidence regarding whether ACST elicits noticeable change in PROM’s is required. Aims: To determine the feasibility of a study to measure a change in PROM arising from ACST for doctors. Specific objectives included the feasibility and acceptability of using Consultation And Relational Empathy measure (CARE) and Patient enablement measure (PROM) as PROM’s within secondary care. In addition, to facilitate the design of a larger study, determine the observed difference between doctors on the PROM in the report for those who have already completed ACST (Alumni).

Method: Two data collections of 75 questionnaires per group were conducted with a participating doctor. Enabling stability of PROM’s to be ascertained in addition to feasibility and acceptability of methodology. Data were gathered using descriptive statistics and Mann-Whitney U test for comparison of group medians.

Results: Ten doctors recruited (5 in each group). Patients returned over 90% of the questionnaire (82.5%, 83.3%). Respondents were representative of outpatient population with regard age and gender. Majority of questionnaires were valid: CARE 80% (25), PROM 64% (24). Stability of PROM scores over first and second data collection demonstrated: Mean CARE score WL group overall mean 44.1 ± s.d. 7.2, median 47 (1st collection 44.0 ± s.d. 7.6, 2nd collection 44.2 ± s.d. 6.7), Alumni group mean 46.2 ± s.d. 5.3, median 50 ± p = 0.000. FEI score: WL group mean 4.3 ± s.d. 4.1, median 3.0, Alumni group mean 5.3 ± s.d. 4.5, median 4.8 ± p = 0.002.

Conclusion: Pilot demonstrates the acceptability and stability of these PROMs in this setting. The results can be used to power a larger study to determine whether ACST does improve doctors’ communication skills and lead to greater enablement of patients.

Abstract number: P1-376
Abstract type: Poster

What Do Inpatients Know and Have Been Told about their Illness? A Cross-sectional Study in a Palliative Care Unit

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Research aims: To know how many patients from a Palliative Care Unit (PCU) say they know about their diagnosis and prognosis and what have been told.

Method: The physicians from a PCU were asked to answer if their patients said to know about their diagnosis and prognosis and if the relatives of the patients confirmed that.

The attending physician had one week to answer after discussing it with their patients in their clinical practice, and should say the reason when it could not be discussed.

Results: 36 patients were in the PCU and were included, mean age 73 years old, 21 (58%) men, 32 (89%) advanced cancer patients. The physicians could not discuss with 19 (53%) patients mainly because cognitive impairment 14 (74%), finally 17 (47%) patients were selected. 13 (76%) patients knew the diagnosis, 4 (23%) patients had been told about the bad prognosis, 9 (53%) had been told that the life is controlled. 10 (59%) patients knew their prognosis and 7 (41%) patients perceived their bad prognosis in spite what had been told. 16(44%) Patients wanted to know about their illness by themselves.

Conclusions: Physicians could discuss with half of the patients. Most of them knew the diagnosis and half of relatives said patients were not completely informed about prognosis. Almost all patients wanted to know about their illness by themselves.

Abstract number: P1-377
Abstract type: Poster

Toward the Development of a Clinically Useful Index of Prognostic Awareness

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Research aims: Clinicians who work with advanced and terminally ill cancer patients often struggle over what, when, and how to disclose prognostic information to their clients. This process of further handicap is further compounded by inherent in determining what clients already know, or understand from their physicians’ disclosures. Awareness of one's prognosis has emerged as a crucial variable in guiding both doctor-patient communications, and understanding patient psychological functioning and decision making at the end of life. This study focuses on the development of a clinically useful tool for assessing prognostic awareness.

Study design: Individuals with advanced cancer (stage III and IV) were recruited for an ongoing study of meaning centered psychotherapy. Prognostic awareness was measured using a series of questions targeting patient understanding of the extent and (when accurate) terminal nature of their illness, their anticipated life expectancy, and their perception of available treatment options. Other variables measured in the current study included mood (measured by CES-D), depression, anxiety, hopelessness, and cognitive functioning.

Results: Data are not yet analyzed, but will focus on developing an integrated measures that encompasses three axes: a) accuracy of the patient perception of the severity/curability of their illness, b) awareness of their likely lifespan, and c) magnitude of any emotional or patient perceptions of a n end. Analyses will focus on the association of these three axes, both independently and when integrated into a single index, with other potential correlates (e.g., psychological distress, cognitive functioning).

Conclusions: This presentation will focus on the development of a clinically useful index of prognostic awareness utilizing data from a recently completed study of patients with advanced and/or terminal cancer.
Psychosocial Care in Hospices

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Identification of psychosocial problems and needs is an important aspect of palliative care, as emphasized in the definition of the World Health Organization. Many patients in the last stages of their life experience psychosocial problems. So far, little is known of the nature of these problems and the professional help that is actually given. We aimed to explore psychosocial problems and needs of patients admitted in hospices and the disciplines involved in psychosocial palliative care.

This study was performed in 4 hospices, and contained 2 parts. First, a selection was made of 80 patient admitted between May 2012-October 2012. All patient files were screened on psychosocial problems and needs and the professionals involved in psychosocial care. Afterwards the Distress Thermometer (DT) was introduced. In the second part, a selection was made of patient and care staff interviews. Ninety-nine (74%) patients (mean age 77 yrs, 48% male) were diagnosed on psychosocial problems in the first part of this study is performed; results are expected in December 2012. Part 2 of this study is conducted, results are expected in December 2013.

Methods: A total of 1062 healthcare workers (N=1062) were asked about their knowledge of the most fearful components helps to find the fear of conscious death, for which psychologists had the trend that emerged was that priests usually had the lowest total MFODS score (p<.001) and with all fear of death. In the second part of this study is conducted, results are expected in December 2013.

Conclusions: Nurse are most frequently involved in psychosocial palliative care for hospice patients. However, after introduction of the DT identification of more psychosocial problems and involvement of more disciplines in psychosocial hospice care is expected.

Abstract number: P1-379
Abstract type: Poster

Choose Profession and Fear of Death - It Has Connection?

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Research aims: The study examined the association between profession and fear of death. Knowing the attitude of healthcare workers towards death is very important, because their efficiency is associated with their fears. Our aim was to explore which attitudes related to death and dying arouse the strongest fear in participants and find out which training or other intervention will help the helpers to make death-related communication more open, decreasing inner anxiety and improving communicating with dying patients and relatives.

Methods: Our quantitative survey took place between 2006 and 2011 in Hungary. Physicians, medical staff, home care workers, and other healthcare workers, priests, psychologists, and non- healthcare workers (N=1062) were asked about their attitudes with regards to the Multidimensional Fear of Death Scale (Neymier & Moore 1994, Zana et al 2006).

Results: Profession was significantly associated with the total MFODS score (p<.001) and with all fear of death factors, with the only exception of the seventh factor expressing fear for the body after death. The only systemic factor that emerged was that priests usually had the lowest scores. A notable exception was the sixth factor measuring the fear of conscious death, for which psychologists had the lowest scores, but that was significantly less fear compared with psychologists and non-healthcare workers.

Conclusions: Fear of death seems rather to be present in professional groups, and the fear is connected with death and dying. Knowledge of the most fearful components helps to find targeted assistance in the work and the daily life, too.

Abstract number: P1-380
Abstract type: Poster

Recruiting Parents to Paediatric Palliative Care Research: Impact of Low Invitation Rates on Sample Bias

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Aim: Recruitment in paediatric palliative care is widely reported as challenging. Low rates of invitation by clinicians are common, but the impact this may have on sample bias is unknown. We aimed to explore this potential bias.

Methods: We studied recruitment to a qualitative interview study about parental decision making for children currently receiving palliative care. Clinicians (doctors and clinical nurse specialists) who are involved in palliative care (PC) team were encouraged to introduce the study to parents during routine contact (face-to-face or telephone) during a 9-month period. They were anonymous information from the PC team database to investigate differences between parents invited and not invited, and asked clinicians to provide their reasons for not inviting some parents. Results: 478 live patients were registered on the PC team database, and were eligible for recruitment unless participating in another psychological study. Clinicians invited the parents of 25 (5.2%) patients. There was no significant difference between parents invited and not invited in terms of demographic variables such as age and ethnicity (p>0.2), but the total family contact time and number of family visits by clinicians during this period was strongly associated with whether a family was invited (p<0.001). The most common reason clinicians gave for not inviting parents was little or no contact with them; others included reduced burden on parents and parents not engaging in communication with clinician.

Conclusion: There was no evidence of major demographic bias as a result of low invitation. However, the strong influence of family contact time may have introduced bias we were unable to measure (e.g. in relation to patient stability and parent- clinician relationships) and warrants further study. Invitation via letter or via additional sources, for example local teams with regular patient teams, might help to boost invitation rates and reduce potential bias. This work is internally funded.

Abstract number: P1-381
Abstract type: Poster

Research Methodology

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Background: Paternal care is personalized when individual experience and preferences influence the clinical decision-making process and delivery of care. While personalized care is needed to support individuals in the work of living with life-threatening illness, few studies report action research approaches to improve personalized care delivered in hospices.

Aims: To develop and to evaluate the impact of an advanced and personalized care model in an Italian hospice to improve patient centered care.

Methods: An action research project was being conducted over a 10-month period from June 2012 to April 2013 with a multidisciplinary hospice team in Italy. Mixed methods data collection strategies to assess the hospice care model are used including interviews, clinical observation and findings from the Frontrime attitude towards the dying (FACT-A2). Results are being produced by researchers to hospice staff members during focus groups to systematically work together in cycles of ‘looking, thinking, acting’ in order to change the way of working in the hospice.

Results: A synthesis of the most relevant results will be presented within the 13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013.

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The Feasibility of Recruiting People with Advanced Dementia into Research

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Abstract number: P-384

Aims: It can be challenging recruiting frail older people with advanced disease to research studies. We aimed to test a method of recruiting seriously ill people with advanced dementia during acute medical hospital admission.

Methods: A study of pain and behavioural symptoms in people with dementia. 

Results: The research took place in 2 large hospitals in the United Kingdom. Ninety-five patients aged ≥70 years with unplanned acute medical admission and a diagnosis of dementia DSMIV with sufficient English language to complete study ratings were eligible. Dementia severity was assessed using the Functional Assessment Staging Scale (FAST); 1= mild, 6= moderate and 7= above advanced. Researchers assessed patients' capacity to give informed consent within 72hrs of admission. For patients without capacity their main carer was approached to give assent.

Conclusions: Previous and current research has reported that studying disease trajectory and symptoms in people with advanced dementia is complex and difficult.

When Is Acceptable for Palliative Care Patients to Participate in Research? A Comparison of Patients’ and Professionals’ Views


Abstract number: P-385

Aims: There is a need for more robust evidence to guide clinical practice in palliative care, yet recruitment to clinical studies can be challenging. Gatekeeping by healthcare professionals is often cited as a cause of poor accrual, yet the reasons for this remain poorly understood. This study aims to identify the priorities of clinical studies that are most and least acceptable to palliative care professionals, and explore the differences between these groups.

Methods: A cross-sectional questionnaire survey in a convenience sample of patients and HCPs from three hospices in Kent, UK. Questionnaires were adapted from a previous Australian study, piloted and revised prior to use. We used the Mental Capacity Act to recruit acutely ill older people with advanced dementia, in an acute setting with a limited time frame. Consent was obtained from patients with capacity and their main carer when no capacity, under the MCA, the main carer was approached to give assent. In cases where no main carer was available, a doctor or healthcare professional was asked to give assent.

Results: Patients attending the interstitial lung disease clinic at a central region were invited to participate. A holistic needs assessment tool, the Sheffield Profile for Assessment and Referral to Care, was used. Patients’ notes were reviewed to identify referrals. The feasibility phase measures recruitment and retention rates in a small number of sites so that processes can be adjusted if rates are not as estimated. Low eligibility rates for the trial and increased risk of attrition because of illness or death require larger population size from which to recruit; this has implications for trial coordination and set up. Gaining NHS permissions in multiple Trusts and support in General Practice in the recruitment of NHS services further complicates trial set up.

Conclusion: Recruitment commenced in September 2012. We shall present recruitment, retention, follow up and attrition data from the feasibility phase. We shall report whether strategies to address the recruitment and retention challenges were successful.

Non-Cancer

Abstract number: P-387

Aims: Heart failure (HF) is a life limiting chronic disease associated with high symptom burden, 24.7% readmission rate and unpredictable trajectory; making palliative care (PC) interventions appropriate for HF patients. This study compares characteristics and outcomes of HF patients in a large urban, acute care hospital with an established PC program to identify patterns in palliative care consult (PCC) requests and triggers to indicate timely requests for PC involvement.

Methods: This is a retrospective review of hospital data on inpatients with a primary diagnosis of HF who died or enrolled in hospice in 2011 versus HF patients discharged to home, home health (HHS) or extended care facility (ECF) in the first 6 months of 2011 (matched on age and diagnosis to deceased and hospice discharged patients). Patients were compared by discharge and outcomes on demographics, inpatient characteristics, co-morbidities and readmissions. Cross-tabulations and t-tests were conducted in SPSS version 17.

Results: Of the 32 patients who died, 59% had a PCC; there were no significant differences between PCC patients and non-PCC patients on any study variables. Compared to patients discharged to home, HHS, or ECF, 
1) deceased and hospice patients had a longer mean hospital length of stay; 2) higher rates of acute renal failure and pneumonia (p<0.005), 2) patients who died had higher rates of acute respiratory failure (p<0.001), and 
3) patients who enrolled in hospice (N=15) had higher rates of dementia and debility (p<0.001). Patients discharged to a HHS (N=67) had the highest 30 day readmission rate (32%)

Conclusion: HF patients are referred to PC late in the disease process. Over 40% of inpatients with HF who die do not benefit from PC or hospice involvement. Earlier PC involvement may benefit patients with specific needs and those most at risk for acute organ failure by aggressive symptom management and prevention of re-admission. The study was hospital funded.

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collaboration and partnership working with specialist palliative care services would optimise management, and may provide patients and their families with greater opportunities to share decision-making, achieve their preferences for care, and achieving a better quality of death.

The study was funded by Collaborations for Leadership in Adult Health Research and Care (CLAHRC) for South Yorkshire.

Abstract number: P-390
Abstract type: Poster
Palliative Care Related Problems among Patients with Atypical Parkinson’s and Motor Neurone Disease (MND) Attending a Public Hospital in South Africa

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Background: Heart failure is a leading cause of death in sub-Saharan Africa. This study aimed to measure the patients’ reported affective care related problems among adult patients attending a public hospital with stage 3 or 4 NYHA heart failure.

Methods: Consecutive patients were recruited from emergency units, cardiology beds, general medicine beds and outpatient cardiology clinics. In addition to demographic, disease-oriented and service use data, patients gave responses to the APCA African Palliative Outcome Scale, a well-validated tool measuring the 3 day period of affective care related-problems.

Results: 98 patients participated (response rate 95%). Mean age 56 (SD 10.5) years, 72% (n=70) were male, only 16% (n=16) in paid employment. The majority (n=76, 77.5%) were recruited via emergency units. 54% (n=51) had at least one hospitalization in the previous 12 months, none had been referred to palliative care. The mean Karnofsky Performance Score was 50. With respect to item analysis, the worst problems were: a sense of being dead (53%); mean time from specialist clinic referral to death was 14 months for MND and 21 months for APD. There was some evidence of advance care planning in 62% (e.g. discussion of prognosis), however documentation of specific decisions for future care was present for 40% of APD and 36% of MND patients. Median time from first specialist clinic referral to death was 4 months by patient report (29 months). Preferred place of death was documented for 11 patients (38%). Specialist palliative care (SPC) referral was made in 17 cases (39%), a median of 4 months before death.

Conclusion: Evidence of specific decision-making regarding future care needs was present in less than 50% of cases. When carried out, better planning of palliative and advance care planning occurred late in the disease trajectory, a median of four months prior to death. In order to improve timeliness of future care planning and SPC referral, a joint neurology/palliative care group is working to raise awareness of indications for SPC referral and use of advance care planning tools. Audit standards have been set and will be measured against.

Abstract number: P-393
Abstract type: Poster
Developing European-wide Best Practice Guidelines and Core Standards for Palliative Care for People with Intellectual Disabilities

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Background: The EAPC Taskforce on palliative care for people with intellectual disabilities was launched in 2012. People with ID make up 2.5% of the population, with numbers rising every year. Those over 50 years old are the fastest growing sector of the ID population. Increasing numbers of people with ID are developing life-limiting illnesses that require palliative care. In many European countries people with ID live in the community and rely on mainstream services for health care. Meeting the growing palliative care needs of people with ID thus presents a major challenge. There are no data available around detailing where people with ID are cared for at the end of life, and when transforming the current system, it is important to grow but growing body of research which indicates that there are a range of issues affecting end of life and palliative care for people with ID.

Aims: To improve palliative and end of life care for people with ID by:
(1) identifying examples of good and promising practice across Europe;
(2) developing consensus guidelines and recommendations and
(3) publishing the good practice examples and consensus guidelines standards which are applicable and influential in Europe and beyond.

Methods: A Member Group, consisting of experts from different countries, has begun to draw up the initial guidelines and core standards, working mostly through electronic exchange of documents and comments. This will be distributed to a large group of 18 European countries, and feedback collected using the Delphi method. Simultaneously, we have invited the submission of examples of best practice.

Results: The guidelines/core standards will be refined and presented, along with a range of best practice examples from different countries.

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
Background: End-stage liver disease (ESLD) is an important cause of morbidity and mortality. It is the fifth largest cause of death in the European Union and rates of death are increasing in contrast to most other long-term conditions. Refractory ascites, (RA), characterised by unresponsiveness to diuretic therapy, is common in ESLD. RA is a life-threatening condition, which triggers frequent admissions to hospital for percutaneous drainage. Aims: to audit the use of PleurX® tunnelled peritoneal drainage catheters for RA in patients with ESLD reaching the end of life. Methods: Approval for use of PleurX® drainage in this patient group was obtained from the New Clinical Procedures Committee of King’s College Hospital, London and an audit of their use was registered. Audit outcomes collected included complication rate, hospital length of stay (LOS), number of days in situ before removal or death and complications. Results: Five drains were inserted in four patients. Three patients were male and the median age at insertion was 75y. LOS was 15 days. Drain insertion was 1d (1-8 days) and patients were discharged home (75%) or to a hospice (25%). The drain remained in situ for a median of 30d (20 - 50d) before removal or death. Those discharged home remained there for a median of 3d before death or admission to a hospice. Two patients died at home and two patients died in a hospice. Eight patients (50%) experienced complications; one patient required a second drain insertion following accidental removal and one patient required a drain insertion secondary to leakage at insertion site and non-fatal bacterial peritonitis. Conclusion: Indwelling peritoneal catheter insertion may facilitate dialysis by pleural drainage outside of the acute hospital in patients with end-stage liver disease and refractory ascites. Larger prospective study is warranted.

Abstract number: P1-396
Abstract type: Poster

The SPARC-Renal Tool - Development of a Holistic Needs Assessment Tool to Assess the Problems and Issues Caused by Chronic Kidney Disease Stage 5 (CKDS5)

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Aims: to develop a specific renal tool for use alongside the Sheffield Profile Assessment for Referral for Care (SPARC), a tool initially developed to assess palliative care needs in a cancer population which may be useful in supporting health professionals to assess the needs of frail and elderly renal patients. Methods: an exploratory qualitative research design with semi-structured interviews. Samples 85% were patients, 15% were family carers of patients with advanced progressive conditions recruited from these sites, 71% were family carers and 29% were medical staff. All patients and carers had a confirmed diagnosis of Chronic Kidney Disease Stage 5 (CKDS5), which was defined as Stage 5 disease with a glomerular filtration rate <15ml/min or on dialysis. Results: 33 interviews were conducted with patients and carers and 31 interviews were conducted with health professionals. The interviews were transcribed verbatim and coded using a deductive approach. Four main categories were identified: 1) clinical (4), 2) economic (1), 3) social (1), and 4) physical (1). Conclusion: the interviews highlighted the importance of interdisciplinary working across services, better recognition of the needs of this population, the need for further research to understand the needs of patients in the early stages of CKDS5 and the importance of palliative care to be discussed earlier for this group of patients.
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Abstract number: P1-401 Abstract type: Poster

Is There Room for Advance Care Planning at a Dialysis Ward? Van der Voort A.1, Hendel C.1, Vermandere M.3, Symons L.1, Weiss J.1, Van den Enden B.1

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Aim: Renal dialysis has a tremendous impact on a patient’s life and his environment, and recent evolution in dialysis techniques has failed to gap the life prolonging treatment with palliative care. Here, Advance Care Planning (ACP) seems even more important for renal dialysis patients. This study looked at how ACP for them could be organized and what possible barriers are.

Methodology: A systematic literature study formed the basis of qualitative research which used face-to-face interviews and a focus group of caregivers for data collection. Results: ACP is a dynamic process that should not be limited to administrative tasks, such as filling out forms. Key elements are: good communication, provision of information at various stages of the illness, and respect for the patient’s autonomy. The absence of these elements has a very important ‘signal’ function due to the trust relationship with the patient. However, the same relationship is often too short for detailed conversations. Other barriers are the lack of privacy at the ward and the limited time available to caregivers. There is also a lack of attention for the family because they are not allowed on the dialysis ward. The cooperation with general practitioner and home care team can much better. Furthermore, decisions are often discussed too late, and caregivers are not aware of the option of stopping the dialysis treatment which results in patients sometimes being dialyzed too long. Finally, it was agreed that one collective medical file accessible to all caregivers, and a regular well organised multidisciplinary team meeting would increase the quality of care.

Conclusion: It is recognized that there is a need for a joint vision of the entire dialysis team, support of this team by the medical doctors for more communication education and training. The first and most important step seems to be that all caregivers of the dialysis ward should realize the importance of ACP.

Palliative Care in the Elderly

Abstract number: P1-403 Abstract type: Poster

Nursing Home Resident’s Wishes for End-of-Life Decision-making - First Results

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Aim: The aim of the present study was to investigate Norwegian nursing home residents’ wishes for end-of-life decision-making.

Methods: Qualitative study with semi-structured interviews of nursing home residents. An interview setting with structured questioning and open interviewing was used. So far 11 interviews of patients who have been included in the study were reviewed and analyzed. Only participants with the ability to formulate and consent were included in the study due to ethical reasons. All interviews were recorded and transcribed verbatim by the researcher himself. Results from the interviews were compared to findings from a literature review.

Results: So far 11 nursing home residents were included in the study by nursing home staff. Their age was between 74-100 years. One participant had to be excluded by the researcher because of cognitive impairment. The interview duration varied from 12-47 minutes.

Important themes and points of view brought up by the participants were about: Absence of Advance Care Planning in nursing homes - treatment of pain and other symptoms at the end-of-life Decision-making by relatives: “They know” Problems with ACP: residence, forms, time constraints, communication. Residents attitude towards planning their end-of-life

Conclusion: Our first results show that Advance Care Planning is absent in Norwegian nursing homes. Most residents want their relatives to make decisions for them if they become incapable to decide for themselves. Some residents are reluctant to plan their end-of-life. As the study is ongoing, further interviews will help to question our first results and to enrich the knowledge on the residents view on end-of-life decision-making in nursing homes. This project has been financed with the aid of EXTRA funds from the Norwegian Foundation for Health and Rehabilitation.

Palliative Care for Frail, Older People: Action Points from a Qualitative Study

Abstract number: P1-404 Abstract type: Poster

Establishing a Method to Identify Older Patients with Palliative Care Needs in the Community

Murphy S.1,2,3, Lynch M.4, Murphy S.1,2,3, Lynch M.4


Research aims: The main objective was to determine existing methods or tools in use in other jurisdictions that could be applied to the Irish national system to support the identification of patients with palliative care needs in general care settings in the community. A significant number of these patients are not included into the category of older people whose quality of life would be greatly improved by the application of a palliative care approach. Increasing population ageing as well as increased prevalence of co-morbidities in older people means that it is particularly important that they do not go undetected in the current healthcare system.

Study design and methods: A number of potential tools were identified based on review of literature, emerging practice internationally, as well as current activity in Ireland. The need for a tool to be relevant for all diseases, applicable in a general community setting and have emphasis on palliative need throughout the older patient’s journey were key criteria.

Results: The Supportive and Palliative Care Indicators Tool (SPICT) tool was identified as the relevant existing tool that will support GPs and primary care teams identify older patients who have palliative care needs due to the fact that it was user friendly and designed to be used in all settings, including the community. SPICT acknowledges the significance of co-morbidities for older people and includes clinical indicators for cancer, dementia, and frailty, as well as liver, respiratory, kidney, cardiovascular and neurological disorders.

Conclusion: Further work is required to determine how SPICT will apply to Irish Health systems, and it is planned to pilot this tool in primary care. This pilot stage will be an evaluation that will determine the benefit of the tool for the identification of the palliative needs of older patient.

Palliative Care for Frail, Older People: Action Points from a Qualitative Study

Abstract number: P1-405 Abstract type: Poster

Where Do We Start with the Improvement of Care for Frail, Older People: Action Points from the Dignity Network Group

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Aim: European governments are now preparing for the predicted increase of care needs at the end of life. Meanwhile, quality of care for frail, older people remains poor in practice. We aimed to identify priority areas for the improvement of care for frail, older people and the actions required to achieve this.

Methods: An international meeting was organized and participants were selected from an expert network of care for frail, older people. The workshop consisted of presentations on priorities from multiple country and disciplinary perspectives with a focus on Europe, and structured group discussions. Analysis applied standard qualitative techniques.

Results: The workshop comprised 20 participants from 9 countries in Europe and Ireland. They identified priority areas of:

1. A conceptual level: a. raising awareness to the importance of quality care for older people, and recognizing staff’s competence, b. developing new care models based on systematic evidence and accurate definitions.

2. A practical level: a. providing care with special attention to quality and patient’s needs, support for care workers, and reduced regulations; b. facilitating living conditions with available medical provisions in place, avoidance of transfer, personal care, regard for families and expertise of care for the dying.

They identified mechanisms to increase quality care through structural changes requiring education to raise the level of expertise in caring for older people, and communication between the different parties involved (public, policy-makers, family, staff and family).

Conclusions: This meeting identified the limits of current care practices in long term care and explored the potential for change. Collaborative initiatives between policy, practice and research were planned to realize the conceptual changes which are the driving force to raise societal awareness and achieve changes in the daily care for older people.

Funding source: Dignity Centre Bergen and Austran Red Cross

Significance of Smell and Taste across the Course of Life - Implications for Palliative and Hospice Care

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Background: Smell and taste contribute to the whole course of life and affect the essential human functions of eating and breathing. Due to an increasing prevalence of changes of these senses caused by aging and incurable diseases, it is necessary to clarify their subjective significance to patients in palliative and hospice care.

Methods: A three step approach was performed. (1) A systematic literature review on smell and taste in elderly was followed by a (2) qualitative experiment in which fourteen visitors of senior-groups gave feedback on selected smell and taste samples. The reminiscences of smells and tastes were audio-taped, transcribed and analyzed using a qualitative hermeneutic research approach and qualitative content analysis. Subsequently a (3) review of literature contextualised findings into palliative care.
Elderly Patients with Advanced Heart Failure in Germany: A Qualitative Longitudinal Study on the Patients’ Needs and Experiences

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Aims: Heart failure is a major cause of death in Germany and worldwide. In advanced stages it is associated with a high symptom burden and poor long term prognosis. This study aimed to: 1) understand the experiences and needs of elderly patients with advanced heart failure;

Methods: Qualitative longitudinal study with 25 patients with advanced heart failure (NYHA IV), aged ≥70 years. Initial interviews were carried out during hospital admission followed by interviews at the patients’ home every 3 months for up to 18 months. Interviews were tape-recorded and transcribed verbatim. Qualitative content analysis was conducted across and within the cases.

Results: The mean age of the patients (14 female, 11 male) was 85 years (71–98 years). Overall 95 interviews were carried out. Qualitative analyses show that the patients do not focus heart failure as a genuine disease. Moreover, discourses due to acute cross or overlapping disease area central, as well as age related health problems which progressively increase the activities of daily living. The salient loss of the mental/spiritual body image and autonomy matters most. Open questions about emerging needs of support or end of life issues are recurrent. A need for information and dialogue varies depending on changing conditions and individual preferences, a relevant person (e.g. family carer, family doctor) needed to be available to address these issues is highly appreciated.

Conclusion: The needs of elderly patients with advanced heart failure are various and exceed the capabilities of the patients’ needs and experiences. Advanced care a multidimensional model is required which should be considered in clinical practice and further research.

Poster abstract number: P-407
Poster abstract type: P

Elderly Patients with Advanced Heart Failure in Germany: A Qualitative Longitudinal Study on the Patients’ Needs and Experiences

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Conclusion: The needs of elderly patients with advanced heart failure are various and exceed the capabilities of the patients’ needs and experiences. Advanced care a multidimensional model is required which should be considered in clinical practice and further research.

Poster abstract number: P-407
Poster abstract type: P
in nursing homes. Moreover, most of the studies published rely solely on self-reports of physicians’ practices. Therefore, we wanted to investigate CSD from both the perspective of the treating physicians and the patients. Methods: All high-care nursing homes in Flanders were included in this study (N = 66). Both the coordinating and advice physicians, as well as the palliative care nurse of each nursing home, received a questionnaire containing questions about their current practice. The survey was delivered by e-mail and followed up by telephone if no reply had most recently treated with CSD if applicable. The questions addressed patients’ characteristics, the indication for administering CSD, the decision-making process, and (clinical) aspects of the course of CSD. The anonymity of the responders was guaranteed through a careful mailing procedure, involving a lawyer as an independent party between respondents and researchers. Results: The general response rate was 72.0% (467 nursing homes). Of these, 1315 questionnaires were filled in by palliative care nurses (84.7%), 380 from coordinators and advising physicians (53.5%), Care homes by 247 nurses (57.3%) and 163 physicians (41.1%). Further results will be presented as the analysis proceeds. Discussion: This is the first study to investigate the practice of CSD in nursing homes from both physicians’ as well as nurses’ perspectives on a nationwide level. The extensive and representative data provide a solid basis to evaluate the actual practice of CSD in nursing homes in Flanders. Funding: Fund for Scientific Research, Flanders, Belgium

Poster sessions

Abstract number: P1-413 Abstract type: Poster

Advance Care Planning in Care Homes - It Works!
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Context: Advance Care planning is a key part of improving end of life care, especially for the elderly in care homes. Advance Care Planning has been introduced as an integral part of The Gold Standards Framework (GSF) Care Homes Training Programme in end of life care to over 2000 care homes in the UK over the last 8 years. The standard for GSF accreditation ensures that every resident is offered an ACP discussion. The GSFCH training programme is a comprehensive phased programme which includes many aspects of end of life care, with over 300 care homes having attained full accreditation.

Methods: A feedback survey of GSF accredited homes was undertaken.

Results: Results showed:
- An increase from minimal use of ACP in care homes to over 90% use.
- Advance Care Planning contributed to an increase in home deaths from 68% to 98%.
- Improved communication skills, and contributed to a culture of openness and realisation.
- A greater involvement in care home staff and use of ACP as a standard part of their care.
- Some additional benefits such as writing of ACP booklet, early discussions with families.
- A very positive feedback as to the value of ACP and few reported difficulties.

Conclusions: The GSFCH Training Programmes, Advance Care Planning in Care Homes was not widespread; some care homes have demonstrated their standards of care and ACP uptake - not just standard practice but enhanced practice - ensuring consistency and continuity.

Abstract number: P1-415 Abstract type: Poster

Care at the End of Life of the Geriatric Patient: Comparison between the Acute Geriatric Unit and the Palliative Care Unit
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Aims: To map the Quality of Care(QoC) at the end of life of the geriatric patient using relevant Quality Indicators(QIs).

The QoC was assessed both at the Acute Geriatric Unit(AGU) and at the Palliative Care Unit(PCU) of a university hospital in Belgium to identify bottlenecks in the care and to compare QoC between both departments.

Methods: The QoC was measured in a retrospective case study by using a set of QIs, collected through systematic literature research and validated via the Delphi method. The target population consisted of patients older than 75 years who had a Do Not Resuscitate(DNR) status and deceased between January 1-2009 and December 31-2010 at the AGU and the PCU and who were hospitalized more than 48 hours.
The Pearson’s Chi Square test was used to determine the presence of significant differences between the scores of both departments.

Results: A set of 17 QIs was composed. The QIs were related to the principal domains of palliative care. In total, 58 patients were included at the AGU(90 QI-score generally varying between 0 and 70%) and 59 at the PCU(QI-score generally varying between 50 and 100%). The PCU scored significantly higher on 7 QIs, particularly with regard to pain screening, oral care and anxiety screening(all p<.01), prescription of rescue medication(<.01) and pain treatment(<.05). Both care units scored low with regard to delirium screening, spiritual care and the involvement of the general practitioner(GP) in the care planning.

Conclusion: This study revealed that the palliative standard of care at both care units could be further optimized. Both departments should perform more delirium screening, should have more attention for the spiritual needs of the patient and should involve the GP of the patient more often in the care planning. For the AGU it is recommended that, if a patient has a diagnosis of palliative illness concerning pain, oral care and anxiety screening should be routinely added to the patient’s record.

Palliative Care in Children and Adolescents

Abstract number: P1-416 Abstract type: Poster

Quality of Pediatric Palliative Care in Lebanon - The Perspectives of Children with Cancer
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Aims: The purpose of this study was to evaluate the quality of life (QoL) and symptom management in Lebanese pediatric oncology patients from their own perspectives.

Design and methods: The design is cross-sectional and descriptive. The Pediatric Quality of Life Inventory (PedsQL) cancer module, and the Memorial Symptom Assessment Scale (MSAS) were administered in Arabic to a convenient sample of pediatric cancer patients over a one year period.

Results: A total of 85 patients, mean age 12.5 years, participated in the study; majority came from outpatient clinics. Blood cancer was the most common cancer type with a higher prevalence among the younger age group (7-12 years). Nausea and worry had the lowest scores on the PedsQL, indicating poor performance. Fatigue and anxiety was the highest. A comparison based on age showed significant differences in pain and hurt, nausea, cognitive problems, and global health status/quality of life (GS/QoL). In children (7-12 years), the most prevalent symptoms were lack of appetite, pain, and nausea while adolescents (13-19 years) experienced greater difficulty of energy, irritability, and pain. Most treated symptoms in both groups were pain and nausea. The strongest positive correlation (r=0.51) was found between pain and hurt and GS/QoL.

Conclusion: The study group had good performance on the PedsQL subscales except for pain and hurt, nausea, worry, and fatigue. The study group had poor performance on the MSAS subscales except for fatigue and anxiety and GS/QoL. The reduction of inappropriate crisis hospital admissions and the increase in hospice admission ensure the standards for quality end of life care are maintained. A review of the current protocol for the reduction of inappropriate hospitalization is required.

Source of funding: Lebanese National Council for Scientific Research
Every child, no matter what their illness or diagnosis, has the right to play and the right need to develop to their optimal potential. Ensuring their participation in Early Childhood Palliative Care (ECP) programmes is an essential part of children’s palliative care in Africa.

For the healthy child, developing physically, cognitively, emotionally and socially requires effort and exercise for the smooth transition to the next developmental stage. Consequently, Palliative Care for life limiting conditions who must develop alongside his or her well peers. This child faces all the challenges of a life-threatening illness in addition to growing and developing. Illness and disease affect children's development for the ill child and often for the siblings as well. This effect differs from age to age but is always a psychological response to this need. We approach was the Hospice Palliative Care Association of South Africa to lead a Task Team to develop guidelines in Early Childhood Palliative Care (ECP). The focus of the project addressed the hospital services who care for young children and for patients with young children. The project will cover:

• The effect of illness on childhood development
• Assessing the need for the ECP guidelines
• Choosing the optimal team to develop these guidelines
• The process of developing the guidelines
• The topics covered
• The future of the product
• The dissemination of this information for use by other African and developing countries through the ICPCN

Abstract number: P1-419
Abstract type: Poster

Use of Opioids in a Paediatric Inpatient Population

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Aims: Guidelines suggest that morphine, oxycodone or hydromorphone are all appropriate first-line opioids. Every patient on opioids should have doses prescribed as required (96% in 24 hour continuous and aspirin required constipation is a common and bothersome side effect, all patients prescribed opioids should be on regular laxatives. We reviewed the use of opioids in a paediatric inpatient population to assess compliance with these guidelines.

Methods: A cross-section of 73 charts was examined from 6 wards over a 4 month period. We identified the prescription using the ward based Misuse of Drugs Act (MDA) records. Hospital records were reviewed and the first opioid prescription for each patient recorded. Demographic information for each patient and their analgesic prescriptions were documented.

Results: A majority of patients were commenced on morphine preparations including 39 commenced on Morphin (54.2%), 26 on Morphine Sulphate intravenous infusion (36.1%), 3 on Sevodal (4.2%) and 1 (1.4%) on MST. One patient (1.4%) was started on each of Oxycodeone intravenous and Oral Oxynorm and Fentanyl intravenous infusion.

Most patients were prescribed other analgesics in addition to the opioid with 56 (77.8%) on a step II drug and 41 (56.9%) on a step III drug and 20 (27.8%) on an adjuvant analgesic.

97% (57 patients) had a medication prescribed PRN. Only 54.2% (39 patients) were prescribed a laxative on commencing opioids.

Most patients (86%) were not referred to either the acute pain or palliative care teams. Conclusion: Our Lady’s Children's Hospital treats many patients who require pain management. The hospital benefits from clinical nurse specialists in acute pain management and palliative care in addition to a paediatric palliative care team. Our results show that pain management guidelines are not being followed in all cases. More education is required for staff to manage paediatric pain appropriately.

Abstract number: P1-420
Abstract type: Poster

Multiple Losses in HIV Positive Children: Interprofessional Palliative Care Makes a Difference

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Background: Martha (10) and her brother Richard (8) stayed with their grandmother (72) in Lesotho after their mother died three years ago of HIV. Both were happy and attended school. Martha was ill for a while and one day when she arrived from school she found her grandmother dead in their hut. Her father’s family came to fetch them and took them to Bloemfontein in South Africa.

Three weeks after the funeral her aunt brought the children to hospital as they were severely malnourished, short of breath and dehydrated. Richard passed away an hour after they arrived at hospital. The diagnosis of pulmonary tuberculosis, severe dehydration and stage III HIV disease was made and treatment started. The next morning she became acutely psychotic, with auditory and visual hallucinations.

Discussion: Previously she lost her mother, her home and her school. Then she lost her grandmother, her friends, her community and then her brother, her health and her mind. Her psychosis resolved on antipsychotic and psychotherapy; her medical condition was managed with intravenous fluid and IVF treatment; and her nutrition improved after she was admitted to the paediatric hospice. She was reunited with her father’s family. She was given Grade VI exams as the top student in her class in 2009.

Lessons learned: Martha experienced multiple losses on all levels according to Bowlby’s Needs Triangle, from basics like things, housing and family and friends to health, confidence and spontaneity. These losses included the body, mind and spirit. Different members of the multidisciplinary team played an important role in her recovery - children are very resilient and flourish on love and security.

Conclusion: A multi-disciplinary approach to manage each child as an individual, and give them lots of love and encouragement.

Abstract number: P1-421
Abstract type: Poster

Learning from the First Two Years of Using an Advanced Care Planning Document

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Introduction: In 2010, our Health Authority introduced a unified Advance Care Plan (ACP) for children and their parents/caregivers, providing a framework both for discussing and documenting their agreed wishes. This tool includes: A do not attempt resuscitation, an agreed plan of action to follow when a patient’s condition deteriorates, a record of families wishes for place of care, and for other choices during life and after death.

Aims: To evaluate the advance care planning tool two years after its implementation, identify levers and barriers to recording preferences and share the learning acquired from implementing this tool.

Methods: Quantitative retrospective review of all ACPS made since the introduction of the new tool (2 year period), within our specialist children’s hospice, examining; chosen place of care, disease category, and an analysis of the notes of deceased children to assess the impact of the ACP on attaining family’s preferred place of care.

Results: A total of 62 ACPS were completed (approach 1/3 of case load). Of these 27% died at home, 53% in a children’s hospice, and only 20% in hospital. Thus our rate of death outside of the acute hospital was 88%. This is in contrast to the data identified by Craft and Killen (2007) where 74% of children died in hospital.

Discussion: We evaluated the value of ACPS in enabling families to make informed choices about end of life care. The ACP has been well used and has contributed to an ‘out of hospital’ death in children above quoted national averages. Also we identified that levers leading to good planning include having a disease for which the management is exclusively palliative from diagnosis or a clear deterioration in a condition for which treatment was previously available (eg relapsed oncology patients). Children with a less predictable course, such as with a static or neurological condition were much less likely to have much evidence of good planning, despite being very vulnerable.

Abstract number: P1-422
Abstract type: Poster

Review of Referral Patterns to a Children’s Palliative Care Service before and after the Appointment of a Paediatrician with a Special Interest in Palliative Medicine

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Aims: To examine medical notes of babies referred in a 12 month period (October 2011 to September 2012) and extract the data reported below.

Results:

1. Principals of life-limiting diagnosis of the patients referred Congenital organ abnormalities with no chromosomal abnormalities 13 (33%)
Chromosomal abnormalities: 10 (25%)
Hypoxic ischaemic encephalopathy or cerebral infarct 7 (18%)
Cerebral palsy 4 (10%)
Other 5 (3%) extreme prematurity, congenital diaphragmatic, epileptic encephalopathy, meningitis.
2. Referral rates: Number of referrals per specialist PC team in the 1 year period 39. 2 babies were antenatally referred with confirmed chromosomal abnormalities
3. Number of babies who died on the neonatal unit: 12 (31%)
11 families elected to remain in hospital
1 baby died before she could be discharged
4. Number of babies died after discharge: 13 (33%) Their place of death: Home 6, Hospice 5
5. Of note, of the babies discharged from the neonatal unit, only 2 subsequently died in hospital.
6. Time taken to discharge following referral: Median 3 days, range same day to 28 days.
7. Time spent out of hospital prior to death: Median 17 days, range: 1 day to 82 days.
8. Number of babies still alive: 14 (36%) 1 still an inpatient on the neonatal unit 13 have been discharged.
9. Time taken to discharge after referral to the PC team: Median 28 days, range: same day to 159 days.
10. Conclusions: A specialist PC service can help facilitate rapid discharge and gives parents real options in deciding their preferred place of care and death for their baby.

Abstract number: P1-424
Abstract type: Poster
Paediatric palliative care (PCC) figures in every paediatrician’s daily practice. During its provision, paediatricians may experience both distress and satisfaction with the care provided. This phenomenological study explores Maltese paediatricians’ (MPs) experience of PCC. It elucidates how Maltese paediatricians (MPs) define PCC, identifies any difficulties encountered during paediatric palliative care provision, and the interventions that may aide them to optimize their provision of PCC.

In-depth, face-to-face, semi-structured interviews were carried out with 11 MPs from a Maltese institution. The transcripts were then analysed using inductive phenomenological analysis. This analysis, apart from MPs’ construct of PCC, resulted in three main emergent themes: ‘struggling’ emotional responses and ‘responding to needs’.

MPs feel that PCC aims at improving the quality of life of children suffering from cancer and living with a potentially fatal illness. It should be instituted at diagnosis of the illness, irrespective of the outcome and involves interprofessional, holistic care. MPs believe that PCC includes an intense symptom reporting, and will therefore routinely call the emergency service to avoid an unscheduled transfer, which is perceived as a personal support mechanism and to enhance quality of care.

The burden of cancer-related symptoms among patients undergoing cancer care is a key factor in palliative care provision. In the UK, many Intensive Care Unit (ICU) deaths occur after planned withdrawal of life-sustaining ventilation (WLSV) when continued treatment was not in patients best interest. As timing of WLSV can be identified, this study aimed to explore the feasibility of offering choice in place of extubation.

Methods: A total of 10 interviews with experts in the care of severely ill children were conducted. Personal interviews were carried out with 11 MPs from a Maltese institution. The interviews were evaluated using qualitative content analysis, and categories produced were standardised in the care of severely ill children and adolescents. The interviews were evaluated using qualitative content analysis, and categories were standardised in the care of severely ill children and adolescents.

Context: The burden of cancer-related symptoms among patients undergoing cancer care is an outpatient cancer rehabilitation clinic. The main outcome measures were Edmonton Symptom Assessment Scale (ESAS) used during outpatient care, medication lists, and clinic notes.

Results: Patients’ median age was 55 years (range, 15–93y), and 52% (103/200) were female. According to a mean ESAS visual analog scale score ± standard deviation, the most intense symptom reported during outpatient rehabilitation clinic was fatigue (4.13 ± 2.84), followed by sleep disruption (3.52 ± 2.96), pain (3.29 ± 2.93), and depression (3.09 ± 3.03). The most common problems noted were appetite (3.09 ± 3.03), depression, or shortness of breath were significantly associated with the patient’s distress, and will therefore routinely call the emergency service to assist them.

Conclusion: We found significant symptom burden in cancer patients during their visit to the outpatient rehabilitation clinic. Although the pharmacist’s primary role is to diagnose and treat, the problem of symptom severity in this population is also important and needed in this cancer patient population.

Abstract number: P1-426
Abstract type: Poster

The Spectrum of Symptoms and its Phase Management in Children with an Incurable Brain Tumor; Insight in the Palliative Phase

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Introduction: CNS tumors involve 25% of pediatric oncology patients leading to death in 30%. The aim of this study is to gain insight in the management of the patients who extend of symptoms during the palliative phase, their treatment, and what course can be expected.

Methods: We retrospected reviewed all medical charts of patients from the Emma Children’s Hospital who died of a brain tumor between May 2005 and September 2012.

Results: 34 children with a brain tumor (medulloblastoma/SPNET, ependymoma 4, ATRT 5, pontine glioma 5, glioblastoma multiforme 7, other) aged 0-17 years were included. After 0-2480 days from diagnosis (median 168) inapactus diagnosis was evident with death following after 1-603 (median 68 days).

Palliative anticancer treatment was given in 66%, comprising chemotherapy solely in 11% (32), and radiotherapy solely in 51% (51) patients, while 6 (18%) received a combination of both. Symptoms were categorized in 17 groups of which most frequently occurring were pain 79%, reduced mobility 74%, change of appearance and disturbed cognition both 62%, dyspnea 55%, decreased appetite 52%, nausea/vomiting 47%, sedation 44%, sleep disturbance 36%. Pain 33%, dyspnea, and sedation are prominent symptoms in these patients.

Conclusions: A diversity of symptoms occurred during the palliative phase of a brain tumor necessitating intensive symptom management, mostly conducted at home. This knowledge enables advanced palliative care planning and helps to prepare parents and professionals to optimize palliative care.

Abstract number: P1-427
Abstract type: Poster

Withdrawing Ventilatory Support in Children and Young People, Outside the Intensive Care Unit – Is this a Feasible Option?

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Aims: Offering choice in place of end of life care is a key factor in palliative care. This is particularly pertinent in the UK, many Intensive Care Unit (ICU) deaths occur after planned withdrawal of life-sustaining ventilation (WLSV) when continued treatment was not in patients best interests. As timing of WLSV can be identified, this study aimed to explore the feasibility of offering choice in place of extubation.

Methods: A total of 10 interviews were conducted out of the material. In-depth, face-to-face, semi-structured interviews with experts in the care of severely ill children were conducted. Personal interviews were carried out with 11 MPs from a Maltese institution. The interviews were evaluated using qualitative content analysis, and categories produced were standardised in the care of severely ill children and adolescents. The interviews were evaluated using qualitative content analysis, and categories were standardised in the care of severely ill children and adolescents.

Context: We found significant symptom burden in cancer patients during their visit to the outpatient rehabilitation clinic. Although the pharmacist’s primary role is to diagnose and treat, the problem of symptom severity in this population is also important and needed in this cancer patient population.

Results: 34 children with a brain tumor (medulloblastoma/SPNET, ependymoma 4, ATRT 5, pontine glioma 5, glioblastoma multiforme 7, other) aged 0-17 years were included. After 0-2480 days from diagnosis (median 168) inapactus diagnosis was evident with death following after 1-603 (median 68 days).

Palliative anticancer treatment was given in 66%, comprising chemotherapy solely in 11% (32), and radiotherapy solely in 51% (51) patients, while 6 (18%) received a combination of both. Symptoms were categorized in 17 groups of which most frequently occurring were pain 79%, reduced mobility 74%, change of appearance and disturbed cognition both 62%, dyspnea 55%, decreased appetite 52%, nausea/vomiting 47%, sedation 44%, sleep disturbance 36%. Pain 33%, dyspnea, and sedation are prominent symptoms in these patients.

Conclusions: A diversity of symptoms occurred during the palliative phase of a brain tumor necessitating intensive symptom management, mostly conducted at home. This knowledge enables advanced palliative care planning and helps to prepare parents and professionals to optimize palliative care.

Abstract number: P1-427
Abstract type: Poster

Advance Care Planning in Pediatrics: The Care Providers’ Perspective

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Background and aims: Advance care planning (ACP) is increasingly regarded as the preferred approach to care planning in patients with life-limiting illnesses. Research has focused on adults, but ACP is also being practiced in pediatrics (pACP). Health care providers may have to deal with unknown diagnoses and prognoses, patients without decision making capacity and a complex social network. However, research on pACP has widely neglected the professionals’ perspective. Our aim was to investigate the experiences and needs of both the facilitators and the recipients of pACP.

Methods: We conducted 16 semi-structured personal interviews with experts in the care of severely ill children and adolescents. Interviews were from different professions, settings and institutions. The interviews were evaluated using qualitative content analysis, and categories were constructed out of the material. Results: pACP is perceived as important by all care providers. Important pACP-elements are: Repeated discussions with the parents, clarifying the treatment preferences for emergency situations in advance, and better cooperation of clinicians with non-medical care providers in the community. An advance directive (AD) should be individualized, completed with a physician, a professional and validated by his signature (shared decision making). Conflicts may arise between intensive care physicians and social-educational care providers or professional and validated by his signature (shared decision making). Conflicts may arise between intensive care physicians and social-educational care providers or professional and validated by his signature (shared decision making). Conflicts may arise between intensive care physicians and social-educational care providers or professional and validated by his signature (shared decision making).

Conclusions: This is the first European study that investigates
A Diploma in Children’s Palliative Care has been developed and is waiting for final accreditation. This will be available for all East African countries.

Training was essential for those institutions in each country. Advocacy has increased awareness in their countries.

The Beacon centre organisations have included services for children in their long-term strategies.

Support from management and involvement of the national palliative care association was essential for success.

Students identified communication skills and pain management as most important. Play and early childhood development were identified as new knowledge by many.

Conclusion: Developing the 3 Beacon centres has strengthened services to children in the Sub-Saharan region through sharing of lessons learned and education.

Abstract number: P1-432

Abstract type: Poster

The Course of Decision-making Regarding Ventilator Support in Families with Spinal Muscular Atrophy Type 1 and Respiratory Failure

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Introduction: Spinal muscular atrophy type 1 (SMA 1) is an inherited neurodegenerative disease presenting in the first year of life. Without ventilator support death occurs within the first two years. A recent treatment may change the majority of children die in early childhood. There are regional differences in physician recommendation for ventilator therapy. However, family supportive, non-invasive ventilation (NIV) to traheotoomy and mechanical ventilation.

Material and methods: We retrospectively analyzed the courses of decision-making regarding respiratory therapy in nine infants with SMA 1. Our Pediatric palliative care team (PCT) cared for them between January 2009 and December 2012.

Conclusion: Discussions about decision making regarding respiratory care were analyzed on the basis of the PCT documentary charts.

Results: In their first year of life 5/9 patients (pt) died, in their third year 3/9 pt and in 1/9 pt is still alive at the age of 18 months without ventilation therapy. n=5/9 had NIV (died in the mean age of 24 months), n=6/9 had ventilator (two pt died suddenly at a mean age of 4 months, three pt died at a mean age of 6 months).

In this cohort no family decided on tracheotomy. In all nine families the discussions about ventilation options were primarily lead by the physicians of the PCT. It was always an ongoing process with recurrent discussions. The physicians however had to rely on a decision made by the PCT and the PCT always supported the choice of the families.

Conclusion: Physicians of a PCT looking after children with SMA 1 should be familiar with all issues regarding respiratory support. Care options should be presented in an open and balanced way. The decision making process should start as early as possible in the course of the disease and may last until the end of care. The physician should accept either decision of the family particular as no international guidelines exist regarding ventilation support in children with SMA 1 so far.

Abstract number: P1-433

Abstract type: Poster

Challenges in Provision of Pediatric Palliative Care in a Developing Country (Kenya)

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Palliative care has fully been integrated into existing health services yet there are pediatric patients who would benefit tremendously from it. Health workers site lack of knowledge and skills, staff shortage and lack of proper equipment and drugs to care for these patients.

5 rural hospitals will be reviewed with an aim of uncovering the bottlenecks to the provision of pediatric palliative care services. It is hoped that this review will enlighten the administration and service providers on the challenges facing them. The solutions will provide the framework of palliative pediatric care services.

Abstract number: P1-434

Abstract type: Poster

Think Ahead as Self-advocacy Tool for the Public in Discussing and Recording their Preferences around End of Life

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Research aims: Think Ahead is the flagship project of the Forum on End of Life in Ireland. Think Ahead is also a public awareness initiative and empowers people to become self-advocates in their care.

A number of pilots were carried out with the aim of gauging public responses to Think Ahead and what might prompt people to participate with the project, as well as engaging the medical and legal professions and community leaders that people may choose to assist them in having important discussions.

Study design and methods: A wide range of consultation processes have been engaged in, including focus groups with the public, as well as a baseline survey and consultations with stakeholders from representative medical and legal organisations, NGOs, and statutory bodies. Respondents to a survey in 2010 said that they would be interested in availing of a service like Think Ahead and the forum and partners saw this as a suitable level of interest.

Participants and Recruitment: The project has identified the effectiveness of public awareness initiatives. It is hoped that this review will enlighten the administration and service providers on the challenges facing them.

Conclusion: Further work is required to fully evaluate Think Ahead as a tool for people to become self-advocates but these findings show significant potential in the area of public empowerment.
Pain Relief in Armenia

The Advocacy Campaign for Access to Adequate Palliative Care: Sharing Lessons on Influencing Global, Regional and National Advocacy on Palliative Care

Shapoval-Deinega K.

Methods: Organisations have worked together to influence the decision making to ensure the inclusion of palliative care within the global discussion on Non-Communicable Diseases. Achievements include the inclusion of the draft monitoring and evaluation framework on NCDs. Conclusion: Palliative care has to date been well included within the global discussion on Non-Communicable Diseases but there have been challenges along the way. Collaboration, consultation and consensus building are key components of successful advocacy at all levels but may also bring challenges. To ensure success, palliative care organisations need to work together, as well as to build coalitions with non-palliative care specific alliances.

Abstract number: P1-437
Abstract type: Poster

The Advocacy Campaign for Access to Adequate Pain Relief in Armenia

Movsanyan N.

Background: According to international human rights law, countries have to provide pain treatment medications for patients suffering from chronic and life-threatening diseases. Treatment obligations under the right to health failure to take reasonable steps to ensure that people who suffer pain have access to adequate pain treatment may result in human rights violations. Conclusion: In Armenia, 70-80% of patients need pain relief and still about 200 of them are treated improperly. Results: Over 3000 people need daily palliative care in Armenia,7 80% of them die in the hospital or at home without providing them access to opioids. Although the oral morphine is the gold standard for palliative care, in Armenia it is still a very new concept and not available to patients. Methods: As a part of a national study, we observed and documented among the patients living at homes, in rural regions, at a considerable distance from district health-care facilities. The interviews were conducted in Mar 2010 - Nov 2012.

Abstract number: P1-438
Abstract type: Poster

Pain Relief in Armenia: The Advocacy Campaign for Access to Adequate Pain Relief in Armenia

Shapoval-Deinega K.

Background: According to international human rights law, countries have to provide pain treatment medications for patients suffering from chronic and life-threatening diseases. Treatment obligations under the right to health failure to take reasonable steps to ensure that people who suffer pain have access to adequate pain treatment may result in human rights violations. Conclusion: In Armenia, 70-80% of patients need pain relief and still about 200 of them are treated improperly. Results: Over 3000 people need daily palliative care in Armenia, 70-80% of them die in the hospital or at home without providing them access to opioids. Although the oral morphine is the gold standard for palliative care, in Armenia it is still a very new concept and not available to patients. Methods: As a part of a national study, we observed and documented among the patients living at homes, in rural regions, at a considerable distance from district health-care facilities. The interviews were conducted in Mar 2010 - Nov 2012.

Abstract number: P1-437
Abstract type: Poster

Hospice Patients’ and Caregivers’ Perspectives on Spiritual Concerns

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Aim: Hospice providers must assess and respond to spiritual pain and symptoms as well as physical pain and symptoms. The aim of this study was to determine whether or not pain and their caregivers recognize spiritual pain or symptoms, and how such inquiries might lead to more successful symptom assessment and management. Methods: This is a pilot, qualitative study of 15 caregivers and hospice patients who were physically and cognitively able to consent and participate in an interview. Content forms and semi-structured interview schedules were created for patients and caregivers. A hospice physician interviewed patients and a psychologist interviewed caregivers. Interviews were audio-taped and analyzed according to methods of grounded theory. Results: All patients had well-controlled pain and symptoms and did not openly express spiritual concerns. Four common themes were identified across patients and caregivers: (i) connectedness to others, (ii) religion, (iii) personal concerns, and (iv) dying. Both patients and caregivers commented that spiritual care was important. Some patients and their caregivers said that spiritual care was important for them. Some patients and their caregivers felt that spiritual care was important for their family. Both families were concerned about future pain, relief, and loss of control and functioning. Families were able to meet the patient’s needs. Functions, stay at the patients’ sides with death to help them cope. Conclusions: Although spiritual issues were revealed in their narratives, families did not name them as such. Future study of how patients and caregivers define and describe non-physical pain and symptoms may lead to better assessment of and interventions for these symptoms. The Summa Foundation funded this study.

Abstract number: P1-440
Abstract type: Poster

EPIONE: Spanish Association for Palliative Care Project to Assess and Promote Spiritual Resources in Patients: Preliminary Results

Banos J.*, Barreto Martin P., Oliver A., Galanía L., Diego Pedro R., García Leal J., Juaristi L.

Background: In Spain, the focus on spirituality in palliative care is limited, but the knowledge on this topic is growing. The aim of this study is to assess patients’ spiritual needs and resources and promote spiritual care in clinical practice. Methods: A self-administered questionnaire was used to assess the level of spiritual needs and resources on a scale from 1 to 5, and a Likert-type scale for each subscale. Results: The spirituality scale showed a high level of reliability. Conclusion: The results of this preliminary study indicate that patients have high spiritual needs and resources that should be addressed in clinical practice.

Abstract number: P1-441
Abstract type: Poster

Palliative Care Project to Assess and Promote Spiritual Resources in Patients: Preliminary Results

Banos J.*, Barreto Martin P., Oliver A., Galanía L., Diego Pedro R., García Leal J., Juaristi L.

Background: In Spain, the focus on spirituality in palliative care is limited, but the knowledge on this topic is growing. The aim of this study is to assess patients’ spiritual needs and resources and promote spiritual care in clinical practice. Methods: A self-administered questionnaire was used to assess the level of spiritual needs and resources on a scale from 1 to 5, and a Likert-type scale for each subscale. Results: The spirituality scale showed a high level of reliability. Conclusion: The results of this preliminary study indicate that patients have high spiritual needs and resources that should be addressed in clinical practice.

Abstract number: P1-440
Abstract type: Poster


Poster sessions
Can a Palliative Care Program Fully Supported on Electronic Records Incorporate Adequate Provision for the Spiritual Aspects of Palliative Care?

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Needs centered Palliative Care (PC) requires knowledge, commitment and robust documentation. Information accessible to professionals helps match complexity to level of intervention and promote comprehensive and multidisciplinary approach raising awareness of PC resources. Single point of entry at referral implies timely PC access, which is often as complex, not too religious and useful in clinical practice. Therefore, a directive for spiritual conversations, if this tool would be developed, should be: avoid too structured, not too religious and useful in clinical practice.

Demographic: The interviewing of 128 patients, their care givers and health care professionals was performed. The respective database was created and systematically measured. To determine whether Electronic Psychosocial Risk and Estimation of Uncertainty Kinescope (SpREUK) was primarily designed to be used in Poland and UK to determine the impact of the face to face study day and the online learning produced for nurses working in the confidence of participants and the poster demonstrates how these compare.

Aim: To test the SpREUK in predominantly Catholic Poland. Polish religiosity displayed an extremely “Church oriented”, in the past decades it has been changing. People stay religious, many become engaged in more private, more personal and more alternative (e.g. yoga) ways of religiosity. In many cases, however, people’s religiosity does not include the Church as an indispensable element. Consequently there is a need of further research regarding spiritual needs of all patients – not just religious. It would be growing number of those who do not find help in traditional rituals during chronic illness or towards end of life.

Background: Spiritual care is an essential component of palliative care, but one that is often neglected in clinical practice and research.

Aims: To identify research priorities in spiritual care, to take forward the provision of spiritual care across Europe. Method: The Halley Stewart Trust Symposium on Spiritual Care was hosted by King’s College London, UK, on 23 October 2012. Invited experts included researchers and clinicians recruited through the EAPC Spiritual Care Taskforce and patients and caregivers identified through the local Symposium Advisory Group. First, state-of-the-science presentations covered three priority areas identified in the 2012 Taskforce spiritual care survey.

Poster sessions

Poster withdrawn

Abstract number: P1-443
Abstract type: Poster

Evaluation of Spiritual Assessment and its Challenges in Georgia

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Research aims: Georgia is the Former Soviet Country with population of approximately 4.25 million. To date, the majority of cancer patients referred the regional specialist PC program EPRC in a 16 month period are registered: 3,000 referrals, over 2000 assessments, Multidisciplinary (MDT) plans protocols as well as over 24,000 contacts to the regional 24h service.

Aim: To test the SpREUK in predominantly Catholic Poland. Polish religiosity displayed an extremely “Church oriented”, in the past decades it has been changing. People stay religious, many become engaged in more private, more personal and more alternative (e.g. yoga) ways of religiosity. In many cases, however, people’s religiosity does not include the Church as an indispensable element. Consequently there is a need of further research regarding spiritual needs of all the patients - not too structured, not too religious and useful in clinical practice.

Abstract number: P1-448
Abstract type: Poster

Implementing the Ars Moriendi model in Palliative Home Care: A Pilot Study

Vermandere M., Betheloth K., Buyse H., Desarne D., De Roover S., Snubbel L., Van Immerzeel C., Vermandere S., Voss M., Aertsgeerts K.
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Background: Assessing the spiritual well-being of palliative patients is often perceived as difficult by professionals. Previous research showed that they would appreciate a directive for spiritual conversations, if this tool would be well structured, not too religious and useful in clinical practice.

Aims: To investigate the experiences of general practitioners, district nurses and patient, to test the Ars Moriendi model as a directive for spiritual conversations in palliative home care.

Poster sessions

Poster sessions

Poster sessions
Spiritual Care and the Ars moriendi Model (AM-model)

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The AM model of Leget (2008) provides a framework for patients and care professionals to enter into a dialogue about life questions.

Aim: To study how palliative patients experience an invitation to discuss spiritual questions with the help of the AM model (Leget, 2008), which helps them to organize and verbalize their needs. This study also focuses on gaining insight on the items palliative patients would like to discuss with a professional caregiver, whether palliative patients benefit from written information about the AM model and whether they think this model with the five themes: Farewell, Suffering, Autonomy, Guilt and Hope, should be extended.

Method: In a qualitative descriptive study, in-depth interviews with 10 palliative patients were held. For validity and reliability different methods were used: e.g. topic list, methodical accountability, peer debriefing and a structured analysis of data using a sw-program Kwalitan 6.0.

Results: The five themes of the AM model have significance for palliative patients. It helps to consider and organize their life questions and they find it useful to discuss this with a nurse, NP, spiritual caregiver or physician. 4 of the 5 themes are recognized by all palliative patients. The theme Autonomy is not known or difficult to understand for 40% of the patients, however, they talk about life questions within this theme. Not all the 5 themes are applicable to all palliative patients.

Some palliative patients think that the graphic design of the AM model does not represent the dynamic dimension of the themes. It is meaningful also to offer written information about the AM model.

Conclusions: The AM model by Leget helps palliative patients to organize and express their life questions. Written information about the AM model facilitates this process. The 5 themes of the AM model are helpful, and they find it meaningful to discuss them with a nurse, a NP, spiritual caregiver or physician.
Poster sessions – set 2

Pain
Other Symptoms
Assessment & measurement tools
Audit & quality control
Basic & translational research
Bereavement
Education
End of Life Care
Epidemiology
Ethics
Family & Care Givers
Medical Sociology
Organisation of Services
Policy
Psychology & communication
Research Methodology
Non-Cancer
Palliative Care in the Elderly
Palliative Care in Children and Adolescents
Advocacy & Media
Spirituality
Dose Conversion when Switching between Oral Morphine and Oxycodone

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Purpose: To explore the opioid doses required when switching from morphine to oxycodone and vice versa.

Methods: A randomised controlled trial of oral morphine versus oxycodone for cancer-related pain was conducted. Doses were titrated according to response using the immediate release formulations. Groups were randomised to either switch as titrated or on a 2:1 morphine:oxycodone ratio, the latter being used in both directions. Doses were recorded at the points of clinical response or non-response. Conversion ratios were individually calculated.

Results: For protocol analysis 95/165 patients (58%) required opioid switching. In those taking morphine first-line the median pre-switch dose was 60mg (range 30-360mg) and the median post-switch dose of morphine was 180mg (range 60-300mg). In those taking oxycodone first-line the median pre-switch dose was 60mg (range 15-340mg) and the median post-switch dose of oxycodone was 50mg (range 15-130mg). In those taking oxycodone first-line, 50% of the patients had pain levels controlled by at least 3 days with Targin® (Oxycodone-with-naloxone controlled-release tablets). As regards the BTcP, all patients were satisfied with the oxycodone treatment and the patients showed preliminary evidence for a survival benefit in patients who received oxycodone (Brauera and Yennarajalingam, 2012).

Method: It was conducted one observational study on lung cancer patients in the palliative stage, with chronic pain controlled by at least 3 days with Targin® (Oxycodone-with-naloxone controlled-release tablets). As regards the BTcP, all patients were satisfied with the oxycodone treatment and the patients showed preliminary evidence for a survival benefit in patients who received oxycodone (Brauera and Yennarajalingam, 2012).

Conclusion: There is substantial inter-individual variation in patient response and switching dose requirements of morphine and oxycodone when switched between the two drugs. Variability in dose ratios was observed, including the need for up and downward titration in each direction of switch. An immediate release preparation allows greater flexibility within this process.

Abstract number: P-002
Abstract type: Poster

Psycho-oncological and Pharmacological Pain Management Therapies for Lung Cancer Patients with Major Pain in the Palliative Stage and Breakthrough Cancer Pain (BTcP)

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The psycho-oncological approaches to pain management ensures patients the most effective options to treat their pain in the palliative care setting. Emotional (i.e., anxiety, depression) distress has been linked to greater mortality related to cancer. Studies by Teme1 et al. and Bakitas et al. showed preliminary evidence for a survival benefit in patients who received oxycodone (Brauera and Yennarajalingam, 2012).

Method: It was conducted one observational study on lung cancer patients in the palliative stage, with chronic pain controlled by at least 3 days with Targin® (Oxycodone-with-naloxone controlled-release tablets). As regards the BTcP, all patients were satisfied with the oxycodone treatment and the patients showed preliminary evidence for a survival benefit in patients who received oxycodone (Brauera and Yennarajalingam, 2012).

Conclusion: There is substantial inter-individual variation in patient response and switching dose requirements of morphine and oxycodone when switched between the two drugs. Variability in dose ratios was observed, including the need for up and downward titration in each direction of switch. An immediate release preparation allows greater flexibility within this process.

Abstract number: P-002
Abstract type: Poster

Palliative Care for 21 Japanese Patients with Bone and Soft Tissue Sarcoma

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Aims: There have been few studies on palliative care for patients with bone and soft tissue sarcoma (BSTS) due to its low prevalence. No case study on patients with BSTS has been reported by palliative care physicians in Japan. The aim of this study is to retrospectively investigate into clinical features and palliative care strategies in a palliative care team (PCT) in 21 patients with BSTS who was hospitalized for chemotherapy. The ultimate purpose is to disclose the current status of palliative care for patients with BSTS and to utilize it for the improvement for future palliative care.

Method: We retrospectively reviewed all medical records of 21 patients with BSTS who received palliative care interventions by PCT during their hospitalization from January 1, 2010 to November 30, 2012.

Results: 21 patients (male 7, female 14) were reviewed in this study. The median age was 60 years (23-87). The histopathological subtypes included 10 cases of gastrointestinal stromal tumor (n=3), Ewing sarcoma (n=2), other (n=6). The median number of chemotherapy regimens was 4 (0-8). The most common reason why patients discontinued was respiratory failure (n=6), followed by bleeding of the tumor (n=4), others (n=3). Reasons of consultation were intractable pain (n=8), psychological support (n=7), lymphedema (n=6).

Discussion: 13 patients (62%) had life-threatening complications, and the outcomes of 10 patients of them (77%) were death. The major cause of complications was most likely due to organ compression by tumor since the symptoms improved by size reduction of tumor. Patients with BSTS tended to be highly distressed by the lack of information about their disease and available treatment. Therefore the PCT was consulted frequently for psychological support in early stage.

Conclusion: Psychological support was highly needed in the early stage of BSTS. Progression of organ compression by tumor was thought to be correlated with poor prognosis in BSTS.
A Method for Switching from Fentanyl Patches Changed Every 24 Hours to Continuous Intravenous Infusion of Oxycodone in Japanese Patients with Cancer Pain

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Objective: We studied appropriate methods for switching from fentanyl patches changed every 24 h (Ftd24) to continuous intravenous infusion of oxycodone (Oxiciv) in patients with cancer pain on the basis of plasma drug concentrations that were calculated from the plasma half-life of each drug in Japanese patients (7 per drug).

Methods: Four methods for switching from Ftd24 to Oxiciv were studied.

Method 1) Treatment with the equivalent dose of Oxiciv (total dose) was started 12 h after patch removal.

Method 2) Total dose of Oxiciv is started 24 h after patch removal.

Method 3) One-half of the equivalent dose of Oxiciv is given from 0 to 24 h after patch removal, and total dose of Oxiciv is started after 24 h.

Method 4) One-half of the equivalent dose of Oxiciv is given from 0 to 48 h after patch removal, and total dose of Oxiciv is started after 48 h. The plasma Ftd24 concentration before switching was considered equivalent to the plasma Oxiciv concentration after switching (steady state) = 100%.

Plasma concentrations of each drug were estimated from 0 to 96 h after switching.

Results: The percentage of time that concentrations were outside the optimal range of 80% to 125% and the maximal plasma concentration-minimal plasma concentration (max/min) ratio were as follows:

Method 1) 52% and 153-77;
Method 2) 95% and 156-99;
Method 3) 38% and 141-100; and
Method 4) 40% and 105-85.

The percentage of time that optimal concentrations were outside the upper limit of the 90% confidence interval for half of the half-life of each drug (%) and the maximal plasma concentration-minimal plasma concentration (max/min) ratio were as follows:

Method 1) 112-23, 158-58;
Method 2) 78-22, 148-34;
Method 3) 81-0, 152-84; and
Method 4) 42-0, 65-85.

Conclusions: Our results suggested that the best method for switching from Ftd24 to Oxiciv is Method 4. Our results can be applied in switching from fentanyl transdermal patches changed every 72 h (Ftd72) to Oxiciv as well as to switching to morphine or fentanyl injection.

Abstract number: P-008
Abstract type: Poster

Oxycodone/naloxone Prolonged-release Tablets (OXN PR) Are Well Tolerated and Efficacious in Long-term Treatment of Cancer-related Pain

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Background: Opioids are recommended for treatment of cancer pain however a common side effect is opioid-induced constipation (OIC). OXN PR tablets contain oxycodone and naloxone in a 2:1 ratio for treatment of pain and to counteract OIC.

Aims: To evaluate the long-term tolerability (n=92) and efficacy of OXN PR, subgroup analyses were performed focusing on patients with metastasis pain of different cancer on the basis of the presence of two specific clinical indicators, i.e. lung (n=40) and/or breast cancer (n=39) with and without metastases.

Methods: Long-term tolerability and efficacy of OXN PR was assessed in a randomized, double-blind (DB), 4-weeks study (OXN PR vs oxycodone OPR (OxyPR) or 6 months extension phase up to 12 weeks), NCT01205095. OPR substudy subgroup analysis includes assessment of pain, bowel function and Adverse Events (AE).

Results: At randomisation mean (SD) pain intensities were comparable between both treatments in all subgroups (metastases: OXN PR 4.8 (2.1), OxyPR 4.1 (2.0), lung cancer OXN PR 4.4 (2.1), OxyPR 4.2 (1.6), breast cancer OXN PR 4.3 (2.0), OxyPR 4.4 (2.0) and improved similarly throughout DB phase in all subgroups regardless of the presence of metastasis. Pain stability was demonstrated for subjects receiving OXN PR (AUC metabolites - 17.3; lung cancer -15.9) which was maintained during long-term treatment. 40 (43.5%) of 92 subjects receiving OXN PR throughout DB and extension phase had related AEs. Only 7 (7.5%) subjects experienced serious AEs - one subject died from opioid-related complications and the assessed patients common AEs were reported for gastrointestinal and general disorders.

Conclusion: OXN PR is efficacious and well tolerated during long-term treatment for cancer-related pain of different origin.

Abstract number: P-009
Abstract type: Poster

A Description of Symptom Prevalence and Intensity in Adolescents and Young Adults (AYA) Daughters of Women with Cancer on Referral to a Palliative Care Service

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Aims: Despite the recognition of AYA as a distinct oncological entity, there remains a paucity of literature describing the specific symptoms living with cancer may experience. As part of a larger study conducted in the AYA population as research has only examined AYAs in either paediatric or adult contexts. Our aims were, 1) To obtain a reliable estimate of the prevalence, severity and mechanism of pain and other symptoms in AYAs on presentation to a palliative care service, 2) To compare symptom burden with an adult cohort matched for diagnosis.

Methods: Retrospective observational study of AYAs (age 15-25) and a randomly matched cohort of AYAs (age > 25), referred between July 2010-June 2012. Eligibility was determined by completion of Edmonton Symptom Assessment Scale and Edmonton Classification of Cancer Pain. Descriptive statistics and Wilcoxon rank sum non-parametric tests were performed.

Results: 32 of 42 screened AYA patients were eligible. The median survival of the AYA group was 14 months versus 9.8 months in the control group. The most common malignancies were sarcoma (52%) and haematological malignancies were studied.

Conclusion: Our limited data suggests no significant difference in symptom burden in AYA patients though they may exhibit a higher prevalence of pain syndromes. Further studies are warranted to assess the perceived symptom distress in this population and its potential link cancer treatment and survival.

Abstract number: P-010
Abstract type: Poster

Therapeutic Decisions Made by Palliative Medicine Physicians in Poland Related to Managing and Modifying Pain Therapy and Factors Affecting Them

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The study’s aim was to identify the therapeutic decisions made by palliative medicine physicians who conduct and modify pain management, in particular the difficulties in conducting pain management and in discovering pain in patients, and the factors affecting their choice.

Participants and methods: The study consisted in thirteen group interviews with 17 physicians (8 men, 9 women) from different centers in Poland. The data were collected using a semi-structured questionnaire and analyzed using thematic analysis.

Results: The major factors that affected the physicians’ decision-making processes were: the nature and intensity of the pain, the drug effectiveness, the patient’s desire and the side effects of the therapy. The authors underline the importance of the patient’s satisfaction with the effect of the therapy and the reduction of the side effects on the pain management.

Conclusion: Our study confirms that palliative medicine physicians in Poland are facing similar difficulties in pain management as their colleagues in other countries.

Abstract number: P-011
Abstract type: Poster

The Cross-roads of Interventional Palliative Care: Advancing Interdisciplinary Care for Patients with Refractory Cancer Pain

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Objective: To provide a literature-based review of interventional procedures for refractory cancer pain.

Methods: We identified and reviewed all the available literature on interventional procedures used in the treatment of refractory cancer pain.

Results: Several interventional procedures have been shown to be effective in the treatment of refractory cancer pain. These procedures include radiofrequency ablation, stereotactic body radiation therapy, and neuroplastic surgery.

Conclusion: Interventional procedures can be effective in the treatment of refractory cancer pain. However, the use of these procedures should be considered on an individual basis and the potential benefits and risks should be carefully discussed with the patient.

Abstract number: P-012
Abstract type: Poster

The Relationship between Subjective Assessment of Pain and the Objective Assessment of QoL and Physical Function in Patients with Breast Cancer who Underwent Radiotherapy for Painful Bone Metastases

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1University of Edinburgh, Edinburgh Cancer Research Centre, Edinburgh, United Kingdom, 2Norwegian University of Science and Technology (NTNU), European Palliative Care Research Centre, Faculty of Medicine, Trondheim, Norway, 3PhD Bioethicists, Translational Medicine and Molecular
Introduction: An objective measure of pain relief is desirable in evaluating the efficacy of assessing of pain relief, in patients receiving transdermal (XRT) in cancer induced bone pain (CIBP).

Abstract number: P2-016

Abstract type: Poster

Assessment of Cancer Pain Management by Services Non-specialized in Palliative Care According to Recommendations of the European Association for Palliative Care (EAPC)

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Recently, the EAPC has published recommendations for cancer pain management.

Objectives: To determine the degree of analgesia adjustment according to the EAPC recommendations, before prevention of palliative care services.

Methods: A descriptive, retrospective study, based on review of medical records. Care setting: Palliative care home program (PCHP) in urban area (admits advanced cancer patients coming from hospital services and primary care) All cancer patients with pain, visited in period July 2011-July 2012, were included. Data analysed, recorded at first visit of PCHP, demographic data, clinical characteristics, analysis before admission to PCHP, and adjustment of analgesia according to EAPC criteria.

Results: N=103. Mean age 65.4 (SD: 12.86, 98-38). Females were 59%. The most frequent primary cancer was colorectal (33.3%). Pain types: visceral 44.7%, somatic 39.8%, mixed pain 15.5%. Edmonton Staging System Cancer Pain: Stage 3/2.0: stage I. Analgesia: 5.8% no analgesics, 32.0% non-opioids analgesics (WHO step II), 18.4% weak opioids (step IV), and 43.7% strong opioids (step III). Seventy-one patients (68.9%) met EAPC recommendations. Disorders with EAPC criteria: no association of first and second WHO step drugs when adequate 13.5%; routine lateral use 9.7%. Discussion: Most patients received adequate pain treatment based on prescription to PCHP. However, there were patients that had an analgesic treatment with which did not meet all the EAPC recommendations. Of note, that a relevant number of patients had no analgesics pain.

The main discordances with the EAPC recommendations were: a) Lack of use of the non-opioid and weak opioids, when adequate; b) Lack of routine use of laxatives for reduced opioid-induced constipation.

Abstract number: P2-017

Abstract type: Poster

Pain Control in Patients with Terminal Illness in Ghana

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Many Ghanaians continue to experience pain associated with life threatening diseases because palliative care has not been integrated into the health care system. In 2006, African Palliative Care Association (AFPCA) has recognized that palliative care was introduced into the undergraduate nursing curriculum in Ghana. Fortunately, between 2011 and 2012 there have been series of workshops for other health workers like doctors, pharmacists clinical psychologists and nurses on Palliative Care. Central University College, a private tertiary institution in Ghana has embarked on the training of nurses in palliative care, with practical components in the community. This year, 2012, 80 nurses are undertaking the core-based Palliative Care Nursing. The study will explore the care provided with emphasis on symptom control, pain measurement and pain management. A total of 80 home - based care notes will be evaluated and individual patient’s demographic data, disease history, symptoms and pain control modalities will be examined. The findings will be presented at the conference.

Abstract number: P2-015

Abstract type: Poster

Aberant Drug-related Behaviors in Patients Prescribed Opioids for Cancer Pain Syndromes

Matudo S1, Tuomela S2, Timunen H1,4, (Ohno Y)1

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Background: Addiction of opioid analgesics is rare in cancer patients. However, little is known about other problems of drug-related behaviors with opioid analgesics in patients with cancer pain syndromes.

Aim: The aim of this study was to clarify the prevalence and characteristics of aberrant drug-related behaviors (ADRBs) among patients prescribed opioids for cancer pain syndromes.

Method: We retrospectively studied the medical records of all hospitalized adult patients prescribed opioids for cancer pain syndromes during the period of May 2008 to February 2011. Information was collected regarding age, sex, history of psychiatric disorders, and ADRBs identified by the model by Paskas and Portenoy and classified in four categories consisted of addiction, pseudo-addiction, chemical coping, and diversion/foreneryg. In ADRBs patients excluding pseudo-addiction, we assessed the types of opioid agonists associated with ADRBs and the association between ADRBs and other variables. The data was statistically analyzed with Fisher’s exact test.

Results: 15 out of 477 patients (3.1%) had ADRBs with prescription opioids, consisted of 2.3% addiction, 1.7% pseudo-addiction, 1.7% chemical coping, 1.3% mixed behavior. All 7 patients excluding pseudo-addiction were male and younger, and had ADRBs related to addiction and fentanyl. No association was found between ADRBs and history of psychiatric disorders.

Conclusion: These results may indicate that intravenous injection of fentanyl have higher risk for ADRBs than other opioids in hospitalized cancer inpatients confirmed with ‘pseudo-addiction’ and that male and young patients were risk factors for ADRBs in patients with cancer pain syndromes as well as patients with chronic non-cancer pain.

Posters sessions

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

Poster sessions – set 2

150
Usefulness of Rikkosan, a Traditional Japanese Medicine, for Intolerable Oral Pain in Cancer Patients

Abstract: The fentanyl buccal tablets are the most effective in BTP episodes, especially in case of nociceptive pain (visceral, bone pain).

Efficacy of Pregabalin for Neuropathic Pain in Cancer

Abstract: There are many kinds of adjuvant analgesics that treat neuropathic pain. For neuropathic pain, evidence-based guidelines suggest gabapentinoid or tramadol extended-release. There few evidence for cancer-related neuropathic pain. Pregabalin titrates faster and more easily on onset than gabapentin. So we researched efficacy of pregabalin for cancer-related neuropathic pain.

Methods: We reviewed the records of patients who were administered pregabalin from 2011 to Sep of 2012. The cause of pain, dose of pregabalin, other pharmacotherapy or treatment, pain score of numerical rating scale (NRS) before and after administration, side effects, changed medication were also investigated. The patient’s prognosis was under 1 month were excluded.

Results: 38 cancer-related neuropathic patients were administered by pregabalin. The dose of pregabalin was 50mg to 300mg per day. 19 of 200 patients, 10 of neuropathy from chemotherapy or radiotherapy, 6 of tumor invasion or compression and 3 of others. Pregabalin was administered to 18 patients. NRS changed from 6.4 to 4.2 after pregabalin administration. While cancer itself or cause of pain was managed by radiotherapy or other chemotherapies, pregabalin’s dose and pain score were stable. But NRS increased when radiotherapy and/or chemotherapy’s efficacy was limited. 10 were switched to clonazepam and 9 to ketamin from pregabalin with opoid’s dose set up by palliative care team consultation.

Conclusion: Pregabalin is effective for cancer-related neuropathic pain while cancer is in controlled radiotherapy and/or chemotherapy. For advanced pain, it was suggested that another strategy like adjuvant switch is needed by expert opinion.

Outpatients with Cancer in a Multi-centre Study - Who is In pain?

Abstract: Pain is a major health care problem for patients with cancer. This is the first multi-centre study to explore prevalence of pain in patients with cancer in Dutch outpatient departments, in all cancer stages.

Methods: A descriptive, multi-centre, cross-sectional study was conducted in patients with cancer visiting one of the seven outpatient departments of regional general hospitals. During five consecutive working days, patients visiting the oncology outpatient department were asked to participate. Patients were eligible if they were diagnosed with cancer and 18 years or older. Exclusion criteria were severe cognitive dysfunction or no ability to understand the Dutch language. Descriptive statistics and subgroup analysis were conducted. Subgroups will be classified by: age, gender, tumor type, treatment intention, education, metastasis.

Results: Four hundred twenty-eight out of 629 patients (68%) completed the questionnaire, of which more than one out of three reported pain (38%). Twenty-six percent of patients in pain, experienced their pain as moderate (5-6) and 23% of patients as severe (7-10). Pain treatment was inadequate more than one out of two patients with pain (62%). Additionally, 89% of patients in pain, experienced pain-induced interference with one or more activities in daily life.

Conclusion: A substantial proportion of patients with cancer in Dutch outpatient departments have pain and are inadequately treated, compared with previous studies in Europe, which varied from 27%-68%. This illustrates that
pain is still a problem in Dutch outpatients clinics. This study explored the current situation to improve pain management in outpatients with cancer in the future.

Fumio Munemasa 1,2,3,3 and Bergh in het Zadel 4 (Dutch Association that funds research).

Abstract number: P-024
Abstract type: Poster

Postoperative Analgesia for Opioid-dependent Cancer Patients

Isono S.5

Methods: We have been using our institutional pain management protocol for chronic opioid dependent cancer patients. With approval of IRB, we conducted retrospective chart review in opioid-dependent adult cancer patients having undergone surgery. Inbrief, our postoperative protocol consisted of the following policies such as 1) Maintenance of preoperative baseline opioids, 2) Epidural analgesia if applicable, 3) Additional opioid by epidural morphine 3 - 4 mg/day or intravenous fentanyl patient-controlled analgesia (PCA) at baseline rate of 0.4 - 0.6mcg/kg/hr in patient receiving preoperative lower dose opioids, 4) 20 mg/day oral morphine equivalents), 3) B) Additional opioid by 30% of baseline opioids in patients receiving preoperative higher-dose opioids (more than 210 mg/day of oral morphine equivalents), 3 B) Additional opioid by 30% of baseline opioids in patients receiving preoperative higher-dose opioids (more than 210 mg/day of oral morphine equivalents), and 3) Baseline opioids in patients receiving preoperative higher-dose opioids (more than 210 mg/day of oral morphine equivalents).

Results and discussion: Between April 2008 and November 2011, 44 cases out of 58 opioid dependent patient surgery cases completed the protocol. No severe opioid related adverse events and symptoms suggestive of opioid withdrawal were documented. Patients received wide-range of preoperative baseline opioids (15 to 1800 mg/day, median: 60 mg/day). Pain management was successful in 18 patients according to our definition, in most of the unsuccessful pain controlled cases, the pain was controllable with increase of preoperative rate of PCA. Our protocol tended to succeed in patients with epidural analgesia, and those who had smaller dose of opioids preoperatively. In very high doses of opioid dependents, we might need to modify this protocol.

Conclusion: Our current pain management protocol is clinically acceptable.

Abstract number: P-026
Abstract type: Poster

Do the Assistance of an External Advisor Improve the Performance of Full-time Hospital Palliative Care Team? A Prospective before-after Study


Aims: To explore pain epidemiology and management practices in a University Hospital. This was a descriptive point prevalence study. Participants were >18 years, hospitalized on medical or surgical services for >24 hours, and able to participate. Assessment was performed at Society Patient Outcome Questionnaire, assessing pain severity was administered. Data regarding pain medications and documentation were collected from electronic medical charts. The response rate was 77%. Participants (N= 368) mean age was 67.6 (SD=17.5) years, range 18-100; 51% were women. Pain prevalence in the inpatient palliative care unit (PCU) was 9.4%. The mean worst pain was 10 (95% CI: 9.5-10.7). Pain medications were used by 54% (89%) of participants. The most common used pain medications were non-opioids (76%), >95% of patients used opioids in the past 24 hours. No significant difference in pain intensity was found between patients who did or did not receive pain medications.

Conclusion: Our current pain management protocol is clinically acceptable.

Abstract number: P-028
Abstract type: Poster

Hyperalgesia and Propofol Terminal Sedation in a Patient with a Right Pelvic Mass

Zoega S.1,2, Ward S.E.3, Sigurdsson G.1,2, Sveinsdottir H.1,2, Zoega S.1,2, Ward S.E.3, Sigurdsson G.1,2, Sveinsdottir H.1,2, Zoega S.1,2, Ward S.E.3, Sigurdsson G.1,2, Sveinsdottir H.1,2, Zoega S.1,2, Ward S.E.3, Sigurdsson G.1,2, Sveinsdottir H.1,2, Zoega S.1,2, Ward S.E.3, Sigurdsson G.1,2, Sveinsdottir H.1,2, Zoega S.1,2, Ward S.E.3, Sigurdsson G.1,2, Sveinsdottir H.1,2

Aims: To evaluate the pain management and improvement of the performance of the F.A.B (Fatigue and Breathing Clinic) Clinic. This was a descriptive point prevalence study. Participants were >18 years, hospitalized on medical or surgical services for >24 hours, and able to participate. Assessment was performed at Society Patient Outcome Questionnaire, assessing pain severity was administered. Data regarding pain medications and documentation were collected from electronic medical charts. The response rate was 77%. Participants (N= 368) mean age was 67.6 (SD=17.5) years, range 18-100; 51% were women. Pain prevalence in the inpatient palliative care unit (PCU) was 9.4%. The mean worst pain was 10 (95% CI: 9.5-10.7). Pain medications were used by 54% (89%) of participants. The most common used pain medications were non-opioids (76%), >95% of patients used opioids in the past 24 hours. No significant difference in pain intensity was found between patients who did or did not receive pain medications.

Conclusion: Our current pain management protocol is clinically acceptable.

Abstract number: P-030
Abstract type: Poster

Is the F.A.B (Fatigue and Breathing Clinic) Clinic Really Fab? An Evaluation of a Novel Clinical Service

Bowler E., McAlpine E.2

Aims: Hospice at Home service works with other community services to fill gaps in end of life care for patients, whose preferred place of care is home. A four hour / seven days a week sitting service is delivered predominantly by trained Healthcare Assistants (Aides), who recognised that anxiety and breathlessness might benefit from immediate, non-pharmacological interventions. Similar interventions can be provided on a domiciliary basis, but are limited by the availability of a hospital based palliative care service.

Methods: A novel community based service ‘Fatigue and Breathlessness Clinic’ (F.A.B) was introduced in a Kent hospice in 2011. The F.A.B Clinic comprises of a partially trained Healthcare Assistants (Aides), who recognised that anxiety and breathlessness might benefit from immediate, non-pharmacological interventions. Similar interventions can be provided on a domiciliary basis, but are limited by the availability of a hospital based palliative care service.

Results: We present audit and survey results of this positive partnership between hospice, Aides, complementary therapists, families and community services.

Conclusion: Fatigue and breathlessness are distressing symptoms experienced by over 90% of patients with malignancies and non-malignant disease. Specific programmes for managing cancer-related fatigue or breathlessness can lead to improvements in patient functioning. The aim of this study is to evaluate an innovative clinic combining management of both patient fatigue and breathlessness.

Methods: A joint Occupational Therapist/Physiotherapist led fatigue and breathlessness clinic (F.A.B) was introduced in a hospice day therapy unit. The clinic includes 2-3 weekly sessions covering breathing techniques, relaxation, energy conservation, sleep, nutrition, relaxation, challenging negative thoughts. Patient data collected as part of the service includes: brief fatigue inventory (BFI), numerical rating scales for breathlessness (completed at course start
The EAPC Guide for the management of depression in palliative care is a helpful tool to increase awareness of risk factors that increase the risk of developing depression. However, we feel that those factors are too frequent in our population to serve us as screening. Our hypothesis is that one or more of these factors are present in more than 80% of our patients.

Methodology: Descriptive cross-sectional retrospective study in palliative home care settings from San Juan De Dios Hospital in Navarre during a year. Inclusion criteria: >18 years, advanced cancer. The social-demographic variables were sex, age and location of primary tumor. The selected cases also included the EAPC guide risk factors, to which we added the awareness about diagnosis and prognosis, and cognitive impairment.

Data analysis was made comparing variable by means of chi-square. Authorization of the Ethical Committee was received.

Results: Among the 414 patients, we randomly selected a sample of 156 (37%). The standard patient was a man of 74 years with gastro-intestinal neoplasm (see table 1 for descriptive results). 85% of our patients presented at least 1 risk factor among the described in the EAPC guide (53% >2, mean 2.92; including P55: 50% and <60 years). People <60 years were more aware of diagnosis (OR 9.46, p<0.0001) and prognosis (OR 2013 p=0.034), as well as greater perception of lack of social support (OR p=0.048). These 3 advanced cancer at diagnoses presented worse functional status than those located at the beginning (OR 2.35 p<0.011), 55.32% suffered from poor symptom control versus 36.7% in the others (OR 2.13 p<0.024).

1. Descriptive results

   1.1. Perception of lack of social support (OR 3.73 p=0.048)

   1.2. Cognitive impairment (OR 3.73 p=0.048)

   1.3. Anticipation of death (OR 3.73 p=0.048)

   1.4. Relative importance of diagnosis/prognosis (p=0.03)

   1.5. Distressing event (p=0.03)

   1.6. Perceived lack of support (p=0.03)

   1.7. Advanced stage at diagnosis (p=0.03)

   1.8. Poor general condition (p=0.03)

2. Bivariate Analysis

   p value

   Variable: Karenia 76.8%

   2.1. Awareness of diagnosis (p=0.0001)

   2.2. Cognitive impairment (p=0.0001)

   2.3. Anticipation of death (p=0.0001)

   2.4. Perceived lack of support (p=0.0001)

   2.5. Distressing event (p=0.0001)

   2.6. Poor general condition (p=0.0001)

   2.7. Advanced stage at diagnosis (p=0.0001)

   2.8. Relative importance of diagnosis/prognosis (p=0.0001)

   2.9. Disease progression (p=0.0001)

   2.10. Patients with Karnofsky 76.8%

   2.11. Other variables (p<0.05)

Discussion: Results confirm our hypothesis that the EAPC risk factors of depression are very common in our population. This leads us to believe that they are not very useful for screening. We have observed some associations that could serve to detect situations of greater vulnerability. More research is needed to study in depth which of the risk factors are specific to our population.

Abstract number: P2-031

Abstract type: Poster

Frequency of Risk Factors of Depression from EAPC Guide in Oncologic Palliative Patients

Home Care Setting

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The EAPC Guide for the management of depression in palliative care provides some factors that increase the risk of developing depression. However, we feel that those factors are too frequent in our population to serve us as screening. Our hypothesis is that one or more of these factors are present in more than 80% of our patients.

Methodology: Descriptive cross-sectional retrospective study in palliative home care settings from San Juan De Dios Hospital in Navarre during a year. Inclusion criteria: >18 years, advanced cancer. The social-demographic variables were sex, age and location of primary tumor. The selected cases also included the EAPC guide risk factors, to which we added the awareness about diagnosis and prognosis, and cognitive impairment.

Data analysis was made comparing variable by means of chi-square. Authorization of the Ethical Committee was received.

Results: Among the 414 patients, we randomly selected a sample of 156 (37%). The standard patient was a man of 74 years with gastro-intestinal neoplasm (see table 1 for descriptive results). 85% of our patients presented at least 1 risk factor among the described in the EAPC guide (53% >2, mean 2.92; including P55: 50% and <60 years). People <60 years were more aware of diagnosis (OR 9.46, p<0.0001) and prognosis (OR 2013 p=0.034), as well as greater perception of lack of social support (OR p=0.048). These 3 advanced cancer at diagnoses presented worse functional status than those located at the beginning (OR 2.35 p<0.011), 55.32% suffered from poor symptom control versus 36.7% in the others (OR 2.13 p<0.024).

1. Descriptive results

   1.1. Perception of lack of social support (OR 3.73 p=0.048)

   1.2. Cognitive impairment (OR 3.73 p=0.048)

   1.3. Anticipation of death (OR 3.73 p=0.048)

   1.4. Relative importance of diagnosis/prognosis (p=0.03)

   1.5. Distressing event (p=0.03)

   1.6. Perceived lack of support (p=0.03)

   1.7. Advanced stage at diagnosis (p=0.03)

   1.8. Poor general condition (p=0.03)

2. Bivariate Analysis

   p value

   Variable: Karenia 76.8%

   2.1. Awareness of diagnosis (p=0.0001)

   2.2. Cognitive impairment (p=0.0001)

   2.3. Anticipation of death (p=0.0001)

   2.4. Perceived lack of support (p=0.0001)

   2.5. Distressing event (p=0.0001)

   2.6. Poor general condition (p=0.0001)

   2.7. Advanced stage at diagnosis (p=0.0001)

   2.8. Relative importance of diagnosis/prognosis (p=0.0001)

   2.9. Disease progression (p=0.0001)

   2.10. Patients with Karnofsky 76.8%

   2.11. Other variables (p<0.05)

Discussion: Results confirm our hypothesis that the EAPC risk factors of depression are very common in our population. This leads us to believe that they are not very useful for screening. We have observed some associations that could serve to detect situations of greater vulnerability. More research is needed to study in depth which of the risk factors are specific to our population.
vascular depression and anxiety subscales (< 9), as well as the levels of anxiety-depression (< 9) of the principal caregivers.

Funded by Valencia Health Agency

Abstract number: P-041
Abstract type: Poster

Dyspnea in Hospitalized Advanced Cancer Patients: Subjective and Physiologic Correlates

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Aims: Dyspnea is one of the most disturbing symptoms in advanced cancer patients. It is unclear if physiologic measures such as vital signs and the Respiratory Distress Observation Scale (RDSO) are useful for assessing dyspnea. We examined the association among the RDSO and physiologic measures according to advanced cancer patients, caregivers and nurses, and various physiologic measures.

Methods: We enrolled consecutive hospitalized patients seen by respiratory therapy or referred for dyspnea. We asked patients, caregivers and nurses to assess the patients’ distress at the time of study enrollment using a numeric rating scale (0-10, worst). The Edmonton Symptom Assessment Scale (ESAS), causes of dyspnea, vital, and RDSO were assessed.

Results: 299 patients were enrolled: average age 62 (range 20-98), females 47%, lung cancer 27% and oxygen use 5.7%. The median RDSO was 0 (Q1-Q3 1.5 - 7.3) and the number of potential causes was 3 (Q1-Q3 2-4), with pleural effusion (N = 166, 56%), pneumonia (N = 74, 48%) and lung metastasis (N=12, 4%) being the most common. The median intensity of patients’ dyspnea (Q1-Q3 = 2) at the time of assessment was 3 (Q1-Q3 = 2-3) for patients, 4 (Q1-Q3 = 1-6) for caregivers (Kappa = 0.45, 0.18 > P>0.05) and nurses (Kappa = 0.36, 0.18 > P>0.05). Distress of patients have been observed (VAS of symptoms were lower after visual stimulation (p<0.05).

Conclusion: Hypoxia leads to decreased brain activation in fMRI during motor and visual stimulation despite a preserved functional cortico-striatal connectivity and an increased functional connectivity to chronic hypoxic conditions might differ between the primary motor and the visual systems.

This work was supported by the German Society of Mountain and Expedition Medicine.

Abstract number: P-039
Abstract type: Poster

Cancer Anorexia and Cachexia Syndrome (CACS): Associations with Quality of Life, Inflammatory Markers, and Survival of Advanced Cancer Patients

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Objectives: To evaluate the prevalence of Cancer Anorexia and Cachexia Syndrome (CACS) in outpatients with advanced cancers in their first visit to the Outpatient Service, and its associations with quality of life (QoL), inflammatory markers and overall survival (OS).

Materials and methods: One hundred and forty two advanced cancer patients and their caregiver (age > 18) that fulfilled our inclusion criteria during an 8-month period were included in the study. CACS was defined according to the criteria of the European Society for Medical Oncology (ESMO). All patients underwent a nutritional evaluation with the EORTC QLQ-C30 (Chemotherapy), cachexia (C), refractory cachexia (RC), and without cachexia (WC).

Those WC were further subdivided into malnourished or not malnourished (G1<18%) and those patients used in order to assess if hypoxia (QoL), Hemoglobin, white blood count (WBC), C reactive protein (CRP), and albumin were also measured.

Results: The results are expressed as mean ± standard deviation (SD), and the differences were considered significant from p-values < 0.05.

Conclusions: CACS was associated with lower levels of hemoglobin (p=0.018) and albumin (p=0.001) and higher levels of CRP (p=0.039), but not with WBC levels (p=0.176). The OS was significantly different between groups of CACS (p=0.001). The worst and best median OS were in the CACS groups (130 and 190 months, respectively).

The aim of this study was to investigate the relationship between the subjective and physiologic measures of dyspnea in advanced cancer patients. It was found that the subjective measures were associated with the physiologic measures, while the physiologic measures were not associated with the subjective measures. The study also showed that dyspnea is associated with physiological measures, such as heart rate, blood pressure, and respiratory rate.

Abstract number: P-040
Abstract type: Poster

Analysis of the Control of Symptoms and Emotional Distress in Patients with Cancer Attending Oncology Outpatient Conventional Hospital: Following of 167 Cases

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Aims: Assess the physical problems and emotional discomfort of patients, with advanced cancer disease, who die at home attended by a Hospice Home Care Team (HCT) or in a hospice, according to caregiver’s perception.

Material and method: Observational study of a longitudinal cohort, with a cross-sectional design, 3-months prospective following, with 146 patients followed during six months from the medical oncology service to their home or to a hospice for palliative treatment. An audit was conducted by an expert from the team care: the functional status by Barthel scale, the cognitive impairment by Pfeiffer scale, the load symptomatic by Edmonton Symptom Assessment System (ESAS) and the patient’s emotional distress with the Hospital Anxiety and Depression (HAD) scale; HAD was also used for the principal caregiver.

Results: A total of 167 patients were included, with a mean age of 71.5 years (sd 11.5), 100 men and 67 women. A 51% (51 cases) suffered form cancer in the digestive area, and 22%, the respiratory area; 16% and 14% had a gynecological and urological cancer. A 60.5% (101 cases) had a Barthel index lower than 55 and a 21.8% (44 cases) a Pfeiffer greater than 4. The mean average intensity of the symptoms assessed during following were: pain 3.6, asthenia 5.4, nausea 1.3, depression 3.5, anxiety, 2.7, drowsiness 2.4, anorexia 4.8, discomfort 3.2, dyspnea 2.9, insomnia 2.9, constipation 2.9 and dry mouth 3.3. HAD mean average of the 109-cases that had been followed was of 4.8 (7.9 - 1.3 - 7.3) and depression 8.9 (7.9 - 8.9). For the 135 principal caregivers, who could be identified, the mean average results for anxiety and depression were 7.3 and 8.5, respectively.

Conclusions: A good control of symptoms and emotional distress of patients have been achieved. HAD was lower of symptoms lower than 4, except for asthma and anorexia, and depression and anxiety subscales < 9, as well as the levels of anxiety-depression < 9 of the principal caregivers.

Funded by Valencia Health Agency
Background: Insomnia is an oft-neglected symptom affecting up to 70% of patients with palliative care needs. It is complex in nature and effective management requires identification of potential causes as well as the use of diverse interventions beyond the use of hypnotic medications.

Aims: To identify the preferences and actions of doctors and clinical nurse specialists in managing insomnia compared with previously published regional standards and guidelines.

Methods: Two simultaneous surveys were done evaluating clinical practice and a case note review of patients referred to palliative care teams. These were disseminated across integrated palliative care clinical networks in the North West of England.

Results: 97 evaluations of clinical practice and 158 case note reviews were completed. 50% of clinicians stated they "always" assessed patients for insomnia - case note review suggested this was higher at 74%. Pain (22%) and anxiety (20%) were the most prevalent factors identified on case note review. Some potentially common causes of insomnia, such as breathlessness and drug withdrawal, were less likely to be routinely assessed.

Conclusions: Insomnia and its symptoms are frequently reviewed in palliative care populations; however some preferences are absent. Causes of insomnia are deemed to be of direct effects of the individual’s life-limiting disease, such as obstructive sleep apnoea and restless legs syndrome, slight to moderate contribution from sleep specialists and emphasise the use of psychological therapies for management of chronic insomnia. Those should be communicated with a priority to insomnia - case note review identified that is was not always possible to go through short psychological interventions. We have updated and developed different palliative care specific guidelines catering to managing insomnia in palliative care populations, presented here.

Abstract number: P2-044
Abstract type: Poster

Renate Fanning at Supported Living Services for the Elderly, in collaboration with the University of Aberdeen and in partnership with the Ailortc Scotia Trust, Aberdeen, UK, and the Ailortc Trust, London, UK.

Background: The study aimed to develop a manual for improvement of palliative care in the care home sector.

Methods: A literature review was conducted. A qualitative approach was used to develop the manual. A Delphi method was used to validate the content.

Results: The manual includes guidelines for the management of symptoms, care planning, and communication. It also includes information on resource allocation and staff training.

Conclusions: The manual can be used by care homes to improve palliative care. It can also be used by regulatory bodies to monitor and improve palliative care in care homes.

Abstract number: P2-045
Abstract type: Poster

Qualitative Results of a Mixed Methods RCT to Assess the Effectiveness of a Nurse-led Palliative Care Intervention in Psychosocial Terms for HIV Positive Patients on Antiretroviral Therapy (ART)

Abstract number: P2-046
Abstract type: Poster

Session details:

Poster sessions

1. Poster 1
2. Poster 2

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Poster sessions
effective for psychosocial symptoms in the 1st month of care, and is of subsequent benefit in giving patients sufficient help and advice to plan for the future. Funding: Diana Princess of Wales Memorial Fund.

Abstract number: P2-048
Abstract type: Poster

Is Neuromuscular Electrical Stimulation (NMES) an Acceptable and Feasible Intervention for Patients with Non-small Cell Lung Cancer (NSCLC) Receiving Palliative Chemotherapy?

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Background: Reduced exercise capacity is common in patients with advanced non-small cell lung cancer (NSCLC) and is associated with increased morbidity and mortality. Physical inactivity due to the cancer or its treatment contributes, and exercise may be beneficial, with NMES a promising mode of intervention. The aim of this study was to determine if NMES is acceptable (by adherence) to patients with NSCLC receiving chemotherapy.

Methods: NMES was applied to four patients with NSCLC who were scheduled to receive chemotherapy. A self-report diary was used to record exercise data for 30 days. Patients were supervised when using the NMES equipment.

Results: Of the four patients, one discontinued the NMES. Of those who continued, there were sessions on average for 28.5 ± 8.7 days. One patient had a high degree of adherence while the adherence was lower in the other three patients. No side effects were reported.

Conclusion: NMES was acceptable to patients with NSCLC receiving chemotherapy. Further research should be conducted to determine if NMES is beneficial to these patients.

Abstract number: P2-050
Abstract type: Poster

A Systematic Review of Hypogonadism and Opioid Use in Patients with Cancer

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Background: Hypogonadism has been found to be more prevalent in patients with cancer. The aetiology is multifactorial, but may be associated with opioid use, previously linked to hypogonadism in patients without cancer. The aim of this review was to determine if NMES is acceptable (by adherence) to patients with NSCLC receiving chemotherapy.

Methods: Medline and Embase databases were searched from 2000 to 2014.

Results: A total of 12 studies met inclusion criteria. Naltrexone was more effective than placebo and had a lower rate of adverse events compared to other opioids. Ondansetron was reported. Ondansetron was well tolerated, but evidence inconsistent with high-quality studies showing both a significant reduction in pruritus and no benefit. In one study, sertaline improved pruritus with minimal side effects.

Conclusion: The evidence reviewed is largely from chronic liver disease patients so guideline recommendations are based on extrapolation, reflecting the grading. Naltrexone and rifampicin are suggested as first-line drug treatments for cholestatic pruritus. Cholestatic pruritus is not recommended with reliably effective treatments limited to the drug. Ondansetron and sertaline may be considered where other drugs have failed or are contraindicated.

Abstract number: P2-052
Abstract type: Poster

Cancer. Effect of Low-dose Morphine on Dyspnea in Advanced Cancer Patients

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Objective: To assess the therapeutic effect and side effects of low-dose morphine in patients with advanced cancer and to observe the effect on dyspnea.

Method: Fifty-six mentally alert inpatients with stage III or IV cancers, ECOG performance status 3 or 4, moderate or severe dyspnea, and estimated survival of at least 6 days were enrolled. All patients were opioid naive. Starting doses of morphine were 1mg by mouth or 2mg by injection. Data on drug and typical side effects were recorded. The total score of the pruritus was measured with the pruritus score. Dyspnea was considered to be improved when the pain score fell by at least 20%.

Results: Forty-seven male and nine female patients aged 21 to 70 year completed the study. At baseline, 31 patients reported severe dyspnea (0-2), 13 moderate dyspnea (3-4) and 12 no dyspnea (5-6). During the 3 days of treatment, 14 patients (22%) reported a 20% improvement in dyspnea (4-6-0). On day six, daily morphine doses ranged from 30 - 160 mg by mouth in six divided doses or 12 - 20 mg by injection 2 - 3 times in the day. At the end of the study, 86% reported a reduction in dyspnea of at least 3 points. Side effects including nausea, vomiting, constipation, dysuria, and sedation were reported.

Conclusion: Morphine is safe and effective for relief of dyspnea in Vietnamese cancer patients.

Abstract number: P2-053
Abstract type: Poster

How to Managing Living with Dry Mouth Can Physiotherapy Help the Palliative Patients who Struggle with Mouth Dryness?

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Background: Experiences from working 18 years with palliative patients has teased my curiosity for a physiotherapeutic aspect helping managing dry mouth. Most of the patients, both in daycare and bedside units, seems to struggle with this symptom. I often instruct them to use their own tongue to produce some saliva. Aim: Can physiotherapy help the patients to manage better: - producing more saliva using the tongue? - Focus on using the patients own muscles. - Focus on something the patients can do themselves. Methods: The project will be added to other stimulants the patients may be using (yam, sahva tea, gel...). And the stimulants will be registered. The project will be conducted at the project to develop a new and simple test. The patients will be instructed to use their tongue every time they have a sensation of dryness (4-6-10). On day six, daily morphine doses ranged from 30 - 160 mg by mouth in six divided doses or 12 - 20 mg by injection 2 - 3 times in the day. At the end of the study, 86% reported a reduction in dyspnea of at least 3 points. Side effects including nausea, vomiting, constipation, dysuria, and sedation were reported.

Conclusion: Morphine is safe and effective for relief of dyspnea in Vietnamese cancer patients.

Abstract number: P2-054
Abstract type: Poster

Locus of Control and Symptoms Severity in Assessing Depressive Symptoms of Advanced Cancer Patients 60 Years Age

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Research aims: The relationship between depression, locus of control and distressing symptoms in advanced cancer patients receiving palliative care, and investigate the predictive power of depression and distressing symptoms on clinical symptom assessment in patients depressive mood disorders.

Study design and methods: 70 consecutive Greek patients with advanced cancer who visited a Palliative Care Unit were included in the study. Demographics and clinical characteristics were recorded. Participants completed the Beck Depression Inventory, the Zuckerman Inner-Circle Scale, the Linear Analogue Scale System (for quality of life) and the Greek M.D Anderson Symptom Inventory. For pain therapy, the World Health Organization (WHO) pain ladder (scales 1-3) was used.

Results: The total BDI questionnaire score was suggestive of depression. Significant correlations were found between the presence of depression and poor quality of life, ECOG, performance status and sense of control over the course of cancer (higher scores, lower scores): p<0.0005. Depression was significantly correlated with pain, distress and poor general activity, overall enjoyment of life and relationships with people: p<0.004, anxiety, fatigue, anorexia, dyspnea, sleep disturbances (p<0.001) (correlation coefficient ranging from -0.569 to -0.435). Poor quality of life and ‘sense of control over the course of cancer’ as well as anxiety, fatigue, anorexia, dyspnea and sleep disturbances produced the strongest prediction of depression (statistical significance in the total model p< 0.0005).

Conclusions: Patients with advanced cancer; younger than 60 years old, are prone to clinical depression. They were concluded that independent predictors of depressive thoughts content in such a patients cohort are: sex, age, treatment, ‘sense of control over the course of cancer, quality of life and the presence of distressing symptoms (shortness of breath, sleep disturbances, loss of appetite, fatigue and sleepiness).

Abstract number: P2-055
Abstract type: Poster

How to Managing Living with Dry Mouth Can Physiotherapy Help the Palliative Patients who Struggle with Mouth Dryness?

Nygaard UV1,2
1Hospice Løvisenberg, Oslo, Norway; 2Løvisenberg Diakonale Sykehus, Løvisenberg Livspleie, Oslo, Norway

Background: Experiences from working 18 years with palliative patients has teased my curiosity for a physiotherapeutic aspect helping managing dry mouth. Most of the patients, both in daycare and bedside units, seems to struggle with this symptom. I often instruct them to use their own tongue to produce some saliva. Aim: Can physiotherapy help the patients to manage better: - producing more saliva using the tongue? - Focus on using the patients own muscles. - Focus on something the patients can do themselves. Methods: The project will be added to other stimulants the patients may be using (yam, sahva tea, gel...). And the stimulants will be registered. The project will be conducted at the project to develop a new and simple test. The patients will be instructed to use their tongue every time they have a sensation of dryness (4-6-10). On day six, daily morphine doses ranged from 30 - 160 mg by mouth in six divided doses or 12 - 20 mg by injection 2 - 3 times in the day. At the end of the study, 86% reported a reduction in dyspnea of at least 3 points. Side effects including nausea, vomiting, constipation, dysuria, and sedation were reported.

Conclusion: Morphine is safe and effective for relief of dyspnea in Vietnamese cancer patients.

Abstract number: P2-053
Abstract type: Poster

Posters - set 2
The Burden of Symptoms of Patients with Haematological Malignancy

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Abstract number: P2-055
Abstract type: Poster

Aims: To explore patients’ views on living with anaemia and the experience of undergoing blood transfusion in a day hospice.

Methods: 10 patients under the care of the local cancer centre who had received between them 90 blood transfusions (including at least 1 in our day hospice) were purposively recruited. Digitally recorded interviews were conducted using a semi-structured interview guide. Interviews were transcribed anonymously and analysed using a phenomenological analysis framework making links and connections between data in order to generate categories. Data sets from all participants were compared and contrasted in order to identify unique and common experiences. A composite summary of categories and then themes completed the analysis process.

Results: Participants had all had multiple transfusions (range 4-13) and were receiving regular transfusions every 2 to 4 weeks. Patients experienced tiredness as the most common symptom of anaemia and the symptomatic response to transfusion. All patients liked the day hospice for their transfusions due to differences in transport, parking, waiting time and space to ask questions. Few had concerns about the routine and frequency of transfusion as long as they had been there before. The majority had no concerns about hospice transfusion and would be happy to return for further transfusion.

Conclusion: This is the first time in-depth qualitative interviews have been conducted where the focus has been bimanual transcatheter. Haematology patients can have good experiences when undergoing blood transfusions in this setting and perhaps hospices should offer this service more frequently to a wider population.

Funding: The study was funded by a Cancer Research Network Charitable Fund. They had no influence on any part of the project or results.

The Experiences of Patients Undergoing Blood Transfusion in a Day Hospice

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Abstract number: P2-056
Abstract type: Poster

A Case in which Ocreotide was Effective against Diarrhea due to Metastasis to the Mesentery

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We herein report a case we experienced in which ocreotide was effective against refractory diarrhea due to metastasis of lung cancer to the mesentery. [Case] A 54-year-old male with lung cancer. With a diagnosis of pulmonary adenocarcinoma, excision of the left superior lobe together with the thoric wall was performed. One year four months after the surgery, an 8 cm intrapancreatic tumor was found through CT imaging, and although extirpation was attempted, the tumor was found to be wrapped around the small intestine and sigmoid colon, and extirpation was thus halted. By a core needle biopsy, a diagnosis of metastasis of lung cancer to the intestinal membrane was made. Chemotherapy was planned, but one month later, the patient was hospitalized due to diarrhea. There was no nausea or vomiting, but an increase in abdominal bloating and bowel peristalsis was observed. Rehydration, administration of antibiotics, and oral administration of antidiarrheal medicine were performed. Even one week after hospitalization, there was no improvement in the diarrhea, and watery stools were repeatedly observed at least ten times per day. CT, an intrapancreatic tumor, as well as gas patterns and phase movement in the intestinal tract were observed. When the continuous subcutaneous infusion of ocreotide was started, two days later; the frequency of diarrhea decreased. Ocreotide was clearly effective, so its administration was continued. One month later, the abdominal tumor had invaded the abdominal wall, and a fistula formed between the intestinal tract and the skin. Intestinal fluids flowed out from the fistula, so management was carried out using a stoma pouch. At the same time, diarrhea from the anus ceased, so ocreotide administration was stopped.

Psychological distress among cancer patients with metastatic disease. 7% of those with cutaneous metastases reported a great amount of similarities with the psychosocial aspects of palliative care. The theme evaluation shows less similarity.

Conclusions: Clinical decision-making in palliative care is a complex process, because many factors influence the selection of a nurse for intervention. The QOL is recommended to give nurses better insight into their own decision-making, because of the influence this has on the quality of symptom management and the quality of care. Additional training on decision-making can contribute to these qualities.

Poster sessions

The Burying of Symptoms of Patients with Haematological Malignancy

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Abstract number: P2-057
Abstract type: Poster

Cachexia: A Dutch Leaflet

vann Bommel M

In the South of the Netherlands the Comprehensive Care Centre started a group of experts to implement the EAPC guidelines about cachexia.

Dietary counselors, therapists, nurses and a general practitioner developed a leaflet for patients in imitation of the EAPC guideline. Finally we asked representatives of non professionals to give their feedback.

We went like present the Dutch leaflet and also a translated version.

Abstract number: P2-058
Abstract type: Poster

Clinical Decision-making in Palliative Care

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Background: Symptom burden influences perceived health status and quality of life in palliative patients. Hospice nurses play an important role in the treatment of the highest scoring symptoms fatigue, dry mouth and appetite loss. Getting insight into the process of clinical decision-making of nurses in palliative care is important to improve the quality of symptom management.

Aim: To explore how Dutch hospice nurses make clinical decisions in choosing interventions related to the symptoms fatigue, dry mouth and appetite loss. To determine which factors influence the decision-making.

Methods: In this qualitative descriptive study, 9 nurses from an academic hospice in the Netherlands participated. Data were collected through a focus group, semi-structured interview and by attending a multidisciplinary consultation. The interviews were transcribed verbatim.

Conclusions: All nurses had experience with decision-making in palliative care. The majority of these related to side effects, particularly respiratory depression, or the practical details of prescribing.

Conclusion: This group of doctors were aware of the use of opioids for refractory dyspnoea and willing to prescribe opioids for this symptom. However, clinical experience was considerably under patient disease. Fears about side effects were prevalent and need to be specifically addressed in the context of opioid use for dyspnoea.

Conclusion: This study could benefit from clearer guidance on prescribing regimes, especially in contexts other than the dying patient.

No funding received.

The Mystery of Livedo Reticularis: What Does it Tell Us about our Patients?

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Introduction: Livedo reticularis (LR) derived from the two Latin words, lividus (blue/pale) and reticulum (net). LR is pinkish or reddish blue mottled net like discoloration of skin. It is due to increased viscosity, deoxygenated hemoglobin and/or decreased blood flow in cutaneous vasculature (arteries, capillaries, venules).

Methods: A systematic literature search (1966-2012) of the human English literature was done. The key words were “Cancer”, “Livedo”, “Reticularis”, “Sneddon’s Syndrome”, “Vasculitis”.

Results: Among 800 citations: 141 papers with common clinical diseases and cancers. LR reported in breast cancer, lymphoma, multiple myeloma, leukemia. LR may be a sign of previously unsuspected breast neoplasm or first sign of metastatic disease. 7% of those with cutaneous vasculitis have associated malignancy (most often myeloma-lymphomoproliferative disease). Ataxia myoma may present

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with LR and non specific skin lesions.

**Conclusions:**
1. LR can be a presenting sign of recurrent or newly diagnosed cancer.
2. Sub-clinical disseminated intravascular coagulation (DIC), vasculitis and paraneoplastic disorders may contribute. A breast irradiation as a major mode of DIC.
3. LR is associated with anti-neoplastic drugs. A fibrin split (an epidermal growth factor receptor inhibitor) b. Interferon-a 2b (an anti-angiogenic agent) c. Gemcitabin (nucleoside analogus)
4. LR clinical significance in cancer undetermined.

**Abstract number:** P2-061
**Abstract type:** Poster

**Breath Work in Palliative Care Patients - A Pilot Study**

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1. University of Munich, Interdisciplinary Center for Palliative Medicine, Munich, Germany. 2. Catholic University of Applied Sciences, Munich, Germany.

**Aim:** The study is aimed to provide breathing exercises in palliative care patients after finishing radiotherapy. The following data were assessed.

**Method:** Patients who were screened in the project period.

**Results:**
- 58.9 +/- 9.8 years after finishing radiotherapy.
- The distance between both electrodes (medioclavicular, preparotid) was 17 head neck cancer patients (16 male, 1 female, mean age 58.9 +/- 9.8 years).
- Measured resistance (Rz) and reactance (Rxc) as markers of tissue hydration and the capacity of cellular parts within the electrical field. The results were analyzed in relation to the clinical grade (0 - none, 1 - mild, 2 - severe) of lymphoma remission of the neck region as a classical measure of its toxicity.

**Conclusions:**
- To be in a palliative phase implies that often the patient will have lower muscle strength which can create high riskfall. What creates fall risk varies from patient to patient. Focus on prevention for falls should be included in the treatment of patients in a palliative ward.

**Abstract number:** P2-062
**Abstract type:** Poster

**Palliative Interventions for Obstructive Uropathies in Advanced Cancer Patients**

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**Objective:**
- To evaluate the quality of life of patients with obstructive uropathies due to advanced cancers requiring interventions were evaluated. The demographic data, and clinical analysis were retrieved from patient charts retrospectively. Obtained data were analyzed in relation to the clinical grade, year, mean, standard deviation etc were performed.

**Results:**
- A total of 1405 advanced cancer patients were treated with BIA. Thirty-two patients (2.27%) who required interventions were included in the study. The mean age of patients was 68.35 +/- 7.8 (mean +/-SD) and 84.3% (n=275) were males. The most common finding was:

- Upper arm muscle area (AMA) (cm²) (38.2 vs. 44.8, p< 0.05) and women (r=0.54, p< 0.05) and explained more strength.
- Patients with AMA consistent with sarcopenia (values < 32 cm²) had lower muscle strength than non-cachectic and change of muscle strength as important domains for inclusion in risk assessment.

**Conclusions:**
- How much longer?' is a common question asked of palliative care professionals (Kirk & Kristjanson, 2004).
- How much longer? is a common question asked of palliative care professionals (Kirk & Kristjanson, 2004). Morita et al (1998) identified 4 signs that precede imminent death, but Hallenbeck (2003) found these are not infallible and further research was called for. The author has noted previously that higher respiratory rates predicted death within 24 hours.

**Method:** A sample of 100 patients on the LCP using basic observations (pulse rate and respiratory rate) were checked. Tachypnoea was 87% specific for death within 24 hours. RR and PR were weakly correlated with time to death. Receiver Operating Curves were constructed to evaluate the interstitial lymph edema of the neck region after finishing radiotherapy of head and neck.

**Objective:**
- To evaluate the possibility of biopondia to evaluate the grade of interstitial lymph edema of the head and neck region.

**Methods:** We have performed monofrequent (50Hz) BIA in 17 head neck cancer patients (16 male, 1 female), mean age 58.9 +/- 9.8 years.

**Results:**
- Median age was 62 (48-88) years. Median survival was 30 (3-151) weeks. Upon inclusion 36 (81%) patients were classified as cachectic. Cachectic patients had lower mid upper arm muscle area (AMA) (cm²) (38.2 vs. 44.8, p< 0.05) but not lower HGS (28.6 vs. 32.2, ns) than the non-cachectic patients. AMA was correlated to HGS in both men (r=0.44, p< 0.05) and women (r=0.54, p< 0.05) and PR of 120bpm was present in more than 50% of the HGS variation (adjusted for sex and age). Patients with AMA consistent with sarcopenia (values < 32 cm²) had lower muscle strength than non-cachectic and change of muscle strength as important domains for inclusion in risk assessment.

**Conclusions:**
- The Sunniva Palliative ward has recorded many falls and so was chosen as a project ward from Haraldsplass Diakonale Hospital.

**Method:** Patients receiving breath work therapy were asked to complete questionnaires before and 24 hours after breath work, including the subscales anxiety and depression of the Brief Symptom Inventory to assess the mental health and 18 numeric rating scales asking for their self perceived quality of life, and their mental and physical state. In addition 0.41 was chosen as a project ward from Haraldsplass Diakonale Hospital.

**Results:**
- 34 patients were screened in the project period.
- In August when the "Stratify" program was used, 4 out of 11 patients scored high fall risk.
- In September, October and November the "Downton" program was used in addition to the "Stratify". 11 of 36 patients scored high fall risk with "Stratify", while "Downton" gave high fall risk for 22 of 36 patients.
- A total of 27 patients out of 36 scored high fall risk during the project period.

**Conclusion:**
- To be in a palliative phase implies that often the patient will have lower muscle strength which can create high riskfall. What creates fall risk varies from patient to patient. Focus on prevention for falls should be included in the treatment of patients in a palliative ward.
Negative pressure dressing. In case of dressing problems or complications, a vacuum regulator was used for the dressing change. To avoid this issue, image insulation of non-certified equipment from certified medical devices (vacuum regulator) was recommended. The system was designed with LabVIEW visual environment, web camera, medical vacuum regulator and various input/output (I/O) modules.

Results: The system was created with small amount of expenses, and it allows to set up and monitor pressure value in negative pressure dressing. In case of dressing problems or critical pressure value, the system remotely calls medical staff.

Conclusion: Designed system creates similar therapeutic effects to commercial systems. The main advantage of this project is lower cost and greater availability.

Aim: Development of a protocol for standardized monitoring of palliative patients who have received, or are expected to receive, a medication for pain or sedation.

Methods: A literature review, we developed an algorithm, with a practical guide (“Practice Points”) and a specific monitoring flow sheet, for use when a patient has a known need for medication for pain or sedation. The measurement is based on the consciousness level according to the consciousness scale used by the attending clinician in 98% of our patients. The distribution of phases was: 21% stable in UK (cf. 30.4% Australia), 35% unstable (cf. 26.6%), 32% demonstrating deterioration (cf. 12% terminal (cf. 13.9%). In the UK, no patients classified stable died during admission whilst 90% of patients classified as terminal died (compared to 4.8% and 55% respectively in the Australian data).

Conclusions: These results demonstrate the feasibility of collecting phase of illness data in a palliative population in the UK. Despite differences in population size, the distribution of phases between the UK and Australia are similar. Further testing of the validity and reliability of this classification system as a potential casemix criterion is needed.

Aim: To assess the feasibility of collecting phase of illness data in a UK in-patient palliative population. With this data, important referrals to the palliative care team over an 8 week period. The distribution of phase of illness in our population was compared with data from the Palliative Care Outcomes Collaborative Report on Palliative Care in Australia (2010). Results: 87 patients (60% male, mean age 67.5 SD 19), 62% cancer, 38% non-cancer were assessed. Outcomes were: 24% died, 71% discharged and 5% ongoing admissions. Median time to outcome was 7 days. In comparison, Australian inpatient data showed 89% had a malignancy and median length of stay was 7 days (13193 patients).

Phase of illness was fully recorded by the attending clinician in 98% of our patients. The distribution of phases was: 21% stable in UK (cf. 30.4% Australia), 35% unstable (cf. 26.6%), 32% demonstrating deterioration (cf. 12% terminal (cf. 13.9%). In the UK, no patients classified stable died during admission whilst 90% of patients classified as terminal died (compared to 4.8% and 55% respectively in the Australian data).

Conclusions: These results demonstrate the feasibility of collecting phase of illness data in a palliative population in the UK. Despite differences in population size, the distribution of phases between the UK and Australia are similar. Further testing of the validity and reliability of this classification system as a potential casemix criterion is needed.

Aim: To assess the feasibility of collecting phase of illness data in a UK in-patient palliative population. With this data, important referrals to the palliative care team over an 8 week period. The distribution of phase of illness in our population was compared with data from the Palliative Care Outcomes Collaborative Report on Palliative Care in Australia (2010). Results: 87 patients (60% male, mean age 67.5 SD 19), 62% cancer, 38% non-cancer were assessed. Outcomes were: 24% died, 71% discharged and 5% ongoing admissions. Median time to outcome was 7 days. In comparison, Australian inpatient data showed 89% had a malignancy and median length of stay was 7 days (13193 patients).

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Session papers

Poster sessions

49 Shades of Grey: Impact of Hospice Ultrasound Use on Patient Care

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Background: Patients with advanced disease require transportation to hospital for ultrasound identification of abnormal fluid and location marking. This is not only exhausting, but introduces service delays, increases work for an already overburdened hospital radiology service and reproducing the exact position of original scan is difficult. Aim: To describe the introduction of portable ultrasound in hospice patient, carer & health professional experience and co-ordination of care.

Method: Two hospice doctors underwent the necessary ultrasound scanning training for non radiologists. Following a selection process, an appropriate portable ultrasound machine was purchased, and support agreed with one of the local radiologists. Results: A retrospective review of two years ultrasound use was undertaken. Sixty two patients had ninety eight separate scanning episodes resulting in forty eight procedures. Inpatient presence & location of abdominal acutus prior to paracetamol, confirmation of location of pleural fluid prior to aspiration, confirmation of full bladder and nephrostomy tube insertion (urethral or suprapubic), monitoring the growth of large intra-abdominal malignant cyst, confirmation of hydrothorax, biliary stent placement or removal in real time neural blockade. The poster includes detailed analysis of use. Conclusion: On each occasion a definitive clinical question was answered over eighty percent of the time. Pain was adequately controlled during paracentesis, and delirium experienced improvement after treatment. Several outcome measures could also be measured, eg 78% (response: 86%) of deceased patients were satisfied with their pain medication.

Abstract number: P2-074
Abstract type: Poster

Assessing Quality of Palliative Care Using a Quality Indicators Set: Results of a First Measurement in Belgium

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Aim: In Belgium, a quality indicator (QI) set for palliative care (PC) was developed using the RAND method. We aimed at assessing quality of care across different PC services using the set.

Method: The QI set was used in 9 specialist PC services in different health care settings in Belgium. Within each service, living patients (n=167) and deceased patients (n=50) were cross sectional selected. Questionnaires surveying outcome and process of care in 3 main modules (physical and psychological care, communication and organization of care) were sent to all living patients and their most involved palliative caregiver, and to a close family member and treating physician of the deceased patients.

Results: For patients under care we received questionnaires of 68 patients (response 53%) and 117 caregivers (response 91%). For deceased patients we received 107 from bereaved family (response 55%) and 125 from treating physicians (response 65%). Several process indicators could be measured, eg general symptom burden was assessed in 95% of patients, pain in 93% (response 84%), delirium in 94%, and 52% of home care planning meeting with the family took place. Several outcome measures could also be measured, eg 78% of patients with pain reported score >40 (response: 65%) in 92% of cases. Family received bereavement support in 51% of cases. Conclusion: It is feasible to gather a comprehensive set of quality indicators of palliative care involving palliative and regular care providers, patients, and bereaved family. Quality seemed good for some indicators whereas others had room for improvement. Further assessment of significant case mix adjusters and the discriminative power of the indicators is needed before the QI set can be used for public comparison between the different services (benchmarking).

Abstract number: P2-076
Abstract type: Poster

Aim: The SPICT™ can support clinical judgment and prompt actions needed to manage deterioration in patients’ quality of life, performance status and care needs. The SPICT™ provides clear guidance in accessible language that can be used to initiate care planning discussions with patients and families, as well as between professionals and teams.

Conclusions: The SPICT™ contains readily identifiable general indicators for any advanced illness and disease specific indicators for common life-limiting conditions. The SPICT™ can support clinical judgment and prompt identification and discussion of deterioration at risk of dying within 12 months who will benefit from supportive and palliative care.

Abstract number: P2-074
Abstract type: Poster

Mapping Specialization in Palliative Medicine across Europe: Report from a 2012 EAPC Survey

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Background: Palliative medicine (PM) has been a specialization in the UK since 1987 and in Ireland since 1995. In 2007, the EAPC Task Force on the Development of Palliative Care in Europe, using CUSP (Curriculum, University of Navarra, Pamplona, Spain, University of Lyon, Lyon, France), designed a survey to identify the extent of PM specialization in 47 European countries, and to determine whether the certification process was based on formal education, training, and supervision.

Method: A questionnaire was designed to explore the situation in each country including official certification name or title, year of approval, process of certification, number of physicians, and website or title, year of approval, process of certification, number of physicians, and website or title of specialty. The data was collected by the research team on the EAPC website. The contact person was asked to complete the survey regarding access to controlled medicines as a fundamental human right, and (c) participants’ evaluation of the conference. Questions focused on (a) barriers and opportunities in gaining access to controlled medicines in their respective country, (b) knowledge and attitudes regarding access to controlled medicines as a fundamental human right, and (c) participants’ evaluation of the conference.

Results: Over the course of the three conferences, a total of 167 participants completed both pre- and post- conference questionnaires (answers ranged from considerably to not at all). 156/167 reported that their knowledge about accessibility of controlled medicines had been enhanced by attending the conferences, 142/167 reported that their knowledge about the regulations in relation to the accessibility of controlled medicines had ‘been changed by attending the conference’, and 162/167 reported that their knowledge and attitudes in relation to the accessibility of controlled medicines had ‘been changed by attending the conference’.

Conclusion: The results of the conference evaluation suggest that the ATOME one-day Improving Access to Opioidal Medication National Conferences in Slovenia, Turkey and Cyprus were successful in enhancing participants’ knowledge and in changing their attitudes in relation to the accessibility of controlled medicines.

Abstract number: P2-079
Abstract type: Poster

Validation Process of a Complexity Classifying Tool in Palliative Care. (In Spanish: Instrumento para Medir la Complejidad en Cuidados Paliativos: ICC-Pa)

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Background: The Access to Opioid Medication in Europe (ATOME) project held one-day Improving Access to Opioid Medication National Conferences in Slovenia (March 2012), Turkey and Cyprus both May 2012. The conferences (the first of twelve scheduled) were organized by Help the Hospices in collaboration with each country team and were attended by government representatives, health-care professionals, regulatory and law enforcement authorities, and experts from the field of palliative care, harm reduction and pain management.

Aim: To evaluate the impact of the conferences on the experiences, beliefs, and potential concerns of participants regarding access to controlled medicines for pain and symptom management.

Method: A pre- and a post- conference questionnaire were distributed to participants before and after the last of the end of the conference. Questions focused on (a) barriers and opportunities in gaining access to controlled medicines in their respective country, (b) knowledge and attitudes regarding access to controlled medicines as a fundamental human right, and (c) participants’ evaluation of the conference.

Results: Of the 167 participants, 156 completed both pre- and post- conference questionnaires (answers ranged from considerably to not at all). 156/167 reported that their knowledge about accessibility of controlled medicines had been enhanced by attending the conference, 142/167 reported that their knowledge and attitudes in relation to the accessibility of controlled medicines had ‘been changed by attending the conference’, and 162/167 reported that their knowledge and attitudes in relation to the accessibility of controlled medicines had ‘been changed by attending the conference’.

Conclusion: The results of the conference evaluation suggest that the ATOME one-day Improving Access to Opioid Medication National Conferences in Slovenia, Turkey and Cyprus were successful in enhancing participants’ knowledge and in changing their attitudes in relation to the accessibility of controlled medicines.
Aim: Create and validate a tool assessing complexity level (LC) based on cognitive-ability elements in terminal situations to optimize resource utilization, based on Andalusian Palliative Care Integrated Strategy's Complexity Classification (PAI CP).

Design:
1. Covert PAI CP into Complexity Classifying Tool in Palliative Care (ICC-Pal V.0) by expert consensus panel.
2. Advance ICC-Pal V.0 tool's content validity:
   - a) Pilot testing through doctor's consultations of terminal patients identifying CEs present, establishing a CL for each case.
   - b) Determination of inter-rater reliability, through filmed simulated terminal patient consultation cases.
   - c) Analysis of usability, format and content of ICC-Pal V.0.

Results:
- 1 ICC-Pal V.0 was developed from PAI CP with 35 CE each one assigned a CL (minimum, medium and maximum), classified CEs.
- 2 Initial pilot of ICC-Pal V.0 released a new version: ICC-Pal V.1, with 40 CE, each with their CL in five dimensions including complex cognition: each CE was assigned with CL assigned for each CE in 80% of ICC-Pal V.1 CE. No CE was considered of minimum complexity, so this level was eliminated.
- 3 New version: ICC-Pal V.2 was established containing 36 CE with their CL, in three dimensions, and a reviewed glossary.

Conclusion: ICC-Pal V.0 and ICC-Pal V.1 were well accepted by professionals. The tool was simplified in its format and a greater number of professionals incorporated. The latest version of ICC-Pal is currently being evaluated by professionals. The final tool aims to be useful to diagnose if the situation of the patient and their families is complex or not and to what degree, in order to select the most appropriate resource to provide the care and to optimize service delivery.

Abstract number: P2-080
Abstract type: Poster

Spanish Version of Patient Dignity Inventory (PDI): Translation Process and Preliminary Psychometric

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Introduction: The Patient Dignity Inventory (PDI) was designed to measured different sources of distress related to diagnosed advanced cancer patients. The aim was: to obtain a Spanish version of the PDI.

Method: A translation-reverse translation method was used bilingual following the guide of the European Organisation for Research and Treatment of Cancer (EORTC). The Ethics Committee on Clinical Research approved the study. Advanced cancer both inpatients and outpatients from the Oncology and Palliative Care department were included, with full cognitive abilities according to the criteria of the EORTC. Spanish validated version.

PDI was being evaluated: internal consistency (Cronbach’s Alpha), concurrent validity with the PDI-EN, EORTC-CPQ, EORTC-FA and EORTC-PID, discriminant validity between inpatients and outpatients, and between different performance status. The utility was obtained by the time of care delivery.

Results: 37 patients were recruited and 35 completed the study. The Cronbach’s Alpha coefficient was of 0.89. The PDI correlated well with the EORTC-CPQ (rs=0.66, p<0.001) and EORTC-PID (rs=0.67, p=0.01), however the correlation with the FACIT was lower (rs=0.41, p=0.047). The survey distinguished between inpatients and outpatients and among patients with different performance status obtained by the Karnofsky’s (KPS) scores (rs=0.48, p=0.004). The Patients took an average of 5.33 minutes to complete the PDI. The PDI was considered that the instrument was clear and easy to complete.

Conclusion: The preliminary data of the validation shows that the Spanish version of PDI presents good psychometric properties. A larger study will be done to measure other psychometric properties as test-retest and factor analysis.

Abstract number: P2-081
Abstract type: Poster

Can Mini Mental State Examination Represent Specific Neuropsychological Tests in Cancer Patients?

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Objective: To verify the correlation between MMSE total score and Digit Span Test (DST), Trail Making Test A & B (TMT), Finger Tapping Test (FTT) and Continuous Reaction Time (CRT) scores.

Methods: Study composed by 181 cancer outpatients receiving palliative care in a public hospital no central nervous system cancer or brain metastasis. Data were collected between 2010 and 2012. Five neuropsychological tests were used to classify cognitive function: MMSE, DST, TMT A & B, FTT and CRT. Statistical analysis was performed by R v. 2.15.1 and correlations between MMSE and cognitive tests were verified by Pearson's test.

Results: Most patients were female (57%). Education mean was 11.6 y (SD=3.3), monthly income mean was US$ 1592.78 (SD=1664.00), and age mean was 61.91 yr (SD=14.08). As expected, MMSE had negative correlation with TMT-A and B (rs=-0.42, p=0.05, respectively). As expected, DST correlation with MMSE was not significant (r=0.03, p=0.01) and FTT (r=-0.23, p=0.01). A negative correlation between CRT and MMSE was expected, but it did not occur (r=0.09, p=0.05).

Conclusion: Cognitive functions are connected and deterioration in one domain may affect others. It was hypothesized that MMSE's ability to assess different domains of cognition, would have good correlation with more specific cognitive tests, which was partially observed. MMSE had weak correlation with the expected direction, with TMT A and B, FTT and DST, but was not correlated with CRT. Weak correlations suggest that these tests evaluate different domains of cognition and that MMSE cannot substitute more specific assessment. Although MMSE is comprehensive, its application is time consuming and apparently not sufficient for detecting cognitive alterations. Given this, researchers should analyze the perimetry of applying a general test or a battery of specific cognitive tests to monitor patients at risk for cognitive alterations or who already presents cognitive dysfunction.

Abstract number: P2-082
Abstract type: Poster

Does the Palliative Care Outcome Scale Capture the Same Constructs as for Non-Cancer Patients? A Factor-analytic Comparison

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Context: The Palliative Care Outcome Scale (POS) is widely used to assess needs and outcomes in palliative care. The POS has good construct validity as well being acceptable to both patients and health care professionals. The internal factor structure of the POS, using self-reported assessment of data cancer patients, has been investigated and showed that the POS captured two factors: ‘psychological status’ and ‘quality of life’. The aim of the present study was to explore and compare factor structures in cancer and non-cancer samples. In this way the validity of the POS across patient groups can be determined.

Methods: Exploratory factor analyses were used for secondary analysis of data from 4 existing POS datasets. The non-cancer dataset included 216 patients (60 OPD, 82 Parkinson, 74 chronic kidney disease stage 5 patients) and the cancer dataset included 94 patients. For the factor analyses we used the principal component analyses with Varimax rotation.

Results: Cronbach’s Alpha was 0.70 for both cancer and non-cancer datasets. The factor structure extracted was based on the number of eigenvalues > 1.0 However the solution was not interpretable so we extracted and rotated a reduced number of factors. The factor correlation structure with one profile was observed. A factor reflecting ‘psychological well-being’ and ‘one reflecting family issues’ were identified in both samples. The cancer dataset the POS item on ‘practical problems’ and in the non-cancer dataset the POS items on ‘practical problems’ and ‘wasted time’ did not load high on either of these two factors. However strong ceiling effects were evident in both samples for these items.

Abstract number: P2-083
Abstract type: Poster

Poster challenges on Cancer Pain Classification: How Do We Make Sense of the Evidence?

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Aims: The complexity of the pain experience in advanced cancer presents unique challenges for pain classification. Currently, there is no universally accepted pain classification system that provides a prognosis of the complexity anticipated, as well as a standard to compare clinical and research outcomes. The Edmonton Classification System for Cancer Pain (ECS-CP) was developed to provide a standardized, comprehensive approach for the classification of advanced cancer pain. The purpose of this paper is to describe the unique challenges associated with conducting research on cancer pain classification, using the ECS-CP as a case example.

Methods: The findings from a recent ECS-CP multi-centre study of 1100 patients were compared with two other recent publications on pain classification, using the following parameters: study design, patients' characteristics, endpoints, hierarchical structure, definition of stable pain control and study outcomes. Results: The three studies varied in terms of study design (prospective vs. retrospective), patients' characteristics, endpoints, hierarchical structure, definition of stable pain control and study outcomes. Conclusion: There has been a recent interest in developing multiple datasets for reporting pain outcomes to enhance the transparency of the research process and facilitate cross study comparisons. The lack of consistency in reporting pain features across studies reinforces the need to develop a standardized pain classification system for describing pain characteristics. Further research is needed to better understand the complexities of a pain classification system for cancer pain using prospective study designs that integrate patient and clinician reports.

Abstract number: P2-084
Abstract type: Poster

Off-label Prescriptions in Palliative Care Patients at our Home Care Unit

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Aims: The use of off-label drugs is considered to be frequent. This pilot study aimed to describe and to quantify the off-label use of drugs that have been prescribed to palliative care patients just before admission in a Home Care Unit and explore the motives of off-label use. The secondary aim was studying if the off-label prescriptions were according with the noso-guides in our environment (we tried four of them).

Methods: A cross-sectional study was carried out. Information was obtained from prescription, sampling 20 beds at our Home Care Unit during six months. Demographic and anthropometric characteristics, clinical background, current diseases and prescriptions just before admission were registered.

Medications were analysed to determine whether they had been prescribed according to the term of the summary of product characteristics (SmPC).

Results: 31 patients (19 women) were included, mean age was 61 (range 17-93) and 51% were considered to be of terminal stage (we tried 17 SmPC), 11 different pharmaceutical products. Patients received from 2 to 14 (mean 8.0) medications for treating 244 health problems (32 different medication). The prevalence of off-label prescriptions was 17%. Opioid analogics were the most commonly used drugs, according the pain which was suffered by 93.5% of the patients. 39 prescriptions (18.1%) involving 26 (83.9%) patients were

Poster sessions – ret 2
off label due to their use in disagreement with the indications authorised in SmPCs. 8 medications affecting 7 patients were off label due to the lack of SmPC. The care for the patients was profoundly off label and the palliative care in patients with terminal cancer by concomitant drugs was the most frequently used off label drug. As for the four guides included in this study, just three of the off label prescriptions weren’t suggested by the authors of the guides.

Conclusion: Off label use is a common practice in palliative care patients and is clearly shown by the gold-standard guides used in our environment.

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(Poster 2/10)

**Poster abstract number:** P2-085

**Title:** Nursing Diagnosis in Palliative Care: The Use of the “Palliative Care for a Dignified Dying”

**Authors:** Tucker T.

**Affiliation:** Palliative Care Education and Research, Ottawa, ON, Canada, but with lower frequency.

**Methods:** These instruments are part of a suite of newly validated tools measuring and comfort/confidence in palliative care, and also knowledge.

**Conclusion:** Medics and students in family or internal medicine, and oncology, who completed rotations in our palliative care program, were recruited to voluntarily completely all tools pre and post rotation. Attitudes and Comfort were measured at baseline and in the OPC, as they are three additional tools: Fremmelt Attitudes Towards Caring for the Dying Scale-Form B (FATCOD-B); Thanatophobia Scale (TS); Self-efficacy for caring the dying (SEPC); the FOCUS-27; ACP and SEPC, coefficients were 0.82 to 0.97. The effect size and canonical correlation analysis indicate that there is considerable redundancy between the FOCUS and OPC on the one hand, and the FATCOD-B, TS and SEPC, on the other. The SEPC is strongly correlated with the OPC (RI) applicable in every care setting.

**Support and Home Care Teams**

Nurses are key players in palliative care teams. They identify nursing diagnosis and fulfill intervention to promote patients’ well-being and family support.

**Methods:** A longitudinal comparative study was conducted both in a hospital support team and in a specialized home care team during one month in Portugal. Data were collected using a nursing diagnosis identification instrument: “The International Nursing Practice Catalogue, INPC® Catalogue, ‘Palliative care for a dignified dying’” The study included 22 patients.

**Results:** A total of 382 nursing diagnoses were identified by the hospital support team: suffering (validated 30 times); spiritual distress (24 times); impaired ability to bathe (26 times); clean the house (22 times), get dressed/undressed (20 times); discomfort and anxiety (15 times each); feelings of powerlessness; caregiver’s stress and social isolation (each one validated 14 times); fatigue (9 times) and pain (8 times). The home care team found: fatigue (validated 37 times); compromised skin integrity (26 times); lack of knowledge about the medication regimen (25 times); compromised family process; compromised family coping (4 cases); caregiver’s stress (14 times); pain and hopelessness (both validated 11 times); lack of knowledge about the treatment regimen (9 times); and suffering (8 times). Other nursing diagnosis were identified but with lower frequency.

**Conclusions:** The study indicates that similar nursing diagnosis were identified in both of types of team (dying, pain, suffering and caregiver’s stress), although with different frequencies. Also, it concludes that specifics about how the tool was identified by considering the typology of palliative care teams. Further studies are needed to better understand nursing diagnosis in palliative care.

**Poster abstract number:** P2-086

**Title:** Validation of the Ottawa Palliative Attitudes Scale (OPAS) and the Palliative Care Scale (OPC): Assessing Palliative and End-of-Life Attitudes in Medical Undergraduate (UG) and Postgraduate (PG) Learners

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6A Prospective Audit on Medication Adherence amongst Moroccan Palliative Care Outpatients

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2Faculdade de Medicina de Lisboa, Núcleo de Cuidados Paliativos - Centro de Bioetica, Lisboa, Portugal.

**Methods:** To evaluate MA and investigate predictors of MNA in a geriatric hospital in Buenos Aires.

**Results:** Adherence to medications (MA) is directly associated with improved clinical outcomes, higher quality of life, and lower healthcare costs across many chronic conditions. Little attention has been paid to non-adherence to MA (NMA) issues among palliative care (PC) populations.

**Aims:** To evaluate MA and investigate predictors of MA in a geriatric hospital in Buenos Aires.

**Methods:** Prospective observation study, covering all visits during a 4-month period; variables collected at baseline: age, gender, year/month of diagnosis; Charlson index and at each visit: Palliative Performance Scale status, current disease modifying treatment; PC phase; drug chronology prescribed and responsibility for supply (patient self-administration or caregiver). MA was considered inadequate when < 75% of the dose prescribed. A physician perceived MA 5-point score (0=non-adherent to 4= totally adherent) was filled out following each encounter.

**Conclusions:** Among the above classes and a logistic regression model assessing factors associated with the likelihood of MNA (perceived MA score < 3) are presented. Results: 2.13 (224 patients, 13% of the encounters) are analyzed. 2% of patients/caregivers didn’t know current medication. The median number of drugs prescribed per patient was 7 (range 1-15). In 27% of visits patients were perceived as non-adherents. Breakthrough pain (BP) rescues (77%), proton pump inhibitors (60%), hypnotics (57%), opioids (69%), antiemetics (49%) and corticosteroids were the most frequently used off-label drugs. According with the four guides included in this study, the prophylaxis of ulcer by proton pump inhibitors and the use of corticosteroids were the most frequently used off-label drugs. Patients were off-label due to the lack of SmPC.

**Conclusion:** When < 100% of the dose prescribed. A physician perceived MA 5-point score (0=non-adherent to 4= totally adherent) was filled out following each encounter.

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Cancer Symptom Assessment: Termination of Treatment Due to Palliative Care

Comprehensive Cancer Symptom Assessment: ‘‘Orphans’’ and ‘‘Champions’’

Abstract number: P2-092
Abstract type: Poster

Background: Cancer patients experience multiple symptoms which can adversely affect outcomes (survival, quality of life). Comprehensive assessment of symptoms is essential for appropriate treatment plans. The treatment should be tailored to patients’ needs. However, some symptoms are not included in common symptom assessment tools. This study was designed to explore patients’ most distressing symptoms and the influence of symptom assessment on decision making.

Methods: This cross-sectional study was conducted from January 2011 to December 2011 in patients with advanced cancer in a tertiary hospital. Two questionnaires were used: the Edmonton Symptom Assessment System (ESAS) and a supplementary questionnaire. The results were compared. The primary outcome was the proportion of patients whose most distressing symptom was not assessed in the ESAS.

Results: A total of 290 patients were included in the study. The median age was 66 years (range: 22–89). Most patients were male (60%). The most common primary tumor was lung (43%). The most distressing symptom was pain in 24% of patients, dyspnea in 19%, fatigue in 15%, and anorexia in 13%. The median number of symptoms assessed in the ESAS was 4 (range: 1–8). The median number of symptoms assessed in the supplementary questionnaire was 5 (range: 1–13). The median number of symptoms not assessed in the ESAS was 1 (range: 0–4).

Conclusion: This study highlights the need for comprehensive symptom assessment in patients with advanced cancer. The results suggest that the ESAS may not be adequate for symptom assessment in this population. Further research is needed to develop symptom assessment tools that are more comprehensive and responsive to patients’ needs.

Abstract number: P2-094
Abstract type: Poster

Palliative Care Consultation in the Intensive Care Unit

Zaleski K., Courage C., Wasilewsky D., Edelen A.
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Although specific trials have demonstrated the favorable impact of early pain control on mortality and hospital stay, high morbidity/severe intensity cancer unit (ICU) patients, have not been national, multi hospital demonstrations of the effectiveness of palliative care consultation in the ICU have been conducted. A quality improvement study utilizing a network of hospitals was standardized screening tool was applied to all about 3000 patients admitted to ICU. Pain screen prompts were sent to 37 QIs. QIs face valid at this 37 QIs. QIs represent key ideas of the effective clinical practice, such as the availability of palliative care teams, the availability of support to provide palliative care for both patients and their relatives, and the presence of an educational interventions for professionals. The included QIs are also related to the process of palliative care, such as the documentation of pain, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

Conclusion: This set of QIs is the first that has 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: P2-097
Abstract type: Poster

Audit & quality control

Abstract number: P2-095
Abstract type: Poster

Decreasing a Framework for Palliative Cancer and Dementia Care: Quality Indicators to Guide Clinical Practice

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Introduction: Large numbers of vulnerable patients are in need of palliative care; however, a wide gap exists between the knowledge of best practice in palliative care and its use in everyday clinical practice. To bridge this gap this study aimed to compose a generic set of quality indicators (QIs) that can help to assess and improve the organisation of palliative care.

Methods: A multidisciplinary, international panel of experts participated in a modified RAND Delphi procedure to compose a set of palliative care QIs. Consequently, panels participated in two rounds without interaction. The panel’s median votes were used to identify the final set of QIs.

Results: The experts considered 37 QIs face valid at three Delphi rounds. These QIs represent key ideas of the effective clinical practice, such as the availability of palliative care teams, the availability of qualified professionals to provide palliative care for both patients and their relatives, and the presence of educational interventions for professionals. The included QIs are also related to the process of palliative care, such as the documentation of pain, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

Conclusion: This set of QIs is the first that has 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: P2-096
Abstract type: Poster

Tools for Risk Management and Increased Patient Safety in Palliative Care

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Aims: Offering advanced health care in a patient’s home is associated with special requirements in achieving high patient safety. In order to successfully manage risk, there is a need for a structured approach.

Design: We have analyzed and evaluated each component in the risk management strategy. We have collected data from our database of reported risks or events.

Results: Being a large unit with high throughput of patients we have been able to retrieve large quantities of data. The more details will be presented at the congress. The main finding is a clear peak in risk reporting adjacent to the ‘Risk awareness week’ and internal risk audits. Over time this peak has been less steep and is accompanied by a steady increase in the risk reporting emanating from the routine reporting activities.

Conclusion: Having a structured approach to risk management and patient safety is crucial in specialized palliative home care.

Abstract number: P2-098
Abstract type: Poster

A Multi-centre Survey of Paracetamol Prescribing Habits for Specialist Palliative Care Patients

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Introduction: Paracetamol is the most commonly prescribed medication in palliative care. There is a lack of evidence regarding full-dose paracetamol in cachexic and malnourished patients.
Aims: To establish how commonly regular paracetamol is prescribed in conjunction with strong opioids for patients with cancer in 4 Specialist Palliative Care Units (SPCU). To investigate whether paracetamol prescribing is associated with morphine equivalent daily dose (MDED), low body weight, concomitant use of enzyme inducers or presence of liver disease.

Methods: A case-note review of all in-patients in 4 SPCU was conducted. Inclusion criterion: age > 18 years, cancer diagnosis, inpatient > 24 hours, able to take enteral medications.

Results: 65 patients met the criteria, of whom 43 (66%) were prescribed regular paracetamol. The MDED was 1580 (330-1800)mg for those prescribed paracetamol vs 790 (400-1000)mg for those who were not. 26% patients on paracetamol were measured to estimate < 50kg. 4 patients were prescribed a reduced dose of paracetamol, 1 of whom was < 51kg. 86% of patients who were prescribed paracetamol were co-prescribed enzyme inducers and 1/3 of patients in both groups had documented liver disease. Patients on paracetamol took an average 21 tablets/day, compared to 9 tablets/day for those not on paracetamol.

Conclusions: Palliative care inpatients with cancer taking strong opioids are commonly prescribed regular paracetamol, seemingly irrespective of known risk factors for potential toxicity. Paracetamol contributes significantly to tablet burden.

Recommendations: Given the lack of evidence for efficacy in this population, we question whether current paracetamol prescribing habits are judicious. In the absence of robust evidence, we should appraise efficacy on an individual basis and take into account known risk factors for paracetamol to do harm.

Abstract number: P2-098
Abstract type: Poster

Are Two Pairs of Eyes Better than One? Exploring Agreement around Clinical Uncertainty between Nursing and Medical Professionals - A Case Note Review


King’s College, London, UK

Aim: To explore the level of agreement between the views of nurses and doctors in the identification of possible clinical instability with limited reversibility at the end of life and explore barriers to reaching consensus.

Methods: Case notes were reviewed for all patients (n=154) on five wards in a UK NHS hospital (from Nov. 2011 to Apr. 2012) who died in hospital or < 100 days post discharge. Consensus was defined and identified independently by a senior palliative care nurse and a physician, for evidence of clinical uncertainty, defined as: deterioration, clinical instability, limited reversibility and being at risk of dying within 1-2 months.

Results: There was an agreement on the status of 71% of patients (109/154). Where there was disagreement (45/154), it was more common for the nurse (28/45-62%) than doctor (17/45-38%) to declare clinical uncertainty. Following a consensus meeting, the final decision was accepted as being either the nurse’s original decision (48%), as the doctor’s (52%). Prevalence of clinical uncertainty was 25% (agreed by both physicians and nurses) for 38/154 cases). However individually they varied, with 36% (55/154) identified by the physician, and 43% (66/154) by the nurse.

Difficulties were noted in predicting deterioration when baseline functional status was low and with expected levels of uncertain recovery (e.g. after stroke). Differences were noted in the decision making process, between the doctor and nurse when there were advance care planning needs, but limited clinical uncertainty. Agreement was reached for all pairs in 10 consult consensus discussion.

Conclusions: This review highlights the contrasting views of professionals in identifying uncertainty. Effective multidisciplinary input of all working has the potential to increase consensus and to optimise care for patients approaching the end of life.

Funding: SCTF Charity.
First, we conducted a Systematic Review, to identify the important measure the quality of care provided to promote the improvement of care at the end-of-life. Aims: To define basic quality indicators of the domain of Structure and Process of Care, for palliative care services using Delphi technique with palliative care experts.

Methods: First, we conducted a Systematic Review, to indentify the indicators to use in the study.

• 92 experts, who had more than 3 years of experience working in Palliative Care were invited to collaborate in the study.
• 3 rounds were done (2 to define the QI, and one to define the standard) of Delphi Method, with 71, 66 and 65 participants, respectively.

The criteria to determine the agreement and consensus were:
• Very high: ≥80% of agreement + Median rating of 5 on the 5-point agreement scale + IQR = 0
• High: ≥60% of agreement + Median rating ≥4 on the 5-point agreement scale + IQR = 1
• Moderate: ≤ 40% of agreement + Median rating ≤ 3 on the 5-point agreement scale + IQR = 1
• Low: <40% of agreement + Median rating < 3 on the 5-point agreement scale + IQR = 1

Results: A total of 33 from 43 quality indicators were defined. These indicators 1 are of structure and 2 of process (their description and standard will be done in the presentation).

Conclusions: We found a total of 14 basic quality indicators which belong to the domain of “Psychological and Psychiatric Aspects of Care”. So they must be used by the palliative care service in Portugal to evaluate and improve the quality of care delivered in this domain.
The questionnaires are submitted anonymously with permission to own comments.

Result: Mean for how patients feel that they have received information about the ward is 78% and for loved ones 58%

90% of both patients and loved ones are satisfied with information about treatment and care.

Almost everyone reported satisfaction with the medical care and as well as in terms of attitude and confidence.

85 % of the loved ones were involved in some kind of planning meeting.

All survivors were pleased with being contacted after the patients’ death.

Conclusion: Our conclusion after ten years of evaluation by questionnaires, in patients and as well as in loved ones, in many ways are satisfied with the care while that there are improvement opportunities regarding information and participating.

It is important with follow-up to provide good and safe care. By continuously using questionnaires, an ongoing assessment of the level of patient care can be done to identify areas that need improvement.

Abstract number: P2-111
Abstract type: Poster

In the Patient Satisfaction Questionnaire (PSQ) an Acceptable Tool for Use in a Hospice Inpatient Setting?

Johansson A1, Finoone A.M.2, Onmark D.2, Henriksson K.M.2

Background: The PSQ is an assessment tool recommended to inform the continued professional development (CPD) of medical staff in the UK, aiming to evaluate patients’ perspectives of their doctors’ attitude towards them and their Interpersonal skills.

The aim of this study was to investigate the acceptability of administering the PSQ to hospice in-patients and relatives.

Method: Over a two week period, all in-patients deemed well enough to complete a brief questionnaire by the multidisciplinary team, were asked to complete a PSQ (9 hospice in-patients and 1 relative acting as surrogate) equating to 45% of all hospice in-patients during that period.

All in-patients asked to complete a questionnaire were subsequently invited to take part in a brief interview study. Semi-structured patient interviews were used to explore patient experiences of the questionnaire process, their interest in completing a questionnaire about their doctor, and any feelings of coercion.

A collaborative inductive content analysis involving members of the study team was then used to identify major themes.

Results: All 10 approached (9 patients and 1 relative) agreed to take part in the interview process following completion of the PSQ.

The findings suggest that:

• Hospice in-patients believe that the PSQ is clear and easy to understand.
• Hospice in-patients do not feel that the PSQ is burdensome in terms of time or effort.
• Hospice in-patients believe they can be honest when responding to the PSQ.
• Some hospice in-patients see themselves as a valuable resource for informing the medical staff.
• Some hospice in-patients view completing the PSQ as an opportunity to be involved and empowered.

Conclusion: The PSQ is an acceptable tool to use in a hospice in-patient setting in order to inform the CPD of medical staff. Many patients welcome the opportunity to be involved in the feedback processes.

Abstract number: P2-112
Abstract type: Poster

Audit of Identification and Advance Care Planning Management of Patients with Heart Failure and Poor Prognostic Features

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The Christie NHS Foundation Trust, Manchester, United Kingdom, Central Manchester University Hospitals NHS Foundation Trust, Manchester, United Kingdom, "Perrinence Acute Cardiac Unit, Manchester Heart Hospital, Manchester, United Kingdom, "Wigan and Leigh Hospice, Wigan, United Kingdom, "Salford Royal NHS Foundation Trust, Manchester, United Kingdom, "Greater Manchester and Liverpool Heart and Lung Network, Stockport, United Kingdom, "NHS Community Health Stockport, Stockport, United Kingdom, "Bolton NHS Foundation Trust, Bolton, United Kingdom, "University Hospital of South Manchester, Manchester, United Kingdom

Background: The prognostic of advanced heart failure is comparable to or worse than most cancers and as such heart failure patients should be offered the same standard of integrated palliative care.

Aims: To assess the management of patients with heart failure,

Methods: A regional retrospective audit of patients who had died from heart failure. Standards were agreed, with reference to best available evidence, by a multi professional group.

Results: 123 patients were included from 8 sites across hospital, hospice and community. 51% of patients were recognised to be in the last year of life, less than three months before death. 27% of admissions in the 12 months prior to death due to worsening symptoms or reduction in functional status were 5.2, 0.9-3.5. 4.5-5.9% of patients were under the care of a heart failure specialist nurse. Within the last year of life, 46% of patients were given the opportunity to discuss the implications of their diagnosis, 12% were given the opportunity to discuss their preferred place of care and 11% were given the opportunity to discuss advance care planning. For patients with an implantable defibrillator, 33% had documented evidence of a conversation regarding its deactivation. 29% of patients were considered for referral to specialist palliative care services and 92% of these were referred.

Conclusions: The pharmacological management of heart failure and poor prognostic features is now well established; however there is a need to improve identification of patients in the last year of life to allow timely discussions about the implications of the diagnosis, preferences for care and advance care planning. Greater collaboration between palliative care and cardiac services may help to facilitate this.

Abstract number: P2-113
Abstract type: Poster

Opioid Prescribing in a Cancer Centre

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North and East Kent NHS Trust, Palliative Care, Northwood, United Kingdom

Background: Opioid medications are commonly prescribed for cancer pain. National studies have consistently shown high numbers of drug errors when prescribing opioids. The National Patient Safety Agency has recommended the use of critical incident reporting systems (CIRS) that could serve to understand kinds, causes and consequences of errors in palliative care and help to prevent them.

Methods: We developed a pilot CIRS for palliative care in Germany that was launched in May 2011. Professionals can anonymously report critical incidents in a web-based platform that is reviewed, anonymised and commented by an interdisciplinary team of experts prior to publication online. Published reports were analysed using quantitative content analysis.

Results: In the first 15 months there have been 12 reported cases. Three quarters were reported by physicians, one by specialist nurses. Most errors occurred in the area “diagnostic and therapy” (n=5, essentially in drug treatment) and in the area “organisation and system” (n=4, specifically in communication).

One only case described the death of a patient as result of an error; in six cases there was a light or moderate harm for the patient, and in the five remaining cases the patient was not harmed.

Discussion: The reported areas of errors are similar to what is known from other medical disciplines. The number of reports, however, is low and the CIRS should be better promoted to enhance its utilization. A larger database is necessary to conduct robust patient safety studies, assess the needs in palliative care and design specific interventions to increase patient safety.

Abstract number: NB-P109
Abstract type: Poster

How to Find out - An Ongoing Follow up

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Sahlgrenska University Hospital, Palliative Care, Gothenburg, Sweden, Sahlgrenska University Hospital, Gothenburg, Sweden, Sahlgrenska University Hospital, Palliative Care Unit 604, Gothenburg, Sweden

Background: It is important that patients as well as loved ones, experience the nursing and medical care as good and safe. To improve and adapt care between professions, it is important that mistakes are identified.

Aims: Patients and loved ones must be able to give their views on the quality of the care; so the staff can identify areas for improvement.

Method: Since 2001 the Palliative Care Unit has been using questionnaires to improve care during a patient’s illness. A patient who is leaving the ward receives a questionnaire at the day of discharge and returns it when completed the same day.

Questionnaires are sent to loved ones to patients who died after two months after the patients death.

The questionnaires contain questions about information about the ward, disease and treatment, perceived participation, attitude and confidence in the ward. The loved ones are also asked about the follow-up call.

All 10 approached (9 patients and 1 relative) agreed to take part in the interview process following completion of the PSQ.
Physicians (RCP) has set standards for medical handover to ensure patient care and safety. Standards: The RCP standards were adapted to include local & regional standards. This resulted in improvements in documentation and casemix. A retrospective 3 months research was undertaken by the team comprising of medical and/delegated staff who conducted an audit to assess the patient’s current conditions. The audit was conducted in 3 months. A total of 126 patient handovers were the subject of the audit.

Results: The results showed that there was an improvement in the information provided during the handover. The data was collected from the records of the patients and the data was analyzed using Microsoft Excel. The results showed that there was an increase in the number of patients who were documented in the records. The analysis showed that there was a significant improvement in the documentation of pain and pain management.

Conclusion: The results of the audit showed that there was an improvement in the documentation of pain and pain management. The audit was successful in improving the documentation of pain and pain management.

Abstract number: P2-115
Abstract type: Poster
Uncontrolled Background or Breakthrough Pain: Are We Differentiating? A Re-audit
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2Heart of England NHS Foundation Trust, Palliative Care, Birmingham, United Kingdom

Background: Pain is common in patients with cancer, affecting up to 75% with advanced disease. Effective pain control requires accurate assessment in order to determine appropriate management. A previous audit identified weaknesses in assessment and documentation of various domains of pain including temporal patterns. The aim of this re-audit was to evaluate pain assessment documentation after introduction of a redesigned pain assessment tool.

Methods: The redesigned pain assessment tool was piloted in 15 patients admitted to the inpatient specialist palliative care unit. Data collected covered the ten recognised standards for assessment and management of palliative patients, including: recording of pain of location, intensity, duration, temporal patterns, quality, exacerbating/releasing factors, and also elements of life, pain significance, and previous pain experiences.

Results: Improvements in documentation were observed after introduction of the redesigned assessment tool. There were marked improvements in documentation of temporal patterns 96% (73%), exacerbating/releasing factors 100% (95%) and early detection of pain 76% (24%) and earlier diagnosis of pain 40% (9%). Previous pain experiences were documented in 21 (15%). 91% of cases there was documentation distinguishing between constant or intermittent pain (55% constant and 40% intermittent).

Conclusion: Redesigning the pain assessment tool to incorporate the ten recognised standards in pain assessment has led to improvements in documentation, altering the patient’s care plan to be better tailored. Inclusion of an additional tool to better describe pain and assess pain quality, exacerbating/relieving factors, and also elements of life, pain significance, and previous pain experiences.

Abstract number: P2-116
Abstract type: Poster
MRS in Palliative Care - Quantifying the Issue
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Aims: This study follows two previous audits of MRS in the palliative care unit (SPCU). The aims were: 1. To determine the prevalence and incidence of MRS in the SPCU. 2. To determine the clinical impact of MRS on palliative patients. Methods: In this prospective study data was collected for all admissions to a 36-bed SPCU over an eighteen month period. A prospective tool was developed to collect demographic data, MRS scoring data, and clinical outcome data for each admission. All patients were screened for MRS on admission and one week later. Prevalence and incidence of MRS was recorded. The length of stay, type of infection, episodes, and mortality data were recorded. Results: Data was collected for 695 admissions and readmissions. This included data for 476 individual patients. The mean age at admission was 69 years (±11 yr) and 473 (68.6%) were male. The mean age at death was 72 years (±11 yr) and 443 (69.6%) were male. On admission 28% of patients had MRS. Of the 28% of patients who were admitted with MRS, 75 (75%) had a malignant diagnosis. The prevalence and incidence of MRS is detailed in the table below.

<table>
<thead>
<tr>
<th>MRS Level</th>
<th>Prevalence (%)</th>
<th>Incidence (%)</th>
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<tbody>
<tr>
<td>1</td>
<td>14.5</td>
<td>11.7</td>
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<tr>
<td>2</td>
<td>6</td>
<td>5.2</td>
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<td>5</td>
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Conclusion: The prevalence of MRS in the SPCU was 28%. Of the patients admitted with MRS, 75% had a malignant diagnosis. The impact of MRS on patient’s care and outcome is significant.

Abstract number: P2-117
Abstract type: Poster
Possible Improvement of Earlier Diagnosis and Control of Pain on a Palliative Care Unit by Standardised Protocols in the Context of a Certification Process
Hofmayer G.1, Jókai M.2, Veres Z.1, Széke M.1, Jákay D.1, Styler P.1, Sindag A.1, Tóth L.1, Tagesi J.1, Sandor-Kiesling A.1, Samogovac H.1
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2Department of Anesthesiology and Intensive Care, Medical University of Graz, Graz, Austria

Aims: About 50-80% of patients with advanced cancer suffer from pain. Therefore, one of the leading threatening symptoms in palliative care units. The main goal is to identify and treat patients with pain as early as possible and to start an efficient pain management and to adhere to the at the up-to-date guidelines at once. It was demonstrated that implementation of standards of analgesics, according to recent guidelines on pain, is a crucial factor for the improvement of pain control.

Methods: Nurses, physicians, and pharmacists scientists in our department have set standards for medical handover to ensure patient care and safety. Standards set out by the existing NHS Lanarkshire guideline were reviewed, the results below show that again patients prescribed regular opioid analgesia had no breakthrough dose prescribed. A significant deficit exists in prescribing of breakthrough analgesia for the management of cancer-related pain.

Conclusion: The results of the audit show that there is a significant deficit in prescribing of breakthrough analgesia for the management of cancer-related pain. A significant deficit exists in prescribing of breakthrough analgesia for the management of cancer-related pain.

Abstract number: P2-118
Abstract type: Poster
Audit of Analgesia Prescribing in Cancer Patients - Are We Meeting the Current Standards?
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Introduction: Cancer pain is frequently inadequately managed, despite guidelines at national, regional and international levels. Current NHS Lanarkshire prescribing practices are guided by regional guidelines developed in 2009 by the NHS Lothian and NHS Lanarkshire palliative care teams using SIGN 106. This audit aims to ensure that prescribing within Monklands Hospital adheres to current standards.

Methods: A cross-sectional study was performed after the medical, surgical, surgical specialties and care of the elderly wards in Monklands Hospital. The notes and drug charts were reviewed of the inpatients with documented cancer pain and assessed to ensure the prescribing was adhering to NHS Lanarkshire guidelines.

Conclusion: The NPS and guidelines were used to review the data. 29 patients were included in the analysis, 6 (20.69%) patients were female and the average age of the study population was 67.7 years (62.2 - 73.1 years). 14 patients had proven metastatic disease.

Abstract number: P2-119
Abstract type: Poster
Does the Liverpool Care Pathway Improve Patient’s Access to Symptomatic Relief?
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2Obstetrics and Gynaecology, Wishaw General Hospital, NHS Lanarkshire, Wishaw, United Kingdom
3Clinical Quality Service, NHS Lanarkshire, East Kilbride, United Kingdom
4Palliative Care, NHS Lanarkshire, Airdrie, United Kingdom
5General Medicine, Monklands Hospital, NHS Lanarkshire, Airdrie, United Kingdom

Five years after its initial introduction in NHS Lanarkshire, this review provides an insight into the use of the LCP. A retrospective analysis of deaths in the three acute NHS Lanarkshire Hospitals – Haemmyres Hospital and Monklands Hospital during February 2012. Case records were reviewed for patients who had died in either the care of the elderly, general surgical, medical or surgical specialty directorate. Data retrieval was by completion of a standardised data extraction proforma.

Results: 36 patients died on the LCP. 80 patients not on the LCP of the 80 patients who died did not care for the LCP. More patients were prescribed regular opioids. 14 (56.00%) patients were prescribed regular analgesia. Of the patients, there were 2 patients prescribed more than one type of regular opioid. Of the patients prescribed regular opioids, 14 (56.00%) patients were prescribed regular analgesia. A(44.00%) patients on regular opioid analgesia had no breakthrough analgesia, a significant difference in the MRSA subgroup. MRSA colonisation conferred a greater risk of infection but did not impact significantly on overall survival.

Conclusion: This audit has demonstrated that prescribing practices at Monklands Hospital are not meeting the current standards set out by the existing NHS Lanarkshire guideline for the management of cancer-related pain. A significant deficit exists in prescribing of breakthrough analgesia for the management of cancer-related pain. A significant deficit exists in prescribing of breakthrough analgesia for the management of cancer-related pain. A significant deficit exists in prescribing of breakthrough analgesia for the management of cancer-related pain.
Abstract number: P2-120
Abstract type: Poster

Assessment of Quality in Palliative Home Care with FEHC

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Aim: To assess the quality of care offered by the home care team and identify the domains with need improvement.

Method: Telephone survey using the Family Evaluation of Hospice Care (FEHC) tool with only one item being removed, as this domain (feeling the right to have unnecessary interventions discontinued such as regular blood tests and antibiotics) did not apply to the type of care provided in FEHC. All items of the tool are scored on a Likert scale from 1 (very bad) to 5 (very good) and the total score calculated. The study included four different types of caregivers (one-week-visit, regular, on-demand and emergency) and 129 eligible families (52% of all families were contacted and 55% of the interviews were completed).

Results: Out of 57 caregivers who died in our care 4 were not complying with the inclusion criteria, 12 families were not answering the survey. The response rate was 80.64%. The results were compared with the inclusion criteria (average score 3.65 for the entire study; 3.36 for home care). The main domain with the least score was the domain ‘Do not recommend care’ (3.5) compared with the inclusion criteria (4.0). The domain ‘Adequate emotional support’ had the highest score (4.1) compared with the inclusion criteria (3.9).

Conclusions: The domains where improvement is needed are those related to the quality of communication and the emotional support provided.

Abstract number: P2-121
Abstract type: Poster

Order of Frequency of Complications for Each Type of Material (Metal/Biomaterial) Regarding Bolus vs. Continuous-infusion Operation Modes

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1Inpatient Specialist Palliative Unit, 2Observatory of Palliative Care (Extremadura’s Health System).

Aim: To assess the order of frequency of complications for each type of material (metal/biomaterial) regarding bolus vs. continuous-infusion operation modes.

Method: Analytical retrospective study of complications related to the type of material used. The order of frequency of complications was determined by calculating the percentage of complications for each type of material.

Results: There were 131 complications in 111 patients. The most frequent complication was accidental release (for the two types of material as well as for each of the two possible uses) was seen to be the most frequent complication for natal catheters.

Conclusions: No significant difference between the two manufacturing catheter materials regarding the incidence of complications was reported for the particular abovementioned use. With regard to the nature of complications, a set of unusual cases (no particular complications were standing out from the rest) were reported for metal catheters. However, accidental release (for the two types of material as well as for each of the two possible uses) was seen to be the most frequent complication for natal catheters.

Abstract number: P2-122
Abstract type: Poster

Improving Documentation of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): A Cross Organisation Spot Audit

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Aim: The South East Coast (NH, England) principles for Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions include using the Resuscitation Council of UK’s red bordered form to document the decision and ensuring this form follows the patient to all settings. In an audit in the South East of England with acute hospitals the form was already in use but needed reviewed to ensure best practice if utilised in other settings.

Method: A cross site spot audit was carried out by one of the authors with assistance from members of the resuscitation team. All acute medical and surgical beds were included in the audit and a sample of 100 was assessed using a protocol allowing the use of the RN Whiteguide, the premade Red bordered form (DNACPR forms) and if not completed to the standard in the first survey, 20% in the second visit.

Results: 133 DNACPR forms were found (18% of all patients), 112 on the second survey (15%). Only 11% of all forms were completed to the standard in the first survey, 20% in the second. Main sections of the form that were incomplete were around communication with patient and family members. In the first survey only 26.7% had a countersignature by Consultant, which is expected, and this increased to 56% by the second survey. Discussion about death was 16.88% wanted more discussion, 37.5% whom didn’t had discussion they would have liked to have.

Support after the love one died 15.29% had less than they wanted; Discussion about spiritual/religious aspects - 36.65% of them wanted more support and 12.72% from those which didn’t get support would like it.

Conclusion: Symptom management is one of our strengths but we need to foster more discussions on end of life care and improve spiritual care and support for emotional issues.

Abstract number: P2-125
Abstract type: Poster

Does it Affect the Type of Material of Catheters Subcutaneous Occurrence of Complications and Duration?

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Aim: To determine whether patients booked for respite in an inpatient specialist palliative care unit are admitted without changes or discharged without changes to planned length of stay, medications or provision of home care.

Methods: Nine months of respite bookings were identified retrospectively using the booking unit copy. Respite care was available in one allocated bed for a 7-day stay. There were no formal criteria for respite referrals. Notes were analysed retrospectively to determine if patients had died prior to admission, were admitted elsewhere, died during admission, length of stay and changes and changes to home care provision. Audit standards were taken from a literature review.

Results: 52 bookings were made and only 32 were admitted (61% of all bookings). The mean time until first complication (p=0.797).

Conclusion: No significant difference between the two groups. It was therefore concluded that the two types of catheter showed the same performance in relation to the duration of the vascular access (p=0.337) and to the mean period until first complication (p=0.797).
Table 1

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Postersessions – eft 2

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
for variance, and whether diagnosis (cancer or non-cancer) influenced PCC achievement. This was essential to assess one aspect of the quality of EoL and informed continuous improvement.

**Methods:** A retrospective audit was conducted using data on all inpatients referred to the specialist palliative care team (SPC) of a large UK teaching hospital over 1 year.

**Results:** PCC data was analysed for 1010 patients. Home was the expressed PCC for 45%, hospice for 18%, hospital for 8%, and care home for 11%. 18% of patients did not express a PCC, 34% died in hospital. Of the 1010, 76% achieved their expressed PCC (excluding those discharged by the SPC before hospital discharge). Reasons for variance included: 15% were actively dying at referral, 13% became too ill to move to their preferred place of discharge during hospital discharge planning to home or care home, and 11% no hospice bed was available. Patients with a cancer diagnosis were 55% more likely to receive their PCC than those with non-cancer (68% vs 44%).

**Conclusion:** The hospital death rate compares favourably with the overall only included patients referred to the SPC. However, the large cohort and setting provide lessons for all referrers and acute SPCs. Routine and comprehensive assessment of PCC achievement is essential for SPCs. Collaboration across care boundaries is necessary to reduce deaths during discharge planning. The rates of those achieving their preferred place of care and the lower rate of PCC achievement for those with a non-cancer diagnosis highlights the need to educate referrers on the value of early SPC intervention and their own responsibility in providing EoL, including Advanced Care Planning in the acute setting.

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**Basic & translational research**

**Poster session – set 2**

**Abstract number:** P-2-131

**Abstract type:** Poster

**ISPC - A New System for Documentation and Benchmark in Outpatient Palliative Care**

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In Germany the so called Spezielle ambulante Palliativversorgung - SAPV (special outpatient palliative care) has been made a patients right by law in 2009. A core document is the so called obligatotory to participate in a network of SAPV. To guarantee continuity of care between all team members and all the different situations (e.g. emergency) ad hoc exchange of patient data is essential. A Care management software for daily care, benchmark, and scientific use is presented.

**Methods:** The ISPC care management software provides the net members with a mobile record of all aspects of patient management and the lower rate of PCC achievement for those with a non-cancer diagnosis highlights the need to educate referrers on the value of early SPC intervention and their own responsibility in providing EoL, including Advanced Care Planning in the acute setting.

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**Abstract number:** P-2-130

**Abstract type:** Poster

**Participatory Research in Palliative Care: Opportunities and Challenges**

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**Aim:** This presentation aims to introduce participatory research to the palliative care audience. There are several key characteristics of participatory research that shape how it is undertaken: its position in a critical paradigm; the focus on action and reflection; participation and engagement as key processes for involvement. Although a number of studies have been undertaken by specialist palliative care in a generalist setting, there has been a lack of data on research undertaken by specialist palliative care to date. There are considerable congruences between palliative care and participatory research. However, other challenges exist when undertaking participatory action research in the palliative context.

**Opportunities:** Participatory research in palliative care can impact upon the individual, the team/group, organisational and the wider system level which leads to a greater, sustainable outcome. As actions are taken to realise the research process the impact of the research in the setting occurs quickly. Such a process also not only contributes to social change but can also add to social science knowledge.

**Challenges:** Challenges arise due to the fact that the research is participatory (challenges in action research); other challenges relating to the field of palliative care (challenges of palliative care research). Most challenges are situated at the intersection of both: issues of relationship, initiation and sustainable participation, processes of change, issues of power, ethical considerations and engagement with sensitive topics.

**Conclusion:** Participatory action research is an appropriate methodology for research in palliative care as they both engage with the whole person in their whole context. Both put the patients and their families in the centre of participation; and, both seek solutions through inter- and transdisciplinary collaboration.

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**Abstract number:** P-2-134

**Abstract type:** Poster

**Improving Pain Management for Community Palliative Care Patients with Advanced Cancer: A Pilot Knowledge Translation Study**

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**Aim:** To determine the effectiveness of the implementation of a multi component nursing intervention, in addressing the evidence – practice gap in pain management for community palliative care patients.

**Methods:** This pilot study has a pre and post implementation effectiveness design. The intervention included individual assessment of patient barriers to pain management and tailored education. Specific knowledge translation strategies including a theory based educational workshop for community nurses and discussion forums supported the implementation process. Outcome measures included adherence to analgesia, level of distress caused by pain and functional status scores. The process evaluation included qualitative interviews with the community nurses to determine factors which influence effective implementation of the intervention. These data were analysed using the Theoretical Domains Framework. Implementation fidelity was documented using implementation logs and questionnaires.

**Results:** A total of 11 participants were recruited to the pre implementation cohort and 10 participants to the post implementation cohort. Descriptive analyses of scores for key outcome variables were similar for both groups, although scores for 12 of the 13 barriers items decreased following implementation of the intervention. All 14 of the theoretical domains emerged in the preliminary analysis of process data from 10 community nurse interviews.

**Conclusion:** This study suggests larger scale research is needed to test the knowledge translation strategies in implementing evidence based pain management interventions in to routine practice in community nursing settings. Future research should inform the development of knowledge translation policies for community palliative care services.

This study was funded by the National Health and Medical Research Council, Australia.

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**Abstract number:** P-2-135

**Abstract type:** Poster

**Undertaking Evaluation Projects in Community Palliative Care: Issues for Research**

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**Abstract type:** Poster

**Aim:** Regular evaluation is necessary in the management of health services, without which improvements in service models would be difficult to achieve and demonstrate. Evaluation is integral to policy, program development and clinical service provision, part of a quality improvement cycle. This is just as important in palliative care services, where there has been increasing reliance on evaluation to determine aspects like the worth, relevance, impact and effectiveness of particular programs or interventions. Information in this paper will describe the authors’ experiences and what strategies and challenges were involved in undertaking a number of evaluation studies undertaken by the authors in a number of clinical sites.

**Methods:** This paper describes experiences and challenges in undertaking a number of independent evaluations of community palliative care services. Particular questions were: to address the experiences and challenges in undertaking independent evaluations; exploring the issues of process and systems in evaluation; and what strategies enable effective evaluation of palliative care interventions.

**Results:** A number of methodologies are discussed, including questionnaires, consensus seeking and surveys. The paper highlights the importance of both understanding about processes and systems of the evaluation itself; namely; challenges arising from project designs; achieving an ethical evaluation process; including balancing the risks of negative outcomes versus possible benefits; working with vulnerable populations and recruitment difficulties; the perceptions of staff to undertaking evaluation work; and the financial and funding bodies. From these experiences strategies are suggested for enabling effective evaluation.

**Conclusion:** As health services are changing in complexity, evaluation has become a necessary aspect of policy, program development and service provision, including palliative care services. Future research is needed to grapple with the challenges described in this paper, in ensuring that their care remains as optimal as possible.
Rehabilitation for the Bereaved Family Following the Death of a Child from Cancer

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Aims: Recognition of bereavement support for families of cancer patients as an essential element has taken root in the provision of comprehensive oncology care. However, the reform of the current system of remuneration and administrative support for bereavement care has been delayed. In this paper, we will describe the progress of our program that bereavement support meeting for families following the death of a child from cancer.

Methods: A few months after separation, we sent invitation letters to the bereaved inviting them to the bereaved family meeting for the OIs who were caring for the patient. The theme and events at the meeting was planned not only for parents but also for sibling participation in mind. After each meeting we issued bulletins for the participants.

Results: 4 to 10 families with 6-month to 6-year bereavement period were available for participation for each meeting. Repeated participation was seen among families. The bereaved family meeting showed meaningful and significant families. The bereaved family meeting we issued bulletins for the participants.

Conclusion: Bereavement family meeting is a place having the during the lifetime to following the death continuity of the care for the families. The bereaved family meeting supports that they are restored a connection with oneself and the society. It also benefits health professionals involved, bereaved, and grief and bereaved in quality of care. Considering the quality of palliative care provided by the University Hospital, we believe the bereavement family meeting has an important role.

Systematic Review of Trajectories of Depressive Symptoms for Bereaved Family Caregivers of Chronically Ill Patients

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Aims: Family caregivers of chronically ill patients shoulder heavy caregiving burden and their suffering can extend into bereavement. Grieving is an individualized process. The few studies showed there are heterogeneous and different criteria in identifying distinctive trajectories. The purposes of this systematic review were to synthesize distinctive trajectories and to estimate the prevalence of each trajectory for bereaved caregivers of chronically ill patients.

Methods: Relevant databases were searched using the following keywords: caregiver, depressive trajectory, bereavement. Inclusion criteria were: (1) prospective assessments, and (2) the studies identified depressive-symptom trajectories. 6 studies were identified. Depressive symptoms were predominately measured by the Center for Epidemiologic Studies Depression (CES-D) scale. Scores for the CES-D were classified as low, moderate, and high, using 10, 16, and 30 as the cutoffs.

Results: Five distinctive trajectories were synthesized, named as “endurance,” “recovery,” “chronically distressed,” and “chronically depressed,” and contained 43.08%, 4.11%, 16.07%, 16.07%, and 18.65% of samples, respectively. Caregivers in “endurance” group have consistently low levels of depressive symptoms over time. “Recovery” is one with moderate to high depressive symptoms initially but rapidly returning to normal. “Recovery” group’s distress lasts several months then gradually returns to pre-bereavement function. “Chronically distressed” and “chronically depressed” groups have high depressive symptoms but “chronically distressed” group’s depressive symptoms decrease gradually during the bereavement period.

Conclusion: Caregivers’ depressive symptoms from pre-loss to bereavement are not homogeneous. Clinicians should identify trajectories of caregiver depressive symptoms and provide suitable interventions to facilitate healthy psychological functions.

The Care about Bereaved in Czech Hospices

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Introduction: Hospices provide palliative care for terminally ill. Palliative care also includes care about bereaved. The paper deals with the question about role of hospice family members, whose loved one died in the hospice. Aims: The purpose of this study was to evaluate the extent of contacts between bereaved on the hospice team and their participation on the memorial programs for bereaved.

Methods: Data were collected using a questionnaire of our own construction. The research sample consisted of 412 bereaved whose loved one died in hospices at least one year ago. Data were analyze using quantitative methods.

Results: For selected socio-demographic factors were not found impact on meeting bereaved with members of hospice team. Participation of bereaved on memorial programs depends on the previous sharing hospice room by family members with loved one (p<0,001) and also depends on family members presence in hospice or distance between hospice and bereaved residence do not affect participation of bereaved on memorial programs. All bereaved were satisfied with hospice support of bereaved.

Conclusion: Czech hospices offer support for bereaved shortly after the death and organize memorial events for families following the death of a child from cancer. Systematic support through individual counseling for bereaved is not currently by Czech hospice offered.

Validity of the Spanish Adaptation of the Perceived Ability to Cope with Trauma Scale (PACT)

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Aim: Spanish adaptation of the “Perceived Ability to Cope with Trauma Scale” (PACT). The instrument evaluates the flexibility for coping with traumatic events. It is comprised of 20 items, divided in two subscales: trauma focus, which includes items related to the active processing of the experience; and forward focus related to the possibility of moving beyond the trauma. The PACT has shown a negative relation between coping flexibility and complicated grief and positive relations with resilience.

Methods: The scale was translated into Spanish by two independent English speakers. Sample was composed by 82 university students (69 females, Mean age=21.27 years, SD=3.7). In addition to the PACT, the Life Optimism Test, the Posttraumatic Symptom Scale and the Adult Attachment Scale were given. Cronbach’s alpha value was calculated to test the internal consistency of each subscale. A hierarchical cluster analysis was performed (p<0.05) to group the items. Finally, bivariate correlations were carried out to assess discriminant validity.

Results: Cronbach’s alpha value for Trauma Focus subscale was .72 and .90 for Forward Focus subscale. The item analysis showed an acceptable typical deviation (around 1), a variety of items in each subscale and a significant correlation with scores of each PACT subscale. Reliability values were .72 and .90 for Forward Focus subscale. The item analysis showed an acceptable typical deviation (around 1), a variety of items in each subscale and a significant correlation with scores of each PACT subscale.

Conclusion: The Spanish adaptation of the PACT has an acceptable internal consistency. Further studies are needed with a larger and more diverse sample. A new version has to be tested on clinical sample like bereaved people or people who have experienced a trauma.
High Fidelity Simulation Training for Multidisciplinary Healthcare Professionals Working in Hospital, Hospice and Community Settings

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Aims: To assess whether high fidelity simulation training can improve confidence in health care professionals providing end of life care in hospital, hospice and community settings.

Method: Seven courses took place between October 2011 and July 2012 for multi-professionals working in hospital, hospice and community settings. Courses were designed for specialist palliative care and non-specialist clinicians. Participants took part in simulated clinical scenarios relevant to their clinical setting. These were videoed and constructive feedback was given to create a safe learning environment. A fidelity patient mannequin was used to simulate life-like signs and symptoms. Courses undertook role play as mandated but were extended for hospital teams; two for community specialist palliative care teams and one course was undertaken (using portable simulation equipment) at a parent and children’s hospice setting. Post and post course questionnaires to rate their confidence in aspects of care using visual analogue scales.

Results: Of 150 participants, there were 40 nurses and health care assistants, 20 occupational therapists, 1 pharmacist and 1 physiotherapist. Evaluation of the mean scores before and after each course demonstrated that having undertaken the course all participants in all areas of end of life care improved following the course. Free text responses revealed that specialists and non-specialists were encouraged to incorporate simulation training into their everyday practice.

Conclusions: Simulation training offers an innovative education model. Participants learn by experience and via facilitated discussion with colleagues. Scenarios can be adapted for the participant’s skill level, discipline and working environment. In order to explore the impact of the training further, a longitudinal qualitative study is being completed by community palliative care nurses 6 months after undertaking the course.

Competencies in Social Work Hospice Practice: An International Update

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Aims: The aim of this panel is to update on the development of social work competencies for social work in hospice care in Canada, the UK, Ireland, and Europe.

Design: In Canada, a Delphi process was undertaken for the development of social work competencies for hospice and end of life care.

Results: The Canadian competencies were completed in 2007 by a social work task group comprised of social work practitioners and educators. The competencies include knowledge, values, and skills for clinical and community practice, education and research. During 2009-2012, social workers, school of social work educators, and providers of continuing education were consulted to validate the competencies. The NCSW develop practical strategies for the utilization of the competencies. In 2010-2012, workshops were held in various venues in Canada and internationally in order to reinforce the competencies. The Canadian competencies were provided a crucial basis for discussion in Ireland and enabled the participation of Irish Palliative Care Social Workers in the development of the National Palliative Care Competence Framework, a work currently coming to completion. In July 2012 the UK End of Life Care Programmes Board and the School of Social Work produced a guidance document for generalist social workers working with people across the various settings of their lives; the competency framework informed some of the document. Social workers in the UK and a range of European countries have contributed to the development of their social work competencies, which is also based on the Canadian work.

Conclusions: The articulation of social work competencies is important in order to advance the profession and the contribution it makes to patients and families in receipt of palliative care. The members of the panel have all been involved in the process in various countries and will report on the state of the development.

The Introduction of an On-line Spaced Education Program to Augment Palliative Medicine Teaching

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Introduction: Final year medical students at the University of Newcastle (NSW, Australia) undertake a week long placement in palliative care. This may involve placement in a tertiary referral palliative care hospital or may be more general with allocation to rural nursing-led community teams. Whilst both experiences reflect the scope of palliative care practice, there is a need to develop a programme of student assessment, optimised symptom control and a high-grade of communication skill is emphasised to all students. These fundamental teaching elements for palliative care are increasingly being recognised as core requirements of the practice of medicine in all settings.

Primary aim: To develop an integrated, on-line spaced education program in Palliative Medicine that is deliverable on a variety of mobile devices across a wide-range of geographical locations to find all final year medical students attending a university in NSW, Australia.

Secondary aims: 1) To compare education experiences of students before and after the implementation of the program; 2) to compare the performances of students rotating through a specialist unit compared with those undertaking general placement.

Methods: Literature search and review of spaced education. Development of a 36 question online spaced education program. Review of pre and post test data from student rotations prior and subsequent to the implementation of the program. Comparison of spaced education results from students rotating through a specialist unit versus community placement.

Results: Student performance before and after the implementation of our education program will be discussed. Any difference in the performance of the students undertaking different rotations will be explored. Spaced education may provide an optimised platform for all staff at any grade to access and the ability to study at their own pace to the level they choose.

Conclusion: This presentation describes the training programme is underway but early results demonstrate a sustained approach to workforce development goes some considerable way towards meeting the objectives of the 2010 Framework for Social Care at the End of Life published by the UK National End of Life Care Programme.

Inspire a Generation!: Growing End of Life Education with the Tree of Knowledge

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Aim: The End of Life Skill Challenge (EoLSC) implemented locally across Community, Hospital & Hospice has inspired staff to undertake End Of Life (EoL) education, which all staff at any age could access. A simple reward system has engendered healthy competition, whilst reaching a wide critical mass of the generic workforce. Design: A tree of education was developed from a combination of e-eclo (National e-learning Programme U.K.) and locally available study days and sessions. Each branch is delivered by existing EoL education and as such has promoted the use of e-eclo online modules. It has also been an opportunity to involve all providers of EoL education across all care settings, e.g. mortuary & transplant services. Staff collect evidence of completion of each topic at 3 levels to receive bronze, silver and gold awards, ‘Olympics’ style. To achieve a gold level award, a reflective case study and an EoL related audit demonstrate the practical application of theoretical knowledge.

Results: Although only just begun, increasing numbers of nursing, allied health professionals, and clinical staff, from across all healthcare settings, are undertaking the challenge. The first bronze awards have been presented and already staff are working towards silver. The poster will show the first six months results.

Conclusion: The EoLSC has complemented the Routine to Success work programme in the locality with limited expenditure using existing resources. The overwhelming incentive for the challenge was the consistency of education for all staff in all settings and the ability to recognise training already undertaken.

Staff have welcomed the active competition, the ease of access and the ability to study at their own pace to the level they choose.

Introduction of the EoLSC has re-invigorated EoL education, through recognition of hard work and achievement giving staff an appetite for more.

Leverage Liverpool Care Pathway: Evaluation of a Nationwide Implementation Program in the Netherlands

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Our hospice has been delivering workforce development programmes on end of life (EoL) care for generalist social care staff across 4 local boroughs since 2010. Our approach is multi-modal aimed at staff at all levels, across disciplines and services, and with crucial buy-in at senior level. It is developed in partnership with local authorities, taking account of priorities and responsive to needs as they become apparent. The 5 core elements of the programme include the development of EoL champions, strategic reviews with managers and broader consultancy. We aim to take local authorities beyond the delivery of isolated training days on EoL to the more holistic approach essential for the culture shift required to improve generalist social care provision, in the UK.

Conclusion: The Dutch version of the Liverpool Care Pathway for the dying patient (LCP), Zorgadvies Stervertijds, is a quality instrument for the care of dying people in the
Netherlands. Since 2009 this pathway has been implemented nationwide in hospitals, nursing homes, hospices and homecare settings. Evaluation of this implementation has identified four optimal strategic methods for implementing other quality instruments.

Aim: Description of the implementation of the Dutch LCP and the main strategies used to overcome barriers from different stakeholders’ perspectives.

Methods: Qualitative and quantitative methods to get insight in the perspectives of stakeholders who were involved in the implementation project. In total 27 stakeholders were interviewed. 7 employees of the regional Critical Care Centre (CCC), 8 palliative care network coordinators and 12 project leaders of successful initiatives were interviewed. Consequently, we organized a focus group with the interviewees to discuss facilitators and barriers of implementation of the Dutch LCP.

Results: Many interviews for institutions to implement Dutch LCP were to improve quality in end of life care, and to create a clear and uniform care plan at the end of life. Also extrinsic motivators were present e.g. by financial incentives of insurance companies. Different successful strategies have been used for implementation of the LCP. Seven CCC’s trained local project leaders and supported them in different ways. Network coordinators especially played a role in informing institutions within their regions about the advantages of the LCP.

Conclusions: In the dissemination process of the Dutch LCP a variety of strategies were used. Stakeholders identified sharing facilitators and barriers, independent of chosen strategies. Knowing these facilitators and barriers can contribute to a successful implementation program, which is also useful for other quality instruments in palliative care in the Netherlands.

Abstract number: P-2-150

Abstract type: Poster

Improving Perception of Pain in Graduate Pain School

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The purpose of this structured pain school is to enhance support group representatives as discussed EAPC 2011. It is advocated that both the patient and caregivers must understand pain in totality. The attending support groups regularly are attentively selected to be enrolled into the ‘Graduate Pain School’. Copious amount of research revolves around the relationship between pain and the meaning of pain specificity in chronic pain. Many patients believe tissue injury remains the core of their problem and those who do not, does not verbalize their condition in terms of nervous system facilitation and barriers, independent of chosen strategies. The latter being spiritual support for some patients.

The amount of patients attending the group sessions greatly influences their attendance and staff to assist with group’s patients who understand what pain is and those that understand how to manage pain, wanted to share their experiences with others. The latter being spiritual support for some patients.

Enrolled patients sign a contract where the punctuality, commitment and confidentiality are discussed. The course program differs weekly. The first day involves around group introduction, team involvement and course content. We use pain diaries to document PQRST pain characteristics, understanding rating your pain and the holistic approach in pain management. Every class concludes with physiotherapy and relaxation.

Feedback from our pain school graduates affirmed our purpose: ‘Sharing my experiences, meeting patients with similar problems, learning to cope, reflecting in my journal researches’ makes me think that people mainly obtain the help they need. It’s about my attitudes, believes and choices. I use this within the clinic, in waiting rooms, in the clinics and often most important of all, to support people experiencing pain’.

Abstract number: P-2-151

Abstract type: Poster

Clinical Supervision in the Reflective Learning Organisation

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Purpose: Children’s Hospice Association Scotland (CHAS) has created a结构化 pathway as an influential leader of children’s and young people’s palliative care in Scotland, the UK and beyond. To ensure that staff understood their role, CHAS identified key goals: practitioner development and reflection, enhancing the quality of the reflective learning organisation to demonstrate a commitment to evidence based practice through structured approaches to learning, development and research; and, contribute to and enhance education of paediatric palliative care professionals.

Process: To achieve the above, CHAS conducted staff surveys, held meetings to capture strategic developments from annual development days, worked with colleagues and achieve the staff identified need for an organisation approach to clinical supervision and reflective learning. Following this, CHAS established a school of work meeting group to meet initially over a period of 10 months.

The aims of the group are to:

• Conduct an annual appraisal of the multidisciplinary clinical supervision models and select the model appropriate for CHAS

• Identify and train facilitators of clinical supervision from within CHAS

• Promote reflective practice

• Monitor, and reflect on the model implemented

• Improve standards of care

Outcome: Staff interest and critical inquiry of the realisation of the clinical supervision model. This demonstrates that CHAS’ professional commitment and enriched the multidisciplinary approach in CHAS. Some staff members have identified themselves as facilitators of supervision. A bespoke clinical supervision training programme has developed. Working partnerships and enhanced professional commitment to quality of care has been observed. It is also intended to use this project to design a future programme of reflective learning for all CHAS staff.

Abstract number: P-2-153

Abstract type: Poster

Simply Schooled! Impact of a Simple Model of Communication Skills on General Staff

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Background: Good communication skills in healthcare professionals is fundamental to quality care. The consequences of poor communication are well recognised with far reaching costs including: reduced treatment compliance; high levels of morbidity, mortality; increased delayed diagnoses, and increased complaints. ‘The Simple Skills Secrets’ is a visual, easily memorised, model of skills secrets. The former group interviews with participants 6-8 weeks post course. Using a purposely sampling approach, 14 participants out of the 153 staff trained, agreed to follow up qualitative interviews.

Results: Several themes were obtained from the qualitative data, including: a method of communicating differently; a structured approach, an easy to remember visual model, thinking differently, increased confidence, using small amounts of time effectively, gaining additional skills and helping the person come up with answers themselves. The qualitative data is a small part of the research findings reported.

Conclusion: This model appears to be easily remembered, increase the confidence of staff, in dealing with difficult conversations. We are more than willing to undertake these otherwise avoidable conversations, which could lead to earlier, shorter interventions & minimise distress.

Abstract number: P-2-154

Abstract type: Poster

Experience of Ukraine to Educate Medical Professionals Involved in Palliative Care

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2Department of Palliative and Hospice Medicine (Dep.PHM) of the National Medical Academy of Postgraduate Education (NMAPE) over the past 5 years from different specialists and their patients and their families require palliative care (PC) in Ukraine annually.

Moreover, the number of specialized PC facilities and lack of Home PC service. It stipulates that every doctor and nurse must have the PC knowledge and skills to control chronic pain and treat end of life patients. Besides the medical care, health professionals involved in PC should have the knowledge and skills on the psychological, social and spiritual support.

According to the recommendations of experts IPHM and Dep.PHM, roughly, 2250 physicians, about 11500 nurses and 2000 social workers specialists, psychologists and chaplains must be taught to provide PC in specialized PC facilities and at home.

The first Dep.PHM in Ukraine was established in November 2009. Seven curriculums for PC training of general practitioners/family doctors, oncologists, geriatricians, PC facilities doctors, health care managers and other health providers were developed. Since May 2010, more than 400 doctors and nurses improved their knowledge and skills at these curriculums. The Palliative and Hospice Medicine Textbook for medical colleges students was developed together with teachers of Zhytomyr Nursing Institute in Ukraine.

Conclusions: The main tasks to improve medical professionals PC training are: to develop of PC standardized curriculums, textbooks, manuals, guidelines, etc. for health providers educating, to advocate of approving the Palliative Medicine Specialty for doctors and nurses by Ministry of Health of Ukraine. Legal problems troubling patients and their families were tackled successfully. To advocate to promoting of MoH of Ukraine of PC facilities staff regulations and working norms, according to international guidelines and standards in Ukraine.

Abstract number: P-2-155

Abstract type: Poster

Learning about Legal Aspects of Palliative Care

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Aims Hospice staff recognise legal problems impact negatively on patients’ daily living. Legal information & referrals. Legal assistance may relieve worries and improve quality of life.

Methods: A group of palliative care & legal practitioners collaborated to develop a manual to address patients’ legal problems. Legal issues put forward by hospices were tackled by 21 writers with legal & palliative care practitioners pairing up to write chapters. Legal issues may include: Who will care for children after parent’s death, who will inherit the family home, how to access pain relief, finding help while facing life-threatening illness and requiring legal advice. Legal information & referrals. Legal assistance may relieve worries and improve quality of life.

Results: The collaboration resulted in 13 chapters and the 1st edition of Legal Aspects of Palliative Care published by HPCA in 2009. This is a practical resource for those working in palliative care assisting people facing life-threatening illness and requiring legal advice.

A new layout in the 2nd edition of 2012 puts the text of international & national law alongside palliative care with new content, now case studies & colour photos throughout. Now with more resources & templates for leaflets (for example - how to draft your Will & living a Living Will: A sideboard for reader’s notes). The book is now also a training resource with training exercises in each chapter. The updated edition was launched to an packed audience during the HPCA 25th anniversary conference in Cape Town.

Three editors/authors presented case studies to demonstrate how the book may be used with the book nearly 2,000 copies in 83 countries and families with legal problems.

Conclusion: Training sessions using material from the book, will help hospice staff to identify legal gaps & provide information or suggest referrals. The booklet will be used to oriental legal practitioners to enhance their understanding of end of life patients. Besides the medical care, health professionals involved in PC should have the knowledge and skills on the psychological, social and spiritual support.

Abstract number: P-2-156

Abstract type: Poster

Grief and Loss in Children and Young Adults

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Background: In 2013 our Palliative Care Unit will celebrate its 10th anniversary. We would like to take this opportunity to contribute to reducing taboos that exist in public around illness and death, and in particular that adolescents frequently experience loss while growing up, adults often find it difficult to address sadness and grief with children. However, the recognition of this can reduce anxiety and feelings of uncertainty, and help to emerge stronger from crises. As such, involving these young people with children is important to do in a safe space. School can be one such space because it is not only the place where they spend the majority of their time, but it is also a key living environment.

Aims/methods: Teachers from different grades and types of schools are asked to creatively engage students regarding the theme of loss and grief. Student participation is on a voluntary basis, and the form of the discussion is determined by the supervising teachers. This approach enables the development of the subject area that can be tailored to the specific situation. The goal is to reduce taboos and to encourage open communication, the acquisition of coping strategies, and the development of an awareness of students for their own needs and the needs of others. A visit to our ward is possible in the context of the project, but is not a requirement for participation.

Results: A total of 9 classes from different school forms are participating in the project. A wide variety of approaches is being used across the classes.

Poster sessions

The Missing Link - Developing a Palliative Care Link Nurse Programme in a Tertiary Cancer Centre


Background: A link nurse is defined as ‘moving towards being an expert and resource person for an identified topic of specialty practice, in which they have an interest and passion’. This tertiary Cancer Centre in the UK has 88 beds with many complex patients with specialist palliative care needs. A job description was developed to help aid the roles and responsibilities of the link nurse. The main purpose and role were to share and provide two-way communication between the specialist team and staff in the clinical area and to act as a resource and a role model for their colleagues.

Aim: To develop a sustainable link nurse programme with clear objectives and an efficient programme.

Method: To outline a robust process whereby link nurses can be recognised professionally for their contribution to the programme.

To provide education and training.

Method: Two link nurses were identified by each ward manager and an initial resource folder was included which included a job description and an outline of the full programme for the following 12 months. A Clinical Nurse Specialist was assigned to each ward to help mentor the link nurses and to act as a resource.

The link nurses were expected to attend at least 3 study days per year and to feed the information back at ward level. The link nurses were also offered a wide range of other educational input.

Aims: To develop the competence levels of a group of ‘Palliative Care Link Nurse’ for theardware and care settings.

Conclusion: The缺少量 link nurse programme is a rich, demanding and rewarding experience that has changed practice.

Meeting the Needs of Emerging Leaders in Palliative Care: Results from a European Wide Online Survey


Aim: To describe the development of a Masters’ programme in palliative care, suitable for health professionals from different care contexts, based on evidence and with high relevance for clinical practice.

Results: The programme consists of 7 separate courses, and is developed in cooperation between clinicians, researchers and lecturers. It is mainly internet based, allowing students nationwide to participate, while continuing their clinical work.

The first course started in September 2012, with students from various settings e.g. ICU, elderly care, primary care and specialized palliative care. Since clinical relevance for individual students is paramount, student engagement is purposely included in the program structure and design. Clinical application and relevance have also been central in developing the study design and teaching methods. Person centered care, academic reasoning and research methodology are integrated themes throughout the programme. Student’s experiences from these courses will be presented and discussed.

Conclusion: Development of higher education with strong relevance for clinical practice, poses challenges for nurses as well as students. Combining students from different clinical settings, with different backgrounds and from different parts of Sweden, allows for dynamic discussions and contributes to spreading knowledge of palliative care.

This is a focused step in increasing the competence levels within palliative care, irrespective of patients’ diagnoses and care settings.
(ii) career development, (iii) sharing knowledge, and (iv) being better positioned to develop services. Success criteria for programme content include: conceptual and theoretical skills in developing and evaluating palliative care across different settings, evidence-based practice, appraising evidence, change management, advocacy, and management skills.

Conclusion: We have identified evidence of unmet leadership skills among PC professionals working across Europe. Moreover, we have identified demand for a new educational programme to develop emerging leaders. This programme is conducted according to the action research positive change in countries where PC is emerging as a new specialty.

Abstract number: P2-162
Abstract type: Poster

Education for Volunteer Coordinators for Hospice-palliative Care. Action Research Conducted in Poland in 2007-2010
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Aims: A chance to serve growing number of patients could be achieved with increase of volunteering. Hospice-palliative care units could contribute to social inclusion at the local level by increasing the educational attitudes and to fill the missing link in the formal care. However, only appropriate coordination of volunteer activities can ensure the efficient performance of patients. Proper recruitment, training and ongoing formation of volunteer coordinators is needed. Nationwide program in 2007-2010 had as a main goal proper training for volunteer coordinators.

Methods: Research has been conducted among the volunteer coordinators in 100 hospice-palliative care centers according to the action research methodology. Data have been a source of information allowing to answer following questions:

What is the relationship between adequate volunteer coordination and recruitment, training and involvement of volunteers into hospice-palliative care?

How the training and textbook for coordinators have influence their work in the caring team and help to build the interdisciplinary team mentality among professionals?

Results: Achieved results showed the position of volunteer coordinators in preparing and implementing team work with volunteers. This research is a record of efforts made by coordinators, who had accepted invitation for proper training in Poland. Data collected during three years program, as well as life stories, written by coordinators from across the country were published in 2012.

Conclusion: Volunteer Coordinator is responsible for his team of volunteers, and builds public trust in volunteering in caring team and local society. Volunteers, with a good coordination role in the caring system, should be prepared and properly trained in the caring, team and in the local community.

Abstract number: P2-163
Abstract type: Poster

Social Education in Hospice-palliative Care. Action Research Conducted in Poland in Years 2004-2010
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Aims: This analysis of series of educational actions of Hospice Foundation in Poland during 2004-2010, shows how experiences from the Gdansk Hospice brought about a series of public events, which resulted in more than a hundred teams working together. Thanks to their efforts and cooperation it has become possible to integrate the hospice-palliative care community in Poland and create social expectations and promotion of volunteering.

Methods: Qualitative and quantitative research has been conducted for this action research methodology. Acquired and elaborated data have been a source of information allowing to answer following questions: What is the relationship between social initiatives designed to improve the quality of palliative and hospice care and the mission to educate the general public about end-of-life care?

Have these initiatives in any way affected individuals, communities and society at large and, if so, how and to what extent?

Action research methodology has been used, and during the process of implementation of presented modifications, were made to their original assumptions. These objectives were relevant in preparing and implementing further steps of team work with volunteers, the change management, advocacy, and management skills.

Conclusion: We have identified evidence of unmet leadership skills among PC professionals working across Europe. Moreover, we have identified demand for a new educational programme to develop emerging leaders. This programme is conducted according to the action research positive change in countries where PC is emerging as a new specialty.

Abstract number: P2-164
Abstract type: Poster

Can Different Cultures Lead to Different Medical Humanities in Palliative Care? A Comparison between Two Countries in Europe
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Italy and Hungary could, respectively, represent Western–Mediterranean culture and a Central-Eastern European one, but not like the two countries have not set in result parallel pathways. Propre recruitment, training and ongoing formation of volunteer coordinators is needed. Nationwide program in 2007-2010 had as a main goal proper training for volunteer coordinators.

Methods: Research has been conducted among the volunteer coordinators in 100 hospice-palliative care centers according to the action research methodology. Data have been a source of information allowing to answer following questions:

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Results: Achieved results showed the position of volunteer coordinators in preparing and implementing team work with volunteers. This research is a record of efforts made by coordinators, who had accepted invitation for proper training in Poland. Data collected during three years program, as well as life stories, written by coordinators from across the country were published in 2012.

Conclusion: Volunteer Coordinator is responsible for his team of volunteers, and builds public trust in volunteering in caring team and local society. Volunteers, with a good coordination role in the caring system, should be prepared and properly trained in the caring, team and in the local community.

Abstract number: P2-165
Abstract type: Poster

Introducing an Evaluation Framework to Measure the Impact of Education on End of Life Care
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Introduction: Clear evaluation strategies are necessary to demonstrate the impact of education and training beyond the classroom. This study aimed to evaluate the impact of education and training on ACP awareness and knowledge, and how to provide continuity of care. Influencing feasibility of evaluation is dependent upon organisational culture. The literature suggests that the impact of education are many and varied, ranging from ‘happy sheets’ (that ascertain the participants’ feelings at the end of a session), through academic assignments (establishing whether learning has taken place), to evidence of behavioural change in the workplace. The literature demonstrates a need to produce a coherent set of measures that show that learning has occurred and brought about change in working practices.

Aim: To introduce an evaluation framework that enables the impact of education to be measured.

The framework: Models of evaluation have been developed in business and social practice, predominately based on Kirkpatrick’s model developed in the 1950s. Clinical models measure patient outcomes while business models measure return on investment (e.g. as charitable donations, but not fit neatly into either a business or a clinical model); both perspectives must be addressed when considering impact.

The approach to measuring the impact of cross core domains through the use of: staff questionnaires; academic assignments; clinical observation; staff interviews; and patient outcome measures. The efficacy of evaluation is dependent upon organisational culture. Challenges will include engaging clinicians in adopting the framework and using knowledge when implementing the framework in practice.

Conclusion: The framework will potentially demonstrate a change in clinical practice but it is directly linked to education. The advantages of the framework are expected to be: individual and team, with an ability to demonstrate the application of learning in clinical practice; organisational, with evidence for commissioners when reviewing standards of end of life care; and the tangible integration of education into clinical practice.

Abstract number: P2-166
Abstract type: Poster

Anticipatory Care Planning (ACP) for Patients Suffering of Chronic Heart Failure (CHF)
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Research aims: To investigate whether education on ACP for family practitioners and psychologists could improve their communication with CHF patients. Study design and methods: In-depth interviews (recorded, transcribed and coded) and file-analyses identified how ten cardiologists and family practitioners applied ACP for patients with CHF. The file-analyses were discussed with the doctors to know if ACP was done formally (written) or informally (only spoken).

One educational session was given to nine participants - non-participation was mostly due to practical difficulties. Evaluation papers were filled the same day.

In-depth-interviews and file-analyses were done respectively 3 and 6 months after the educational session, to evaluate the impact of the training

Results: The most frequently cited barriers to use ACP were: "having too many patients", and "lack of time". There were diverse ACP practices. For instance, some cardiologists always discuss ACP when considering an ICD, some never do that. ACP often occurred informally. All participants received the evaluations session well.

The last in-depth interviews showed that all doctors knew better about ACP. The last file-analyses showed that more participants had received ACP, and more often formally.

Conclusion: This small-scale study investigated the attitude and self-reported performance of medical doctors concerning ACP. The results suggest that education can improve their ACP communication skills. It is recommended that more studies, rather on a larger scale, will be done to evaluate the impact of post-graduate medical education on palliative care and ACP.

Patient opinion on ACP; clinical outcomes linked to ACP and performance of (heart failure) nurses, geriatricians and palliative care doctors could be the subject of future investigations.

Funding declaration: No funding.

Abstract number: P2-167
Abstract type: Poster

Catalysts Identified to Make Continuity of Specialist Palliative Care Possible Beyond Out of Hours Provision
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Finding the right balance in patient and family care is at the heart of what constitutes Specialist Palliative Care (SPC) and how to provide continuity of care out of hours. There remain a challenge for policy makers, managers and professionals. The debate is furious alive; out of hours care provision yet to be solved. Some groups are specially affected: children, adults with non malignant disease in rural communities as continuity goes beyond out of hours provision.

Aim: To identify, appraise and clarify relevant factors to avoid families feeling disempowered; patients abandoned. To implement appropriate changes to make SPC accessible for all who need it, when they need it based on early identification of needs/ program inclusion, continuous domiciliary expert palliative care and central contact point for patients, carers and professionals.

Method: Prospective, longitudinal, descriptive design to analyse up to date data from an electronic database collection (SPC) strategy in its 5th year.

Results: Data from 6.5 m population attended by 700 PC professionals, including 12 exclusively dedicated groups providing 24/7 care show clinical activity, incoming and outgoing phone calls, round the clock generalist and expert vis-à-vis response from over 25 000 contacts to central expert resource.

Conclusion: Continuity of SPC is possible when barriers are overcome: sufficient communication; evidence-based programmes (including 12 excl. dedicated); providing 24/7 care show clinical activity, incoming and outgoing phone calls, round the clock generalist and expert vis-à-vis response from over 25 000 contacts to central expert resource.

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More Patients were Informed about Transition to End-of-Life Care after an Educational Intervention

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Background: A Swedish Register of Palliative Care shows that 45% of dying patients in Sweden are informed by a doctor about transition to end-of-life care according to their medical records. Since information is an important prerequisite for high quality end-of-life care we wanted to examine if an educational intervention to doctors and nurses could increase the proportion of informed patients.

Methods: Two municipalities (in charge of nursing homes and palliative care) and two hospitals in Sweden were randomized to receive an intervention. Doctors and nurses at these places were invited to an interactive half-day educating about the history and status of dying patients and about transition to end-of-life care, led by palliative medicine and care specialists. The proportion of informed patients before and after the intervention was assessed with the register database. Register data is collected by a web-based questionnaire answered by health care staff after death of the patient.

Results: The proportion of patients informed by doctors about transition to end-of-life care increased from 29% (during a six months period before the intervention) to 39% (during a six months period after the intervention). In the hospitals the proportion of informed patients increased from 18% to 33%, and in the municipalities from 37% to 44%. Further analysis showed that patients with matched control hospitals and municipalities that did not receive the intervention will be performed.

Conclusions: This study results in a doctor informed by a doctor about transition to end-of-life care according to their medical records after an educational half-day intervention directed to medical and non-medical personnel working outside the specialized palliative care.

Funding: This study was funded by the Swedish Register of Palliative Care, which receives financial support from the executive committee of the National Quality Registries in Sweden and from the Swedish government.

Abstract number: P 2-169

Abstract type: Poster

Interpreters in Palliative Care: On Speaking Terms—Matters of Life and Death

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Background: This study explored how interpreters’ skills may develop to effectively provide interpretation in palliative care. The study was set against a backdrop of the European Parliament’s declaration that palliative care is a human right. The objective of the study is to engage in a reflection on the role of the interpreter in the palliative care environment.

Methodology: Focus group discussions with specialist palliative care staff in caring for LLP patients/families to improve access to care and information using a LEAP (Language and Education Access Project) tool, part of a European project exploring the role of language in palliative care. Ethical approval was obtained from the local research and ethics committee.

Results: Three major themes emerge from the discussions: How interpreters may become involved in delivering high quality end-of-life care, how the role of the interpreter needs to be acknowledged by the healthcare system, and an exploration of inter-organizational strategies for effective practice.

Conclusions: Future plans are to expand the programme to larger cohorts of trainers and to introduce ongoing evaluation of the programme.

Abstract number: P 2-170

Abstract type: Poster

Development of a Strategy for Palliative Care Training in the Republic of Serbia

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Aims: A national palliative care (pc) strategy was passed by the government of the Republic of Serbia in 2009 in order to support a comprehensive government policy to develop pc in Serbia. In line with the strategy it is essential that all health professionals are adequately trained. Therefore a comprehensive strategy for pc education was developed, including the provision of in-service education to the multi-disciplinary teams.

Design: Standardisation & accreditation of education programs is a key part of the national strategy. A team of national & international pc experts met to develop an in-service training program. The development process included reviewing existing curricula, deciding on numbers & cadres to be trained, developing 3 levels of training which was reviewed by the education & steering committees for the project, including the Ministry of Health, & the finalisation of the program.

Results: In-service training program was developed on 3 levels: Level 1 ensures health workers have foundation knowledge on the principles & philosophy of pc; level 2 training builds on this & level 3 training, provides a smaller number, includes self-directed learning, clinical placement, clinical supervision & mentorship. Comprehensive Serbian training materials were developed & the courses accredited by the Health Council. To date, 682 doctors, nurses, social workers, physiotherapists & psychologists & 1385 patients & relatives have been trained.

Conclusion: The development of an accredited national pc training program, developed in Serbia, is feasible. In-service training is a vital part of a national pc strategy. This work is funded by the EU project ‘The Development of Palliative Care in the Republic of Serbia’ (EuropeAid/129769/C/SER/RS)

Abstract number: P 2-171

Abstract type: Poster

Medicine and the Arts: Using Visual Art to Develop Observation Skills and Empathy in Medical Students

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The integration of medical humanities, including the visual arts, into medical curricula is recognised as a means to enhance patient empathy, improve understanding of whole person care and aid in the construction of personal and professional values. The visual arts and observation skills, in particular identification of key pieces of data, pattern recognition, and interpretation of significance and meaning, can be central to developing the therapeutic and interpersonal skills of patients within their own personal context. By following our eyes, feelings and ideas, we are able to gain insight into the ways of looking and thinking that have practical implications far beyond the realm of art.

This presentation will elaborate on collaborations with the Academic Programmers in Art and Medicine in the National Gallery of Victoria and the Royal Melbourne Institute of Technology. The projects aim to improve students’ visual literacy and perception of story and narrative through visual cues thus possibly raising the quality of their diagnostic and therapeutic skills. In addition it aims to improve social and cognitive skills such as empathic communication.

The programme involved around the use of key pieces of art to develop such objective, subjective and narrative analytical skills with students encouraged to explore various interpretations of a piece of art. Subsequent parallels are drawn with clinical case scenarios and observations.

Abstract number: P 2-172

Abstract type: Poster

Coordinate My Care - Changing a Culture Requires Training

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Aims: Coordinate My Care (CMC) is a clinical service underpinned by an electronic solution. Its aim is to provide information that can be accessed 24/7 by multiple care professionals at end of life (EOLC) to enable seamless care to take place between the acute and community settings.

CMC represents a culture change that requires training. A training program was developed and implemented in London (7.7 million).

Methods: The CMC training module has been standardised across all locations of the network, identifying how to use CMC, discussion around EOLC, consenting, care planning, advance care planning, DNAR and how to use the electronic record.

Aims: Aims were specialist palliative care nurses. London is divided into 5 clusters. A stakeholder event is set up for each cluster to map existing EOLC resources and how CMC could support best practice. Training is delivered to nurses who were identified in each locality. The CMC team offers training days/100 000 population. Each locality has access to a place on one-day user super user training.

Results:

• 2774 CMC records created.

• Professionals created 156 records: GP: 7%, district nurses 42%, acute 17%, hospice 34%.

• 1200 clinicians trained, 4500 to be trained by April 2013

• In-service training is vital to the programme. The trainers have had the benefit of local knowledge. The trainers need to be flexible in how/when the training is offered and to ensure that the training relates to present clinical practice.

Conclusion: CMC involves a culture change

• Training has to include end of life care skills and knowledge

• Training encourages a pathway of care

• Training emphasises sharing information and trusting other professionals’ care plans

• Good practice is identified through dynamic reporting and best practice can then be shared with other localities.

Abstract number: P 2-173

Abstract type: Poster

Singing as a Social Force in Changing Living and Dying: The St Christopher’s Community Choir

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Over the past decade, there has been an increased interest regarding the impact of singing on people’s health and wellbeing. A growing number of studies suggest that singing, especially within group settings (e.g. choirs), can alleviate physical symptoms and be a catalyst not only to emotional, but also social wellbeing (CMT 2001). However, the role of signing within the context of end-of-life care and education has not been explored.

The belief that death and dying are social experiences is at the heart of the hospice’s life work. Death is not to be hidden, but to be experienced and shared within the communities that people live. St Christopher’s has therefore developed a range of initiatives to educate the local community, and promote healthier attitudes towards death and dying (Hartley, 2011).

St Christopher’s Community Choir was founded in June 2010 as part of the hospice’s community education initiatives. The choir functions as an open, drop-in group and involves patients, their families and friends, bereaved people, staff and volunteers as well as members of the local community. The choir comprises of more than 60 members and is an important link between hospice and community. Also, the choir’s performances both within the hospice and (diagnostic and nuanced interactions between patients, carers and medical staff) that patients may have encountered during their palliative care rotations. Conclusions are made with regards to the methodological principles of differential diagnosis, the handling contradictory data and seeking to understand the patients’ larger narrative.

Future plans are to expand the programme to larger cohort of students and to introduce ongoing evaluation of the programme.

Abstract number: P 2-174

Abstract type: Poster
public places are a powerful medium for introducing the hospice and its work to a society in a non-threatening way. This presentation shows the development of the St Christopher’s Hospice in London, as well as its role in changing dying and living both within the hospice and the local community.


Abstract number: P2-174
Abstract type: Poster

Experiences of Introducing Physiotherapy Undergraduate Students to Palliative Care

Hewitt E.
Sacred Heart Palliative Care Service; St Vincent’s Hospital, Darlinghurst, Australia
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Aims: Physiotherapy undergraduate clinical education in Australia has typically focused on the three clinical areas of musculoskeletal, neurological, and cardiorespiratory physiotherapy. In recent years this focus has expanded to include areas such as paediatrics, geriatrics, women’s health and pain management. There has been progress in introducing Palliative Care into the physiotherapy undergraduate curriculum at most Australian universities; however the student’s clinical experience are still relatively rare. The aim of this presentation is to describe the experiences of one specialist palliative care service in introducing physiotherapy students to Palliative Care.

Methods: In conjunction with one university, clinical placements of five weeks duration have been offered to physiotherapy undergraduate students over the past eleven years. A maximum of three clinical placements have been undertaken each year with a maximum of two students on each placement. Clinical supervision on the placement has been the responsibility of the Senior Palliative Care Physiotherapist, with support from a clinical academic at the university.

Results: Anecdotally, the experiences of the university, clinicians and students have been varied, though proportionate to their placement experiences. Unexpected resistances met initially to the introduction of undergraduate physiotherapy students from within the Palliative Care service, however this has diminished over time. It has also been observed that students earlier in their undergraduate training adapt better to the Palliative Care environment than their more experienced peers.

Conclusions: Our experience has been that the introduction of physiotherapy undergraduates to a Palliative Care service is not only possible but rewarding. It is hoped that by introducing students to this clinical area, the future of physiotherapy in Palliative Care will become more secure.

Abstract number: P2-175
Abstract type: Poster

"Do I Have to Go There?": Supporting Experiences of Introducing Physiotherapy to Palliative Care

Hewitt E.
Sacred Heart Palliative Care Service; St Vincent’s Hospital, Darlinghurst, Australia
Contact address: bhewitt@stvincents.com.au

Aims: Physiotherapy new to Palliative Care are often apprehensive about working in this clinical area. Their concerns can be quite varied, ranging from fear of doing things differently, to inadequate understanding of the patients’ needs. Feedback obtained anecdotally in preliminary surveys with a university college choral society, Christopher’s Community Choir, as well as its role in public places are a powerful medium for introducing the hospice and its work to a community in a non-threatening way. This presentation shows the development of the St Christopher’s Hospice in London, as well as its role in changing dying and living both within the hospice and the local community.


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Abstract number: P2-181

Aim: With changes in National Health Service structures striving for improved integration between hospital & community services, & implementation of tools to aid End of Life Care (EoLC) in these settings, opportunity arose for a novel 2-day teaching package. It takes to equip non-specialists with knowledge and skills to deliver the best possible EoLC. Further details are in abstract A-518-007-00798.

Design: We set up a local bimonthly course for about 30 delegates. Topics cover practical aspects of EoLC including use of specific EoLC pathways & care bundles (eg AMBER & Liverpool Care Pathway), symptom control, syringe drivers, discharge management and bereavement. Delegates complete pre-course assessments to ascertain their confidence & ability in different skills relating to the provision of end of life care on a numerical scale 1-10.

Results: 391 completed questionnaires were received. Significant data suggest that delegates have attended from a variety of disciplines based in the community & in hospital. Evaluations have been positive with a median post course confidence score of at least 8/10 in all skills (5.77/10 p<0.001). Greatest improvements were seen in understanding the criteria for initiating the AMBER care bundle (5.77/10 p<0.001), assessing symptom control guidelines (6.06 to 9.16 p<0.001) & understanding the rapid discharge process (5.59 to 8.56 p<0.001). 90% of delegates rated courses & teaching materials as leverage, has been well received and feedback confirms its usefulness. We are now collecting data to see if the learning has translated into practice.

Abstract number: P2-182

Aim: This project charts the evolution of a programme of palliative care education for General Practitioners in a rural area of the UK. The aim was to increase knowledge and confidence in the subjects GPs found most challenging, and so enhance the care they are able to give to patients dying at home.

Methodology: Information collected from palliative care providers in the entire country, the faculty of Medicine, Nursing and Social Sciences on palliative care education, the background of palliative care trainings held in Mary Potter Palliative Care Centre - Karra, the level of information provided, topics included, duration of the activity and their extent.

Results: Acquaintance with the palliative care level of education in Albania is very scarce. 90% of health professionals either lack important information on this regard or it very scarce. 90% of health professionals in Korca Region have already been trained in the palliative care, but it is not studied as a revision aid for exams. They found the sections on prescribing and symptom control most relevant. The majority of delegates found communication skills was considered least useful.

Conclusion: Future educational opportunities will need to focus more on communication training and also include other important aspects such as end of life decisions, pain management, and self-directed learning.

Abstract number: P2-185

Aim: To increase the skills and confidence of 525 care home staff. Over 2 years the programme developed into more than an education programme. It became about changing the culture, teaching. Students develop skills in directing their own learning in order to progress.

Methods: Following their attachment, students were asked to give anonymous feedback on each exercise in the workbook using a numerical scale and free text comments. The students were also asked the extent to which they had used the workbook during the placement and to rate it as a revision aid.

Results: Feedback was obtained from 19 students. The majority completed at least some of the exercises in the workbook during their attachment in palliative care. They valued it as a tool to support learning and also rated it highly as a revision aid for exams. They found the sections on prescribing and symptom control most relevant. The majority of students found communication skills was considered least useful.

Conclusion: Medical students will utilise tools provided to support their self-directed learning, even if these are not compulsory.
In recent years, over 43% of people dying in Norway end their life in a nursing home. Many seriously ill and terminally ill patients with complex medical conditions are being transferred directly from hospitals to nursing homes. This situation creates many challenges for health care personnel in nursing homes who are required to increase in competence to meet these demands. Oslo has approximately 50 nursing homes, many of which employ unskilled health care personnel and also experience a relatively large turnover of staff.

In view of this situation, a Hospice in Oslo started in 2005 to attend nursing homes in order to achieve new knowledge, multiple methods of competence in basic palliation in nursing homes in Oslo. In hospital and nursing homes and provides guidance on provides supervision during patients' transition between in palliative issues together with bedside teaching for Specialist nurses from the palliative team provide guidance Oslo have worked together on this program.

Method: Competence improvement is achieved by means of study days, lectures, hospital visits and networking. Specialist nurses from the palliative team provide guidance in palliative issues together with bedside teaching for patients with special needs. The palliative team also promote and facilitate transition between hospital and nursing homes and provides guidance on specific nursing home resident cases when this is requested.

Results: Co-operation between specialist health care and municipal health care is essential in order to increase the competence in basic palliation in nursing homes in Oslo. In order to achieve new knowledge, multiple methods of implementation are required. Our experience and the method used will be presented on a more detailed basis.

Abstract number: P2-188
Abstract type: Poster

Job Satisfaction of Nurses in Palliative Care Services
Tunji J.
Hospital ‘Casa Sperantei’ Brasov, Brasov, Romania

Background: Society’s reflex question “How can you work at hospice?” prompted me to analyze and better understand the nurses reasons choose to work and stay engaged in Palliative Care Setting.

Aim: The aim of the study was to investigate job satisfaction of nurses working in palliative care services, the existing correlation with organisational aspects, and to explore the main motives for nurses choosing to work in the palliative care of the system.

Methods: A mixed method was used: initially, in-depth interviews to understand the phenomena and generate questions for the survey. The survey was designed and was used to gather data in a questionnaire with 26 items, administered face-to-face to 43 nurses out of 45, working in our Palliative Care Services (home care patient, outpatient, both adults and paediatrics).

Results: The results show that the most satisfied nurses are those who are from the 20–40 year old adult service (91,7%) and those that have worked for the organization for more than 5 years (73,9%), that nurses gain the most satisfaction from the profession and that they feel that their work is important and even indispensable (90,6%). The greatest motivating factors were: the relief of suffering, quality of work, professional and self development, the holistic approach, being part of a multi-disciplined team with potential, the smiles on the patients’ faces and personally and professionally challenged by the complex patients.

Conclusions: The majority of nurses working in our palliative care service are fulfilled in their job. The factors which motivate motivate are closely linked to how they view their work and can be summarised as “The pleasure of coming to hospice, which is not a job but a calling”.

Abstract number: P2-189
Abstract type: Poster

Death Anxiety in Palliative Care and Other Health Care Settings
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Nurses from all specialties must deal with the death and dying of patients while also providing support to the bereaved family. This presents personal and professional challenges and requires the nurse to be comfortable with death and dying. This paper combines findings of a number of research projects that examined different clinical specialties, where death anxiety in staff emerged as a significant issue.

Aims: The study sought to examine levels of fear of death anxiety and coping responses in nurses working in emergency departments, acute care, aged care and palliative care environments.

Methods: Most studies used mixed methods and participants were from health care services across Melbourne, Australia. Both quantitative and qualitative data were collected using questionnaires and interviews. In some countries, fear of death anxiety was examined by the 32-item Death Attitude Profile-Revised instrument.

Results: Differences were identified between nurses groups for anxiety about death. Aged care and acute care nurses exhibited activities and behaviours which separated and hid the dying from other patients/residents. Palliative care nurses were more satisfied with their work and reported significantly higher coping skills than for other groups. Coping with families was rated as more difficult than coping with patients. And specific death education was regarded as the most effective intervention. Detailed results from studies will be presented.

Conclusions: Differences between nurses regarding their attitudes to death and dying, depending on their specialisation, which affects clinical care. These studies suggest further work is required to develop and evaluate an intervention designed to support nurses to improve the quality of care provided to dying patients and their families.

Abstract number: P2-190
Abstract type: Poster

Trends in Morphine Consumption at Mulago Hospital: Impact of an Interdisciplinary Hospital Based Palliative Care Service
Turyahikanga J.S., Namukwaya E., Leng M., Kivumbi G.
Makere Palliative Care Unit, Department of Medicine, Kampala, Uganda

Aim: To study the trends in morphine consumption at Mulago hospital as an impact of an integrated hospital based palliative care service.

Methodology: A retrospective chart review of pharmacy records from 2006 - 2012 was carried out. This charted the use of oral morphine across Mulago Hospital and the Uganda Cancer Institute.

Results: There was a 350% increase in morphine consumption over a 5 year period from 2008 with an average increase of 65% per year. The results imply a significant difference when the MFUCJ began operational. Discussion: To increase morphine consumption, it is imperative to target barriers to opioid use. Education and training as well as other social model are vital to dispel fears and myths of opioid use. This has been achieved in our setting through the creation and implementation of an integrated hospital based palliative care unit. Our next step is the development and implementation of clinical management protocols to support pain and symptom control.

Abstract number: P2-191
Abstract type: Poster

Palliative Care in Primary Care
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Programa Argentino de Medicina Palo alvina Fundacion FEMEBA, San Nicolas, Argentina

Palliative care in Argentina it is neither available nor accessible to most patients that need it: it is estimated that only 1-5% of patients that need palliative care can be served adequately. The above is explained by the most palliative care services are in secondary and tertiary level. In 2012 the Ministry of Health of Argentina decided to initiate large-scale development of palliative care through the national program REMEDIAR + Redes, a training program for primary care professionals training.

Objective: To evaluate the ability of faculty from different medical schools to teach the basics of palliative care.

Method: An online training week including 12 hours in 3 modules. Based on constructivist teaching, 3 facilitators are available online 3 hours, 5 days per week, for both synchronous and asynchronous participation. The content, based on the IAHPC Essential List of Palliative Care Practices is organized in 10 modules, lasting 1 to 2 weeks each one.

Teachers and participants have a 2 days face to face meeting. Knowledge and attitudes are evaluated at the beginning and end of each activity.

Results: A course for 35 faculties from 21 universities began in September 2012. Preliminary results are few have experience in palliative care, only half of the group participates actively, involved participants are interested and motivated, and there is little interaction between students. Conclusion: Specific research studies are needed to teach palliative care in primary care. If the teaching process of primary care professionals is not efficient, necessary changes for the implementation of palliative care will be delayed.

The Programa Argentino de Medicina Palo alvina Fundacion FEMEBA provides the funds for the study.

Abstract number: P2-192
Abstract type: Poster

Developing an App for Medical Students to Review Palliative Medicine
1University of Leeds Medical School, Leeds, United Kingdom; 2University of Leeds School of Medicine, Leeds, United Kingdom, 3St Gemmi’s Hospice, Leeds, United Kingdom

Aims and objectives: Technology enhanced learning has been shown to be beneficial in both undergraduate and postgraduate settings and the development and use of technology in medical education has increased dramatically in recent years. 4th year medical students at the University of Leeds School of Medicine are all provided with an iPhone which is used for learning and assessment. The aim of this study was to design an iPhone app on hospice research that could be used to re-enforce learning and in preparation for the end of year Objective Structured Clinical Examination (OSCE), and to study how effective this source of learning was.

Methods: The app includes a variety of OSCE station topics including; breaking bad news, pain management and prescribing of medication for syringe drivers presented using video clips and text. The app was distributed to 4th year students who had completed palliative care teaching as part of the Cancer and Continuing Care Module. A questionnaire previously used to assess students’ experience of technology assisted learning was given to students.

Results: The contents of the app were easily produced. Videos played a large role within the app as they is used as a learning tool. Further qualitative and quantitative data will be presented. The main limitation was the amount of information that could be included within the app as it is a form app.

Conclusion: This app is a novel and original source of revision for medical students preparing for their OSCE but also at re-enforcing learning from face-to-face teaching sessions. Apps are portable making them a handy revision and reference tool. However more research into the use of such apps is required to assess whether new technologies can play a wider role in the education of palliative medicine.

Abstract number: P2-193
Abstract type: Poster

Using a Bespoke DVD to Raise Health Care Professionals’ Awareness of End of Life Care within the Acute Hospital Setting
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1BHRLHospitals University Hospital Trust, Palliative Care, Romford, United Kingdom; 2BHRLHospitals University Hospital Trust, Palliative Care, Romford, United Kingdom

Aims: To make a short film to serve as an innovative way of raising awareness of end of life care within a large acute hospital as part of the UK National Dying Matters Awareness Week. To use this film as an engaging resource for training health care professionals (HCPs) within the hospital setting.

Method: The project team recruited a volunteer film producer. HCPs were invited to participate in the project, being interviewed on camera answering four questions: When in a small action have you had experience of end of life care? What’s hard about talking to people leading up to death? When do you think it’s the right time to discuss end of life care? You thought about what you would want at the end of life?

Results: There was a positive response with 11 HCPs agreeing to take part. The participants included a Consultant Neurologist, Clinical Nurse Specialist, physiotherapist, ward sister; health care assistant, hospital chaplains and junior doctors. Over 2 hours of material was edited to a 6 minute film. Since then, 754 hospital staff have seen the film as part of educational end of life care sessions. It has also been shown to the Executives, the End of Life Experience Group and other senior managers. Whenever it is used, it generates discussion and interest in the subject.

Discussions: Success hinged on the recruitment of a skilled volunteer film producer. However, both the process of
End of Life Care

Aim: In 2009, Somerset Primary Care Trust and Wyeview Health GPS Commissioning Consortium funded GSF home care for 64 Care Homes. The first 33 homes started training in June 2009, and their performance was compared with that of all the other Care Homes in Somerset.

Method: Data was obtained from Secondary Uses Service, the Exeter system, and the Office for National Statistics. Data on admission to 244 Care Homes in Somerset has been analysed, from 2 years before the project started, to 6 months after the final workshop.

Results: Admissions per month: between the start and end of the programme, both groups’ admissions reduced. However, admissions reduced by 20.2% in the GSF group, and 10.5% in the non-GSF group. The difference between the two groups seems to continue, and comparing the changes from the start of the programme with the final quarter available, July-September 2010, the GSF group has admissions reduced by 20.2%, compared to 7.4% in the non-GSF group. This exponential 29 hospital admissions a quarter saved by that time or 16/year.

Place of death: From the start of the project to the last quarter available, deaths in acute hospitals of patients from GSF homes reduced by 5.9% from 18.8% to 13.1%, and from non-GSF homes by 3.9% from 32% to 28.1%. The percentage of people dying in their home care rose by 5.8% in GSF homes and by 4.5% from 64.7% to 71.9% in non-GSF homes.

Conclusion: There was a reduction in acute hospital admissions of 20.6% in homes using GSF, compared to 7.4% in non-GSF homes. The percentage of people dying in their care home rose by 5.8% in GSF homes and by 4.5% in non-GSF homes. Deaths in acute hospitals for patients from GSF homes have decreased from non-GSF homes by 5.9% and 4.5% respectively. In comparing GSF and non-GSF trained care homes over the same 2 years, the increased benefit of GSF training was apparent in patients dying more at home and reducing hospitalisation.

Supporting People with an Intellectual Disability and Palliative Care / End of Life Needs in the Community: A Descriptive Survey

Background: Based on the principles of normalisation, inclusion, participation and rights, care provision for persons with an intellectual disability changed to a community-based model. However contrary to these principles, anecdotal evidence suggests a trend towards a return to institutional care for persons with intellectual disability and palliative/end of life needs.

Aim: This presentation discusses findings from a study which described the incidence and experience of communication and decision making involving relatives taking about their experiences of the end of life care provided for their loved ones within the hospital.

Reasons for referral to palliative care included support, therapeutic intervention, assessment and end of life care. Factors impacting on provision of palliative care included nurses’ knowledge and experience in intellectual disability or palliative care, previous knowledge of the family and patient, professional skills and attributes and teamwork. The majority (87.2%) of respondents reported requiring education in developing understanding and communicating with persons with intellectual disability and 64.9% required palliative care education.

Barriers and Facilitators of Timely Recognition of Palliative Care Needs by the Family: A Qualitative Study

Methods: Semi-structured interviews were carried out with the families who construct them. The study aimed to identify how the families interpret need of palliative care, their percepiton of care needs and barriers to care provision. The data was collected retrospectively and analyzed using NVivo10.

Findings: Several barriers emerging in different main actors were identified, of which the most important are that: (1) the physician focuses mainly on acute and physical needs and they lack the time to detect all the needs; (2) other caregivers do not always transfer information about their patients’ care needs to the family physician and (3) patients often do not contact their physician in certain phases of the disease and tend to conceal their needs to the physician. Pro-active communication (e.g. an exchange information phases) and (2) other care givers do not always transferred information about their patients’ care needs to the family physician and (3) patients often do not contact their physician in certain phases of the disease and tend to conceal their needs to the physician. Pro-active communication (e.g. an exchange information phases) and (2) other care givers do not always transferred information about their patients’ care needs to the family physician and (3) patients often do not contact their physician in certain phases of the disease and tend to conceal their needs to the physician.

Palliative care involves multiple actors and barriers for recognizing care needs can be found in all of them. These findings are a basis to recommend strategies for family physicians and other care givers to handle the barriers in recognizing various palliative care needs in their patients.

Do the Different Scales of Performances Correlate with the Health Status of Patients in Turkish Advanced Cancer Population

Background: Several studies have explored the predictability of some palliative care performance scales in Turkish patient population living in a Northern city of Turkey.

Material and methods: One year ago a multidisciplinary palliative therapy study group was formed in our University Hospital and started cancer patients on weekly basis. The study included the patients followed during this period. A printed form was used to evaluate each patient. The form was completed by the nurse who carried out the interview. Two performance scales were used to explore the advanced cancer patients on weekly basis. The data was collected retrospectively and analyzed with Pearson correlation test using SPSS 13.0 programme.

Results: The study included 64 patients with the mean age of 64.9 years ± 11.6. 43 (67.2%) was male and 21 (32.8%) was female. Patients were followed by 53.7±5.09 days (mean±SD). The duration of follow-up was positively correlated with the scores of KPS and PPS (r= 0.384 and r= 0.567 respectively and p<0.01 for both), whereas negatively correlated with the scores of ESAS (r= -0.544, p<0.01). Highly significant correlation between KPS and PPS score was found (r= 0.932, p<0.01).

Conclusions: The performance scale analysis with KPS, PPS and ESAS in palliative care setting of terminal cancer patients well correlate with duration of survival. Both scale can be used effectively in palliative care setting.

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
illness. Patients and their families often express the need for existential support and a need to talk about life issues. Aims: To offer a patient-centered end of life care that assures all patients and their families have the right to discuss the most important existential issues by creating a new model for offering existential support. Methods: The study is based on a survey of patients and communication with specialists on the hospital’s research department and members of the clinical staff, a standardized care plan on existential support was created, as well as, a “hands-on” tool containing useful information on existential issues.

Results: The tool includes goals and “to-do- statements” at specific occasions, from enrollment to the end of life. It also specifies who holds the responsibility for delivering such support. By including existential support, patients with PC need, only one-third has the relevant knowledge. Conclusions: Identifying and alleviating existential suffering is by the use of a standardized care plan - just as important as diagnosing and relieving physical symptoms for patients in advanced palliative care. Offering each patient the opportunity to talk about end-of-life issues (EOL), might enable a sense of closure and comfort for the patient at the end of life.

Abstract number: P2-300
Abstract type: Poster

The Attitude and the Opinion of Physicians about Palliative Care for Terminally Ill Cancer Patients

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Aims: Palliative care (PC) is defined as “a humanitarian need” by WHO. However, the institution of PC varies according to the cultural, social, economic and health policies. The attitudes of physicians on the necessity of PC care of paramount importance in the success during the establishment of PC facilities in Turkey. Therefore, we aimed to evaluate the opinions of physicians dealing with cancer patients on PC.

Materials and methods: The study was designed as a cross-sectional and descriptive one and included all physicians dealing with cancer patients primarily in a provincial state. A questionnaire with 46 items corresponding to the socio-demographic features of the physicians and the opinion of the physicians was developed. The questionnaire was sent to the physicians. The completed questionnaires were returned back and the data was analyzed with Chi-square testing using SPSS 18.0. Statistical significance was considered at p<0.05.

Results: 86 physicians out of 115 (74.8%) completed and returned the questionnaires. 68.6% was male with the mean age of 37.9±5.8. 15.1% of physicians experienced cancer in their first degree relatives. Only 33.7% had palliative care education during their training. While 82.6% of physicians delivered to the physicians. The completed questionnaires were returned back and the data was analyzed with Chi-square testing using SPSS 18.0. Statistical significance was considered at p<0.05.

Discussion: Progress has been made towards enabling patients to die in their preferred place of care. However, it is not clear how this might apply in the context of those dying in critical care. The aim of this study was to determine the experience of, and attitudes towards, transferring critical care patients home to die by conducting a national survey containing 123 hospitals.

Methods: An online survey was developed informing the literature and analysis of six focus groups with Health Care Practitioners and patients/families. The tool uses web-based questionnaires to explore inpatient palliative care needs and patient preferences.

Results: A total of 180 HCPs completed the online survey (response rate 24%). At home 36.1% of responses reported experience with transferring a patient home to die. The majority (89%) of respondents agreed with the statement that transferring patients home to die is a good idea in principle, while 36% agreed that it would be unethical to prolong a patient’s life to facilitate a transfer. 82% agreed that transfer is important as patients should be able to die in their preferred place of death. Thirteen percent agreed that a transfer was not worth the risk of dying in the ambulance whereas 27% responded ‘neutral’ to this statement. Further, multiple different services for same reasons were found for physicians and nurses, as well as differences between those who had transferred a patient home and those who had not.

Conclusion: This study is the first to explore views of health care professionals about transferring patients from critical care home to die. Research is generally positive, particularly about honouring preferred place of death but reservations were expressed in terms of ethical and practical concerns and the potential for complications. The study highlights the need for education and further research.

Abstract number: P2-202
Abstract type: Poster

A National Survey Exploring Views and Experience of Health Professionals about Transferring Patients from Critical Care Home to Die

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Background: There is growing interest in policies to promote end of life care in hospital settings. Some attempts have been made to estimate the numbers of hospital patients that might be in need of palliative care, but there is little understanding of what portion of the hospital population would benefit, and how best hospital services can be oriented to end of life needs. Aims: To establish in one jurisdiction (Scotland) the likelihood of death within 12 months, of all patients in hospital on a given census day.

Design: Record linkage study of patients in all 25 of Scotland’s teaching and large general hospitals on the nights of 31 March 2010.

Results: We identified 10,743 hospital inpatients on the census night, of whom 9,986 (28.3%) died within the next 12 months. 1,001 patients (9.3%) died during the recorded period of admission which accounted for 32.3% of all deaths within one year. We established that many had died at 1 days, 20% (3.9 days), 8 (6%) at 3 months, 16% (2.1 days), 9 months (25%) and 12 months (28.8%). Propensity to die was closely related to age and also to: gender: men of all ages were more likely to die within 12 months than women (50.4% vs. 27.5% p<0.001); and between the ages of 60 (22.6%) and 85 (45.6%) each increase of 5 years in admission age was equivalent to 4.2% higher risk of death (R² = 0.95). The most deprived patients were twice as likely to die as other patients during admission (OR 2.0; 95% CI 1.2: 3.4) but were not more likely to die (Q1: 29.8%, Q5: 28.0% p = 0.215).

Conclusion: We are not aware of any other study of this kind, since the required record linkage is not readily available. The data indicate the large numbers of patients nearing the end of life and that a large proportion of hospital patients at any one time. Such data could aid in advocacy for these patients and should influence end of life care strategies in hospital.

Abstract number: P2-204
Abstract type: Poster

Primary Palliative Care for People with Intellectual Disabilities; A World to Win?

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Background: It has been widely acknowledged that general practitioners (GPs) are well placed to actively initiate the process of advance care planning (ACP). The attitude of both patients and physicians support the idea of ACP, the prevalence of ACP discussions remains low.

Objectives: The objective of this systematic literature review is to identify the factors that hinder or facilitate GPs to engage in ACP discussions with their patients about care at the end of life.

Methods: Four electronic databases (PubMed, CINAHL, EMBASE, PsycINFO) were searched for studies published from 1990 to 2011. Further relevant studies were identified by contacting first authors of included studies, known experts in the field, searching through relevant journals and reference lists.

Results: Eight qualitative studies (semi-structured interviews and focus groups) and eight quantitative studies (cross-sectional studies) were included. All identified barriers and facilitators were categorized as GP characteristics, perceived patients factors or health care system system characteristics. Stronger evidence was found for following barriers: lack of skill to deal with patients’ vague requests (GP characteristics), difficulties with defining the right moment (GP characteristics), the attitude of patients to engage in ACP discussions (GP characteristics), fear of depriving patients hope (perceived patient factors). Stronger evidence was found for following facilitators: GP characteristics, foreseeing problems in the future (GP characteristics), skills to deal with patients initiating discussions (GP characteristics), personal conviction about who to involve in ACP discussions (perceived patient factors), a longitudinal patient-GP relationship (health care system characteristics).

Conclusion: Initiation of ACP in general practice can mainly be improved by targeting GP-related barriers and facilitators, but changes in health care system factors may also be required.

Abstract number: P2-205
Abstract type: Poster

Planning: A Systematic Review

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Abstract number: P-205
Abstract type: Poster

Continuous Subcutaneous Infusions - Are We Certain Patients Are Receiving the Treatment We Prescribe?

Christina A. McElroy, Laura E. Spanagel, and John T. Spain

Introduction: Continuous subcutaneous infusions (CSI) are commonly used to maintain symptom control in the UK once the oral route is no longer available. There are over 15,000 potential combinations of drugs that can be administered via CSI. In 2006, a national survey of UK practice identified a list of drug combinations that were administered via CSI. The authors of this work concluded that compatibility and stability data were available for less than half of the most frequently used combinations. In 2010, an analysis of an in-house CSI database identified the ten most frequently used combinations of drugs. The current availability of CSI compatibility and stability data to support local practice is unknown.

Aim: To identify the chemical compatibility and stability of locally used frequent combinations of drugs administered via CSI.

Method: A literature review was performed to identify chemical compatibility and stability data for combinations of drugs that are currently administered via CSI. The search was extended to include the literature review were compared to the list of frequently used combinations identified from the in-house database.

Results: Ninety per cent refer to two-drug combinations, with only 10% applicable to three-drug combinations. There were no reports for four or more drug combinations. Chemical compatibility and stability data are available for only 33% of the identified frequently used combinations. A total number of 269 combination were found in the literature and 137 combinations were found in the database.

Conclusion: In order to ensure high quality, safe and effective therapy, studies reporting on the chemical compatibility and stability of commonly used drug combinations administered via CSI are urgently required.

Poster number: P-206
Abstract type: Poster

Using Data from COUINS to Inform Innovation That Drives up and Sustains Quality in End of Life Care across Health Authority Boundaries

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In the UK, the Commissioning for Quality and Innovation (CQUIN) framework allows Trusts to define standards and measure the quality of care provided in a standardised format against specific targets. Such data helps to highlight gaps in practice and, as such, encourages Trusts to develop robust action plans to improve the quality of care. Currently, 54% of patients die in an Acute Hospital. One CQUIN target aim in England is that 75% of patients to be discharged from hospital or they deteriorated and died in hospital. The result prior to this study was compared to the list of frequently used combinations identified from the in-house database.

Results: Ninety per cent refer to two-drug combinations, with only 10% applicable to three-drug combinations. There were no reports for four or more drug combinations. Chemical compatibility and stability data are available for only 33% of the identified frequently used combinations. A total number of 269 combination were found in the literature and 137 combinations were found in the database.

Conclusion: In order to ensure high quality, safe and effective therapy, studies reporting on the chemical compatibility and stability of commonly used drug combinations administered via CSI are urgently required.

Abstract number: P-207
Abstract type: Poster

Abstract withdrawn

Place of Death is Associated with Holiday Periods: Implications for End of Life Care

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Background: Mortality was found to be associated with specific holiday periods. However, no study has investigated whether similar links exist in other healthcare settings. This study is important for effective service planning and service organisation at the end of life.

Aims and Objectives: To explore the association between PoD and holiday periods.

Study design and methods: A whole population observational study design, using all deaths in 2001-2010 in England extracted from the National Death Registration Database. PoD was described as percentage of deaths in individual locations, non-hospital communal establishments, home, and elsewhere. The independent association between holiday period (including special days and weekends) and place of death was evaluated using log-binomial model, adjusting for confounding factors (age, gender, year of death, marital status and region and index of multiple deprivation) and clustering effect within geographical unit.

Results: A total of 4,567,639 death records were analysed, of which 22.3% died in New Year, 1.9% in Easter, and 94.5% in normal period. Hospital deaths accounted for 57.6% of all deaths, followed by non-hospital communal establishments (22.3%) and home (19.0%). Compared with the normal period and hospital death, patients are more likely to die in home during New Year (Adjusted proportion ratio (APR) 1.03, 95% CI 1.01-1.05) and Christmas (APR: 1.02, 1.01-1.03), and slightly lower chance of home death during Easter (APR: 0.97, 0.97-1.00); deaths in non-hospital communal establishments were more likely in Christmas (APR: 1.02, 1.01-1.03), and less likely in New Year or Easter periods (APR: 0.97-1.00).

Conclusion: Place of death did vary by holiday periods. Christmas has consistent lower chance of deaths in hospital. Healthcare organisations may need to take into consideration of the holiday effects when planning and deliver end of life care service.

Abstract number: P-209
Abstract type: Poster

The Hospice Friendly Hospitals Programme in Ireland

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Background: The Hospice Friendly Hospitals (HFH) Programme in Ireland is a multi centre intervention to develop end of life care capacity, advocate for patients and families and create systems level change in the delivery of hospital care at the end of life. The programme has been developed and supported within the Irish Hospice Foundation (IHF).

Aim: To construct a narrative history of HFH in its first five years (2007-12) drawing conclusions to influence its future development and sustainability.

Method: Documentary analysis of programme documents, reports, minutes of meetings, media outputs, promotional and educational materials, qualitative interviews with HFH staff and stakeholders (n=42); field and ethnographic observations.

Results: We identified key milestones in the development of HFH from as early as 1996, to 2012. The programme consisted of four main components: design and dignity/the physical environment; communication/competence and compassion; integrated care/planning and co-ordination; patient and family support. Major contributions were made in the production of standards for end of life care in hospitals and in a baseline ‘audit’ of end of life care in Irish hospitals. Total funding (€1.26 m) was used by 90%.

Conclusion: HFH is an ambitious, multi-faceted programme that has involved over 40 acute and community hospitals and has developed a comprehensive Health Service Executive. Whilst elements of the four programme components contributed to achieving impact, significant successes occurred in the roll out of communications training, in standards development, in the use of symbolic resources at ward level and in aspects of the audit. The programme now moves into a phase of more limited funding, when it will seek to mainstream its activities within the participating hospitals - aiming at achieving sustainable impact.

Abstract number: P-210
Abstract type: Poster

The Knowledge and Barriers of the Advanced Cancer Patient Signed Advanced Directives in Taiwan - A Nationwide Survey of the Public, Physicians and Nurses

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Research aims: The Natural Death Act has been legalized for ten years in Taiwan. The aim of research was to find the relative important predictors of pre-signed advanced directives by advanced cancer patients.

Study design and methods: This study used the transectional method to collect quantity and quantitative data based on general population, cancer patients and families, medical staff. After twenty sessions of focus groups, to comprehensive interview with participants by random sampling from multi-countries, and then we made a cross-sectional questionnaire survey from 18 medical centers or local hospitals, using unequal proportion two-stage system random sampling. A total of 12,001 people participated who met the criteria and were analyzed.

Results: 1. The patients that are informed of the terminal illness, the worse their families feel about revealing the disease. 2. For the behavior intention of provide or sign an advanced directives, the effective predictors explain 30.7%-60.3% of variabilities. In addition to patients’ families, medical staff, general public; and patients, education of knowledge of cardiopulmonary resuscitation (CPR), choosing life quality rather than survival time for end of life therapy, and having positive attitude by himself/herself about signing an advanced directives, will intend to discuss or sign the advanced directives.

Conclusions: The research result will provide these obstacles and design different strategy as educational practice materials for constructing systematic and efficient end of life care that will respect concepts of Chinese filial piety. This model could also be developed as a reference for ACP clinical practice guidelines in the future.

Poster number: P-211
Abstract type: Poster

Place of Death after Stroke - Views of Health Care Professionals on an Acute Stroke Unit

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Introduction: Stroke is the third commonest cause of death in the United Kingdom, and a significant cause of disability and dependence. In the UK, acute stroke care occurs in hospital. Previous research suggests that most stroke patients die in hospital; a core barrier to effective end of life care is a lack of expertise and rarely consider that patients could die at hospital. This study aimed to examine how stroke unit staff in the UK view end of life care.

Study design and methods: This study used the triangulation method to collect quantity and quantitative data. The participating hospitals - aiming at achieving sustainable impact - were selected from all acute stroke units in the United Kingdom (UK) and then we made a cross-sectional questionnaire survey from 29 medical centers or local hospitals, using unequal proportion two-stage system random sampling. A total of 1,613 stroke unit professionals participated who met the criteria and were analyzed.

Results: 1. The fewer patients that are informed of the terminal illness, the worse their families feel about revealing the disease. 2. For the behavior intention of provide or accept an advance directive, the effective predictors explain 30.7%-60.3% of variabilities. In addition to patients’ families, medical staff, general public, and patients, education of knowledge of cardiopulmonary resuscitation (CPR), choosing life quality rather than survival time for end of life therapy, and having positive attitude by himself/herself about signing an advanced directives, will intend to discuss or sign the advanced directives.

Conclusions: The research result will provide these obstacles and design different strategy as educational practice materials for constructing systematic and efficient end of life care that will respect concepts of Chinese filial piety. This model could also be developed as a reference for ACP clinical practice guidelines in the future.
wards. HCP reported requests from families for patients to die at home were rare and believed patients were often too poorly to travel home. HCP had experience of getting patients to die at home. Perceived barriers to discharge include lack of family support, absence of community nonaggressive feeding and delays in funding, coordination and delivery of equipment. 

Conclusions: Families and patients rarely request discharge home before death. The majority of patients could have been managed at home with LCP, impaired capacity, cognition and communication, rapid deterioration, prognostic difficulties, families' expectations, lack of family, delay in delivery of equipment or package of care. In the event, patients did not patients could die at home.

Recommendations: Further research into preferred place of care/death after stroke
Encourage patients with capacity to discuss place of care
Develop guidelines on family and patient participation in clinical meetings
Facilitate patient communication
Improve links with primary care, social care, palliative care and volunteer organisations

Abstract number: P2-212
Abstract type: Poster

Multidisciplinary Management of Patients near Home Care Package, one had been awaiting transfer to LCP staff. All doctors felt involved in decision-making, despite nurses this was noted more in the cohort of trained staff. Where surprise was expressed about a death; for doctors were then questioned.

Results: The retrospective analysis of data and quality appraised the 24 included papers. This analysis is on-going and definitive results will be available to present by the time of the conference. We found evidence of significant psychosocial and physical characteristics which indicate dying is imminent; decision making around diagnosing dying patients; evidence of pandas focused towards care oriented treatments rather than systematic planning for end of life care and inequities exist in the care of dying patients particularly amongst those dying from non-cancer related deaths.

Conclusions: There remain issues around diagnosing dying patients which impacts on decision making and care at the end of life.

Abstract number: P2-214
Abstract type: Poster

Interventions Dying Care and Spiritual Support in Nursing Care for Patients Suffering From Death Anxiety in the Final Phase of Life

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Research aims: Death anxiety causes distress in patients. Dying Care and Spiritual Support interventions are performed by Czech nurses in patients with death anxiety in the final stage of life. Study design and Method: Qualitative research, structured questionnaire using Likert scale. Variables: type, workplace, nurses' religious belief. A group of 468 nurses, 43.7% believers, workplace: hospital, geriatric Institute for long-term patients, Home for the Elderly, Home care. Statistical analysis: ch²-squared test using Bonferroni correction, Mann-Whitney and Kruskal-Wallis tests. Results: In Dying care interventions, nurses always performed: Assist with basic care, as needed (79.5 %), Monitor pain (79.3 %) and Provide frequent rest periods (71.6 %), regardless of workplace (p<0.05). There was a significant relation in Support care that the family's efforts to remain at the bedside (48.7 %; p=0.011), Facilitate obtaining spiritual support for patient and family (10%) were also important aims of treatment. Symptom control (42%) accounted for the commonest aims of treatment performed: Assist with basic care, as needed (79.5 %), Monitor pain (79.3 %) and Provide frequent rest periods (71.6 %), regardless of workplace (p<0.05). There was a significant relation in Support care that the family's efforts to remain at the bedside (48.7 %; p=0.011), Facilitate obtaining spiritual support for patient and family (10%) were also important aims of treatment. Symptom control (42%) accounted for the commonest aims of treatment

Conclusion: There remains issues around diagnosing dying patients which impacts on decision making and care at the end of life.

Abstract number: P2-215
Abstract type: Poster

An Update on Use of Opioids in Terminal Patients and Survival

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Aims: The various kinds of caring works tasks may increase or to the caregiving burden. The effect of caring for a dying cancer patient on caregiving has been explored primarily with small sample sizes or short-term follow-ups in western countries, but has not yet been investigated in Taiwan. The purposes of this study were identify the trajectory of the caregiving burden of families (F.C) of terminal ill cancer patients in Taiwan, and investigate the determinants of the caregiving burden of F.Cs, in a large sample and with longer follow up.

Methods: This longitudinal survey study was conducted with 226 F.Cs who had a relative with terminal stage cancer. The Caregiver Reaction Assessment (CRA), the Symptom Distress Scale (SDS), the Sense of Coherence (SOC), the Maslach Burnout Inventory (MBI), and the Social Support Survey (SOS) were administered during follow-up until the time of patient's death. This study initially aimed the predict the probability of a patient's death as a continuous variable to assess its association with the CRA scores, using a generalized estimation equation (GEE). Results: The study showed that the caregiving burden of caregivers was significantly improved on the patient's death approached. Time of death came closer recent indicated that the caregiving burden reflects the patient's increasing symptom distress (β=0.1, p<0.05), high intensity of total assistance in cancer care (β=0.4, p<0.0001), and evidence of significant psychological and physical characteristics which indicate dying is imminent (β=0.60, p=0.003), the financial difficulty of F.Cs (β=0.81, p<0.003), lower social support (β=0.16, p<0.001) and weak SOC (β=0.13, p<0.001).

Conclusion: Caregiving burden was a non-significant change from the time of the patient's death in Taiwan. This study contributes to the family caregiving literature by using longitudinal data to confirm that the confidence in caregiving, social support, and psychological recourse are important predictors of caregiving burden.

Abstract number: P2-216
Abstract type: Poster

Reversing the Irreversible: Antibiotic Prescribing in the Last Week of Life?

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Aims: To examine the prescribing pattern of systemic antibiotics in the last week of life within a network of Specialist Palliative Care Inpatient Units in the United Kingdom.

Methods: A retrospective review of 20 consecutive deaths from four separate Specialist Palliative Care Inpatient Units over a defined period of time in 2012. Patient records were analysed and the use of systemic antibiotics was recorded in the last week of life, last 48 hours of life and at the point of death. Indicator, aim of treatment, route of administration and prescriber details were all recorded. Results: A total of 99 patient records were reviewed and analysed. Over a third of patients (38%) in the last week of life, a fifth of patients (21%) in the last 48 hours of life and a modest number of patients (7%) at the point of death were on antibiotic therapy. Reversing sepsis (66%) and symptom control (45%) accounted for the commonest aims of antimicrobial therapy. Interestingly both patient (21%) and family wishes (10%) were also important aims of treatment. The rate of administration of oral (76%), enteral tube (5%) and intravenous delivery (26%). A time limited trial of antibiotic therapy was recorded in only 4% of cases.

Conclusion: This study reveals that a significant number of patients within a hospice setting receive antibiotic therapy at the wrong time, with the most common error being for antibiotic treatment to reverse sepsis. Firstly this suggests that the prescribers do not view antibiotic therapy as an aggressive modality of care, which may be influenced by both patient and family wishes. Secondly, the perception that sepsis is reversible may be unrealistic and suggests diagnosing death remains difficult. A prospective study will be undertaken by the authors, including qualitative research methods, to further explore the prescribing pattern of antibiotics at the end of life.

Abstract number: P2-217
Abstract type: Poster

An Update on Use of Opioids in Terminal Patients and Survival

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Background: Opioids are drug frequently used in palliative care. However, a common thought among some physicians is that these drugs hasten of death. Few studies have addressed the relationship between survival and opioids use. The aim of the present work was to thoroughly review published data on this issue.

Methods: We reviewed all studies about the effect of opioids use on survival from 1987 to 2012. Methods

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included database searching (PubMed, MEDLINE), snowballing, specialized books and personal contact with physicians in palliative care.

Results: Eighty-six did fulfill the criteria: five retrospective, one prospective and two cohorts, one of them multicenter. These papers were designed with the aim to assess the impact on patients or on the institution. In these studies there was no statistically significant difference between patients with high doses of opioids or dose increase during the last days of life. In addition there was no difference between applying double dose and risk of death.

Conclusion: It has not been demonstrated that opioids used to treat symptoms in terminal patients shorten the survival of patients.

Abstract number: P2-218
Abstract type: Poster

ATLANTES Research Program: “Human Dignity, Advanced Illness and Palliative Care”. A Project within the Institute for Culture and Society (ICS) of the University of Navarra

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Background: Late stage illness and the prospect of death raise profound questions within modern culture. Palliative care is commonly seen in terms of advanced medicine for end-of-life care. In 2012 the Institute for Culture and Society (ICS) embarked upon the ATLANTES Research Program: “Human Dignity, Advanced Illness and Palliative Care”. A Project within the Institute for Culture and Society (ICS) of the University of Navarra.

Objectives: To promote in society a positive attitude toward the work of palliative care. The overall objective of this five-year project is to promote in society a positive attitude toward the work of palliative care. The overall objective of this five-year project is to promote in society a positive attitude toward the work of palliative care. The overall objective of this five-year project is to promote in society a positive attitude toward the work of palliative care. The overall objective of this five-year project is to promote in society a positive attitude toward the work of palliative care.

Method: ATLANTES will adopt perspectives from history, psychology, sociology and anthropology to illuminate the understandings of palliative care. It will also encompass contributions from public health, geography, communication studies and education.

Results: ATLANTES will focus on fundamental aspects of palliative care as well as the implementation of strategies to promote it at institutional, professional and societal levels. One of the main outcomes of the study is the intangibles in the interactions between palliative care and the individual, the anthropological and spiritual foundation of palliative care; a ranking of the development (and an associated Atlas) of palliative care in Europe and Latin America, education in palliative medicine, a workshop on “The message of palliative care” and a “Think Tank on Ethics and advanced palliative care.

Conclusion: ATLANTES will approach these issues in a manner consistent with the work of an academic institution: scientific investigation, professional training and dissemination of knowledge acquired. It will be done in ways which are consistent with the institutional characteristics and Christian perspective of the University of Navarra and with a clear willingness to cooperate with other institutions that work for similar objectives, as well as those who may adopt differing perspectives.

Abstract number: P2-219
Abstract type: Poster

Czech Public Awareness about Palliative Care

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Introduction: The topic of palliative care is not yet in the Czech Republic sufficiently discussed. The research try to attempt to identify current levels of awareness of palliative care within the Czech population.

Aims: The research aimed to identify what are the current levels of knowledge of palliative care and what factors contribute to knowledge. It also asked a number of additional questions relating to who respondents think should receive palliative care, what they think palliative care should consist of, when they would want information on palliative care and whether respondents feel that in the Czech society there is sufficient discussion of issues surrounding death and dying.

Methods: The research was carried out through a postal survey. 2.000 individuals in Czech were identified at random from the telephone book. To ensure geographical representation stratified random sampling was used in total, 785 questionnaires were received.

Results: Overall the majority of respondents reported some knowledge of palliative care, with under a third reporting no knowledge. Only a very small number of respondents reported a high level of knowledge of palliative care. The vast majority of respondents feel that palliative care should be offered to all patients at the end of their severe illnesses. The majority of respondents cited pain relief as important in end of life care with many stating this as their first, most broadly important service. One quarter of respondents requested for end of life care was family support, including adequate services and information and someone for family talk. To respect or dignity were also commonly cited. More than half of respondents stating that we do not discuss death and dying enough.

Conclusion: The survey findings confirm many of the existing views and policies within palliative care and point to possible directions and challenges for future development.

Abstract number: P2-220
Abstract type: Poster

What Kind of Palliative Support Do Nursing Professionals Need in Different Hospital? A Study about End of Life Care in Acute Hospital Settings Using PASIALecal Questionnaire

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Background: In Germany the majority of palliative patients is spend time in hospital in the final year, and nearly 50% in hospital. Due to the system German with different types of hospitals there are differences in the structural and process quality in End of Life (EOL) care. The extent of difference and improvability up to now remains unclear due to a missing valid measuring instrument.

Objectives: The aim of this study is to create a valid instrument which is able to measure the palliative skills of nursing professionals and the conditions of dying in hospital. PASIALecal questionnaire will provide a possibility to identify local strengths and weaknesses and the kind of palliative support needed.

Methods: The study was designed as a quantitative, descriptive survey based on a questionnaire which consists of 48 items. For the testing a teaching hospital (TH) and general hospital (GH) were chosen. The questionnaire was addressed to all nurses of different wards including the intensive care unit.

Results: The questionnaire was addressed to 1005 nurses (790 TH; 215 GH). 170 questionnaire returned, 16,3% of the total nurses. There was no difference between applying double dose and risk of death. In Germany there were differences in the structural and process quality in End of Life care. There was no statistically significant difference between applying double dose and risk of death.

Conclusion: In conclusion our pretest shows that there’s a many difference in knowledge and skills about end of life care between different sites. These studies there was no statistically significant difference between applying double dose and risk of death.

Abstract number: P2-221
Abstract type: Poster

Enhancing Knowledge and Attitudes of Fourth-year Medical Students on Code Status Discussions and End-of-Life Care Decisions through Teaching Conferences Using Feature Films

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Background: Cineeducation has become increasingly popular in medical education with the majority of its use in teaching about psychosocial aspects of illnesses and specific symptom presentations as well as areas such as professionalism and therapeutic management. Doctor-patient communication is also a key area that involves a great deal of art, emotion, and humanitarian facets. Using such creative strategy to encourage students to think about the living process and personal choice in end-of-life care can enhance teaching.

Methods: A teaching conference for the medical clerks incorporated didactic content about the feature film "Wit" designed not only to enhance student knowledge of the stages and process of grief and the complexity of human reactions when facing end-of-life situations, but also to engage students in thinking about the importance of quality of life in palliative care. Our session focused on code status discussions and end-of-life care decisions. The feature film "Wit" complemented the didactic portion of the teaching conference by depicting clinical scenarios when it would have been timely and appropriate for doctors to initiate discussions on advance care planning and did not address how this evidence was actually used in the kind of end-of-life care that the patient received. To assess the efficacy of this approach, we designed a pretest to be given once at the beginning, and once at the completion of the session.

Results: The 4th year medical students indicated that their understanding of death and dying areas improved significantly, regardless of code status discussions and end-of-life care decisions in clinical practice increased significantly.

Conclusion: We used the feature film to provide medical students about death and dying and code status decisions and end-of-life care decisions. The results of the subjective assessment of this approach indicated that it was successful in accomplishing our objectives.

Abstract number: P2-222
Abstract type: Poster

Using the Medical Research Council (MRC) Guidance to Develop a ‘Complex Intervention’ for the Prevention and Management of Heart Failure and Palliative Care Homes for Residents Near the End of Life (EOL): Results from Phase 1

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ACP has become increasingly important in terms of its perceived role in improving care planning for people near EOL. The aim of ACP is to enable people to die in the place of choice and at the time of their choice. It is necessary to reduce unnecessary hospital admissions and burdensome interventions towards EOL. Improving the process by which future care is planned in relation to care home residents, as many residents view the care home as their home and may wish to live and die there. Recent guidance in the UK has provided guidance in relation to the development of a complex intervention in end of life care. CINAP will enable complex process and relies on a number of interactions: with multiprofessionals, relatives/carers/residents.

Aims: To present phase 1 of the development of a complex intervention for ACP.

Method: An iterative process of development, process mapping and consensus building (using Nominal Group Technique) will be engaged to create a complex intervention for ACP within care homes, in accordance with the MRC guidance.

Results: From phase 1 will be presented, outlining recommendations to aide further development of the ACP intervention and provide a context from which to evaluate care delivery in the care home setting.

Conclusion: A consensus driven process for ACP incorporating best evidence from the available literature, expertise from multiprofessionals and stakeholders will developed for pilot evaluation within care homes in Liverpool.

Abstract number: P2-223

Heart Failure and Palliative Care

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Aims: The objectives of this audit were to identify if the following standards were met:
1. Are patients are provided with information regarding their diagnosis and disease management?
2. (End of life care issues are being approached and discussed with patients as part of their heart failure management plan.
3. (Patients were being referred to palliative care services appropriately according to referral criteria.

Standards used within the audit were based upon local and
national published clinical guidelines. 
Methods: Case note review of 42 patients admitted to a district general hospital with a diagnosis of heart failure. Participants were selected from the heart failure nurse database during the period January 2011 to April 2012. 
Results: Of the population studied 40 patients (95%) would have been appropriate palliative care referrals. The remaining four patients (95%) would have been appropriate palliative care referrals. Conclusion: Implementation of this protocol should incorporate palliative care from diagnosis through to end of life. There is evidence to demonstrate several strengths of the protocol in end of life management. However, the evidence also suggests that we need to consider how to increase and raise awareness amongst clinicians regarding who refer patients to palliative care services and how to establish palliative care input amongst patients with a diagnosis of heart failure. Several recommendations are made to accomplish this.

Abstract number: P2-224
Abstract type: Poster

Changed Attitudes among Surgical Nurses Caring for Dying Patients in a - Pilot Study of an Educational Intervention on Existential Issues
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Aim: To test the feasibility of an educational intervention about existential issues for nurses in surgical care, and to describe care attitudes towards patients dying of cancer. Specifically aims were to explore the effects on nurses' estimated confidence in communication and on reflections on existential issues.
Methods: The intervention included five 90 minute sessions with theoretical group lectures and self-studies about the meaning. All registered and enrolled nurses at one rural hospital who were interested in participating in the study participated. 42 surgical nurses at three wards were randomly assigned to an education or non-education group. All nurses completed questionnaires at equivalent time intervals: at baseline before the intervention, directly after, and 3 and 6 months later. 11 nurses in the education group participated in face-to-face interviews directly after the intervention and after 6 months. Non-parametric tests were used to analyze changes, differences and relations between the education and non-education groups. Interviews were analyzed with qualitative content analysis.
Results: Results concerned significant short-term and long-term changes. Nurses' reported estimated confidence and increased reflection in communication as well as increased feelings of value in caring for patients 3 and 6 months after the intervention. In addition, they described enhanced awareness on existential issues and increased reflection.
Conclusion: This study indicates that an understanding of the patients' situation, derived from enhanced awareness and increased reflection, precedes changes in attitudes towards communication after participating in an educational intervention on existential issues. This small-scale study indicates positive outcomes but the intervention must be tested on a larger scale to be solid and reliable.

Abstract number: P2-225
Abstract type: Poster

Transforming End of Life Care in Acute Hospitals Project
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Aim: This poster will demonstrate the development & implementation of the Transforming End of Life Care in Acute Hospitals Project as led by the Specialist Palliative Care Team covering two acute hospitals in the North West of England.
Background: Over 50% of people die in acute hospitals in England, many of whom do not currently receive optimal end-of-life care. Health care professionals from a number of different specialties and environments in acute care can provide palliative care at the end of life in their own way and at this time, they are the most important person in a patient's life. The focus was on improving end-of-life care in acute hospitals was highlighted in the 2008 End of Life Care Strategy. The Route to Success in End of Life Care - achieving quality in acute hospitals’ was published in 2010 as the first step towards a national improvement programme.
Method: The presentation will detail the improvement methodology undertaken throughout the development and implementation of the project and as recommended by the Advancing Quality Alliance (AQuA) and supported by the NHS Institute for Innovation and Improvement (NIII).
It will also demonstrate the outcome measurement process and audit methodology.
The project is underpinned by the Sustainability Model and Guide published by the NHS III.
Additional content:
The poster will provide information about the five key enablers contained within the Transform Programme:
• Advance Care Planning
• Electronic Palliative Care Co-ordination Systems (E-PaCCS)
• AMBER care bundle
• Rapid Discharge from TE to Pathway
• Liverpool Care Pathway for the Dying Patient

Abstract number: P2-226
Abstract type: Poster

Terminal Care Protocol Implementation and Impact on Clinical Staff
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Background: Terminal care protocol was the first protocol introduced in our unit, leading to organizational and practices changes.
Aim: To identify the perceptions, attitudes and impact on clinical staff of the implementation of the terminal care protocol.
Methods: Qualitative study, data collected through 2 focus groups with staff in home care team (n=8) and inpatient unit team (n=8), 3, 6 and 12 months after the introduction of the protocol. Coding by 2 both researchers and thematic analysis was performed.
Results: Five domains were identified: participatory education, family as caregivers, clinical team, moment of protocol initiation and monitoring process with themes and subthemes. Staff initially expressed resistance in using the protocol due to fears of excessive documentation and comfort with current practice but the educational protocol had a key role in overcoming fears by changing the perception on the protocol and allowing staff to become an active part in implementation process by adapting the medication prescription and documentation. The protocol offered the opportunity to change the practices especially in the area of spiritual and religious care and better structure the process of care. It led to a better doctor-nurse collaboration and joint decision making. Family as caregivers perceived the initiation of the protocol as giving the right moment and were prepared to assume the role of giving medication subcutaneously. Staff expressed concern that they won’t be able to perform medication subcutaneously due to time the terminal stage leading to not applying the protocol at the right moment.
Subhemes: This study shows the need of recognizing staff and family members responsibility in implementation of the terminal care protocol especially in a culture where the family controls the care delivery. It also highlights the importance of the education throughout this process.

Abstract number: P2-227
Abstract type: Poster

Can Comprehensive Specialised End of Life Care Be Provided at Home? Evaluation of an Innovative Consultant-led Community Service in England

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Background: The UK, along with other developed nations, faces a challenge in providing specialist hands-on palliative care for a growing number of people who prefer care at home. The Sheffield’s Palliative Care service is a consultant-led, multi-disciplinary team that aims to provide round the clock care and advice at home, in community hospitals and in care homes. The team provides a wide range of palliative interventions, including IV procedures, parametresis and intrathelial analgesia. In one year (2008-2009), the service received 389 referrals of which about 85% were patients who applied with cancer, from a population of about 15,000 served by 19 general practices.
Method: A mixed methods study was commissioned by Macmillan Cancer Support with three purposes: to assess whether the Sheffield Macmillan palliative care service meets the needs of patients, to gather evidence for funding decisions; and to assess the applicability of the Midhurst model to other areas. We used data from NHS sources, surveys of GPs and bereaved carers, and interviews with health care professionals, patients and carers.
Results: During one year 283 patients died under the care of the service. Bereaved carers reported receiving good or excellent support from Midhurst. The mean cost saving for the referral is about £3,000 per patient, with £1,900 being the mean cost of Midhurst service interventions on cancer patients over the last year of life. Individual patient's costs are compared, the costs of the Midhurst service are similar to hospice services, taking substitution of NHS costs into account.
Conclusion: The quality, flexibility and holistic nature of the care provided by Midhurst appear to allow GPs and hospital consultants to refer patients to end of life care. Some outcomes include satisfaction with care at home, fewer emergency admissions, decreased hospital stays and 71% of patients dying in their own home. We suggest that this model may have application elsewhere in providing consultant-led specialist palliative care at home.

Abstract number: P2-228
Abstract type: Poster

The Role of Arts for Social Engagement in Palliative Care: The St Christopher's Social Programme
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As part of its vision to offer high standard palliative and bereavement care to terminally ill people as well as to those close to them, St Christopher's has a number of arts-based community-based projects. These projects aim to introduce the hospice's work to the public, as well as to dispel myths and change attitudes towards the hospice, death and dying by enabling the development of relationships between local community members, hospice patients, and their families and carers (Hartley, 2011; Hartley, 2012). In 2011 St Christopher’s introduced ‘The Social Programme’ which consists of a series of weekly arts and music-based social events or activities aimed to promote the St Christopher’s Community Choir, Pottery and Quilling Groups, a Pizza and a Curry night, as well as the Dame Cicely Saunders Concert Series and other live music events. All of the programme activities are open to the public and take place within the common social spaces of the hospice throughout the week. The Social Programme provides opportunities to connect people at all stages and from all walks of life. All of the activities introduce the hospice, as well as issues around death and dying in a creative and dynamic way, by enabling people to become active members of the hospice's community. This presentation introduces the St Christopher’s Social Programme. It provides an outline of its events and activities as well as its role within the hospice and its potential for social engagement and change. Also, ideas for development of similar initiatives in other end-of-life contexts are provided.

Reference:

Abstract number: P2-229
Abstract type: Poster

Can Holistic Interventions Improve the End of Life Care of People with Chronic Obstructive Pulmonary Disease (COPD)? A Systematic Review
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Purpose: To undertake a systematic review of all published studies investigating the effects of holistic interventions on the end-of-life care of people with COPD.
Method: Systematic searches were conducted of the following electronic databases: Medline, Embase, CINAHL, AMED, Cochrane, and the British National Griffiths Reference Library. The search terms used were: different aspects of holistic interventions and Chronic Obstructive Pulmonary Disease. Review articles, expert opinions, and commentaries were excluded. The quality of the studies was evaluated using the PEDro scale.
Results: Five studies were included in the review. The studies used a variety of holistic interventions, including exercise, relaxation, music therapy, and spiritual care. The findings were mixed, with some studies reporting improvements in end-of-life care, while others found no significant differences.
Conclusion: Holistic interventions have the potential to improve end-of-life care for people with COPD, but further research is needed to determine the effectiveness of different interventions.

Abstract number: P2-230
Abstract type: Poster
Poster sessions

controlled clinical trials (CCTs) of holistic interventions for patients with severe COPD in any healthcare context. Date range January 1990 - March 2012, no language or geographic and health-related quality of life (HRQOL) was the primary outcome. The interventions were led by nurses and data extraction followed Cochrane Collaboration methodology.

Health-related quality of life (HRQOL) was the primary outcome. The interventions were led by nurses and data extraction followed Cochrane Collaboration methodology.

Abstract number: P2-230
Abstract type: Poster

Volunteering in End of Life Care - Presenting and Exploring the Changing Landscape

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This paper poses a number of important questions regarding the current trends and future challenges for volunteering in end of life care within the UK (1). It gives a unique perspective from an organisation which has undergone a large change programme regarding identifying new possibilities and the potential for a more effective utilisation of volunteers across end of life, health and social care service provision. Using a large London hospice as a case study, the change management programme was designed and described, highlighting important areas such as recruitment and selection, appropriate training and education, and effective and necessary support and supervision structures. Some individual stories are added, as well as the content analysis of a qualitative evaluation study, in order to give a more personal sense, and a broader perspective, of the changing benefits and rewards for individuals choosing to volunteer as part of the changing landscape of good quality end of life care. These benefits and rewards include offering back to work possibilities for those who are unemployed, or a first step on the other ladder for those with little or no academic qualifications. It is an important question for end of life care in general, and hospice care in particular, as to whether the volunteer programme that is offered is “fit for purpose” (2) both within the current climate and as part of an altered future. The model utilised and developed as part of this particular organisation will be shown to be suitable across a variety of institutions, cultures and other players concerned with improving the experience of people facing the end of life who wish to remain at home. Its findings suggest that hospice at home could be a valuable service for people who are dying and their carers in the future, reflective of the priorities of UK End of Life Care See further references of individuals. It identifies areas for further work and investment, including further research.

Abstract number: P2-231
Abstract type: Poster

Health Professionals’ Experiences of Using the Liverpool Care Pathway for the Dying Child Pilot Document in a Hospital and a Community Setting

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Background: The Liverpool Care Pathway for the Dying Child (LCPC) is a multi-professional integrated care pathway that provides an evidence-based framework for the delivery of care to children in the last hours or days of life. The LCPC Pilot Document (LCPC-PD) was introduced in a children’s hospice and a community outreach team in the UK in 2006. A developmental study is currently underway to develop the LCPC Model Pathway (LCPC-MP).

Aim: To explore health professional’s experiences of using the LCPC-PD, to inform the development of the LCPC-MP.

Method: 24 health professionals (2 nurses, 2 health care assistants and 1 counsellor) who had contributed to the 26 pathways completed 2009-2012 were recruited purposively. Focus groups in individual interviews (2) were conducted, audio-taped and transcribed verbatim. Data were analysed thematically using a framework approach.

Results: End-of-life care in both settings was nursed and medical professionals’ involvement was limited. Diagnosing dying in children was challenging and some nurses lacked confidence in making a diagnosis in the PD and in having conversations with parents about their child’s plan of care. The LCPC-PD only provided partial guidance, but also as a checklist that parents may perceive as limiting the individuality of their child’s care. Supporting education had been limited, and highlighted misunderstandings in completing the LCPC-PD.

Conclusion: Medical professionals must participate in the multidisciplinary implementation of the LCPC-MP and support nurses in diagnosing the dying phase. This will be a challenge in the current nurse-led culture. Communication goals must be emphasised in the LCPC-MP to ensure parents understand their child’s plan of care. A rigorous education programme must underpin implementation of the LCPC-MP to ensure the robust documentation of care provided to children in the last hours or days of life.

Project funded by Alder Hey Imagine Appeal.

Aims and methods: A recent survey of care delivered by 76 hospice at home services in England and Wales over a 3 month period begins to answer this question and build an evidence base regarding home care services including describing inputs and outputs of just over 4500 completed episodes of care. Anonymised data was collected by the individual services and focused on data extraction for collation and examination. Some initial examination of the data has already yielded initial results. Further analysis is planned. Results: The amalgamated results demonstrate that H@H does have an important role in caring for people in the last days and weeks of life. 87% of patients who die under the care of H@H die in the place of their choice, 76% of these patients died at home. The inputs for the service are relatively small in terms of resource, suggesting a small investment for the future. However inequalities exist particularly around diagnosis. Another limitation of the service is its relatively small scale in relation to the number of people who could benefit from it.

Conclusion: The survey identifies further actions required 1. to establish an inventory of H@H services, those licensed and those not; 2. to understand other players concerned with improving the experience of people facing the end of life who wish to remain at home. Its findings suggest that hospice at home could be a valuable service for people who are dying and their carers in the future, reflective of the priorities of UK End of Life Care See further references of individuals. It identifies areas for further work and investment, including further research.

Abstract number: P2-232
Abstract type: Poster

Experiences and Health Care Needs during the Last Year of Life of Older People with End Stage Renal Disease (ESRD) Managed without Dialysis in Thailand

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Background: Symptom experiences and unmet health care needs are an important issue of concern in older patients with End Stage Renal Disease (ESRD) managed without dialysis in Thailand. It has been argued these patients are a neglected group (1) to whom it is likely to have unmet needs with respect to healthcare and suffer from symptoms that could better be managed.

Objectives: To explore symptom experiences and health care needs during the last year of life of older people with ESRD managed without dialysis from the perspective of bereaved relatives in Thailand. To develop and adapt a form of the VOICES questionnaire for use with a Thai population.

Methods: A mixed-method exploratory phased design (instrument development model). Retrospective, exploratory interviews have been undertaken to collect data about older peoples’ experiences of ESRD managed without dialysis from the perspective of bereaved relatives. Purposive sampling was used to recruit participants from the renal units of hospitals in Thailand between September-December 2011. Semi-structured interviews with 12 bereaved relatives of elderly ESRD patients managed without dialysis were conducted. Interviews were digitally recorded, transcribed and analysed through Framework Analysis.

Results: The experiences and health care needs of older people with ESRD managed without dialysis were explored under four themes (sub-themes) including: 1) symptom experiences (physical, psychological and spiritual aspects), 2) impacts, 3) symptom management and 4) health care needs and utilization (health care provision, home visiting, spiritual need and financial support). Conclusion: The qualitative finding revealed important information about symptom experience and unmet needs of older people with ESRD managed without dialysis in Method:.

Abstract number: P2-233
Abstract type: Poster

A Survey of Inputs and Outputs of Hospice at Home Services in England and Wales

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Background: Hospice at Home (H@H) is a recognised service provided by hospices across the UK. Whilst those delivering H@H agree that it has an important role in providing care to people at home who are approaching the end of life there is little evidence regarding the detail of the care delivered, its impact and whether this varies between services who share the name of H@H.

Aims and methods: A recent survey of care delivered by 76 hospice at home services in England and Wales over a 3 month period begins to answer this question and build an evidence base regarding home care services including describing inputs and outputs of just over 4500 completed episodes of care. Anonymised data was collected by the individual services and focused on data extraction for collation and examination. Some initial examination of the data has already yielded initial results. Further analysis is planned. Results: The amalgamated results demonstrate that H@H does have an important role in caring for people in the last days and weeks of life. 87% of patients who die under the care of H@H die in the place of their choice, 76% of these patients died at home. The inputs for the service are relatively small in terms of resource, suggesting a small investment for the future. However inequalities exist particularly around diagnosis. Another limitation of the service is its relatively small scale in relation to the number of people who could benefit from it.

Conclusion: The survey identifies further actions required 1. to establish an inventory of H@H services, those licensed and those not; 2. to understand other players concerned with improving the experience of people facing the end of life who wish to remain at home. Its findings suggest that hospice at home could be a valuable service for people who are dying and their carers in the future, reflective of the priorities of UK End of Life Care See further references of individuals. It identifies areas for further work and investment, including further research.

Abstract number: P2-235
Abstract type: Poster

“Allow your Voice to Dance till Death.” Music Therapy at the End of Life

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Description: Analysis of some essential and touching moments taken from the backstages of an extraordinary
The Big Five Revisited - Wound Management

Aims:
Funding:
Setting/participants:
Method:
Results:
Conclusion:
Abstract number: P-236
Abstract type: Poster
The Big Five Revisited - Wound Management Education in a Kenyan Hospital

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Aims: Following an invitation of the palliative care unit (PCU) in Kenya to conduct educational training, researchers spent one week in Nairobi in order to discuss feasible and budget-friendly ways of management of malignant wounds. The Kenyan PCU team has been working as a wound management (WM) consultancy team throughout the hospital and strives to expand their outpatient service at the PCU to a WM advisory center.

Methods: The Kenyan team organised a one-day seminar with various speakers on WM for hospital staff (nurses), including pre-posttest, anatomy & physiology of the skin, evidence & treatment of malignant wounds, wound assessment and wound care product information. This also introduced the German team to hospital staff. In the next few days, the German & Kenyan nurses were invited to assist and observe different malignant wounds in several wards, discuss wound care options with the staff and to show how to change the dressings. The team also saw outpatients at the PCU and visited a patient at her home.

Results: Five major challenges emerged throughout the visit. These included attitude (use of rescue medication before dressing changes), treatment goals (treatment of patients with severe malignant wounds who were not informed of their prognosis), there was a vivid discussion about press and cons of WM options and the best possible management of certain problems. An evaluation at the end of the visit indicated that this was an important step to improve the knowledge of WM on non-palliative wards and towards the establishment of a wound advisory center.

Conclusion: As a next step of this cooperation a regular or one day workshop could be established (consultation via email or Skype).

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Abstract type: Poster

The Role of ‘Breathing Change’ in Recognising the Imminently Dying Phase

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Background: Recognising when patients are approaching the imminently dying phase (last hours or days of life) is an important aspect of providing end of life care. However, this recognition can be challenging and multiple factors need to be considered. In a study to explore the processes by which hospice staff recognise the dying phase, the importance of ‘breathing changes’ was frequently encountered. Aims: To describe the significance of ‘breathing changes’ in recognition of the imminently dying phase.

Method: An ethnographic qualitative study, guided by grounded theory, performed in 2 specialist hospices using retrospective case-records of the last 7 days of life, observation of clinical meetings and semi-structured interviews with hospice staff. This was followed by a Delphi study seeking consensus on key themes and factors identified from the qualitative research, asking opinion from regional and national hospice staff.

Results: From case-note analysis, ‘breathing changes’ was the most commonly documented group of physical factors identified. The frequency of case-note entries relating to breathing increasing towards the last 48 hours before death. Multiple descriptions of breathing were found, e.g. rapid/slow/irregular breathing, chest, costations, chyne-stones breathing, apnoea episodes, increased dyspnoea. During interviews, participants agreed the importance of ‘breathing changes’ but found difficulty in describing specific aspects. The Delphi study confirmed strong agreement for the importance of breathing changes. Chyne-stones breathing followed by irregular breathing pattern and death. These were included in the strongest level of agreement. Increased dyspnoea showed lowest agreement.

Conclusion: ‘Breathing changes’ appear to be a significant physical factor in the dying phase. This study has helped clarify the relevance of certain aspects of breathing, but further research is needed to improve specific clinical depictions.

Abstract number: P-238
Abstract type: Poster

Experience of Life- and Death anxiety among Patients with Severe COPD

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Background: Recognising the imminently dying phase (last hours or days of life) is a key part of providing end of life care. However, accurate recognition can be challenging and there is little empirical evidence on this process, including the factors considered by healthcare staff.

Aims: To seek consensus on key factors considered by hospice staff when approaching the imminently dying phase.

Method: A Delphi survey building on previous qualitative research. Experienced multi-disciplinary hospice staff (the Delphi experts) from UK hospices were asked opinion on questions derived from core qualitative themes using a web-based survey. Observations from a core group of facilitators provided detailed feedback on the Delphi rounds were reviewed.

Results: Round 1: 19 staff from 9 hospices participated (64.1% >5 years hospice experience). Asked ‘What factors do you consider important that a patient is entering the dying phase?’ 250 individual responses were received. Strong agreement was seen for consideration of potential reversible causes for deterioration and importance of knowing the individual patient to better recognise the disease. The Delphi experts included the appearance, breathing changes, conscious level and fatigue. Round 2: 24 staff participated (67.4% >5 years hospice experience). Further clarification was sought on factors identified in round 1 including: potential reversible causes (hypocalcemia /infection /rapid opioid medication /medication side effects) and patient actions (agitation /withdrawal).

Conclusion: Recognising the imminently dying phase is complex and a variety of factors need to be considered. This Delphi has gained consensus on aspects of this process, which could be used for further research or development of educational tools.

Abstract number: P-239
Abstract type: Poster

Visible Workers, Hidden Labour: Emotional Support Provided by Health Care Assistants (HCAs) Caring for Dying Patients - Their Views and those of Bereaved Carers

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Aims: In the UK HCAs comprise 30% of the nursing workforce and are unregulated. They commonly care for the dying at home. Lack of recognition and understanding of their role has been described as Invisible workers. Few studies have described the full extent of their work. We aimed to explore their views by interviewing HCAs and bereaved carers who had experienced their care.

Method: Semi-structured interviews were undertaken with 10 HCAs from three diverse services in the West Midlands. Themes were developed as part of the project's in-depth analysis. This qualitative approach is compatible with both description and explanation. The interviews were transcribed and thematically coded using Atlas ti - set 2.

Results: HCAs described their role as practical work and providing emotional support, including: relieving the burden of caring, encouraging self-care for carers and listening to patient and carers' concerns. HCAs valued building relationships and providing continuity of care. Initial findings from bereaved carer interviews indicate that they were mostly very satisfied with HCAs care, acknowledging previous presence of the HCA, sensitivity and spontaneity in recognizing their needs; listening to patient and carers' concerns and ongoing involvement after death. HCAs also described specific issues such as attending funerals. Some bereaved carers specifically recognized and valued the emotional support that HCAs gave. HCAs were particularly appreciative that HCAs had developed an ongoing relationship with patients and family members. Conversely, if HCAs did not show sensitivity or fail to engage with them during care, somebereaved carers were critical and discontent. This rarely occurred.

Conclusion: HCAs offer a wide variety of skills in their work with dying patients and their care significantly improves emotional support. Their work is highly valued by bereaved carers and its full extent should be recognized and acknowledged in the services in which they work.

Funder: Dribbley Cancer Care

Abstract number: P-241
Abstract type: Poster

Poster sessions - set 2
**Poster sessions**

**Introduction:** In Japan, estimation of the number of cancer mortality cases began in 2009. Occupational therapists are involved in many facilities in the field of palliative care. However, there have been few reports on occupational therapy (OT). Here, we surveyed the attributes of patients who received hematopoietic stem cell transplantation (HSCT) and compared patients followed by OT with patients not followed by OT.

**Subjects:** The subjects were 273 HSCT patients who received treatment between March 2005 and October 2011. HSCT patients followed by OT patients not followed by OT.

**Methods:** All patients received HSCT were examined. We compared attributes (age, sex, disease classification, the survival situation, the survival days, transplant type, recurrence, Performance status (PS), Karnofsky performance status scale (KS), Hematopoietic cell transplantation-specific comorbidity index (HCT-CL) Total, acute Graft versus host disease (GVHD) II between two groups. The Kaplan-Meier method was used to examine the survival curve from the day of transplantation to the last day of survival.

**Results:** Disease classification (p=0.000), the survival days (p=0.000), transplant type (p=0.000), recurrence (p=0.000), HCT-CL Total (p=0.033) were significant differences between two groups. The 5-year survival rate of OT group was 44% (95% confidence interval 3.241 - 0.5466). The outcomes were better for all groups were discharged for home (75%), 31 patients died (19%), and 9 patients switched to another physician.

**Discussion:** Our group was many severe cases. The 5-year survival rate for HSCT patients was low. Rate of death was high at 19%, and we found that there were many opportunities to perform OT in end-stage patients. In future studies, we plan to examine the effectiveness of OT in end-stage patients.

**Abstract number:** P2-242

**Abstract type:** Poster

**Improving End of Life in Community Hospitals: Community hospitals have an important role in the community. Many elderly people are transferred to community hospitals from the acute sector following long stays in an acute ward. Although some would choose the community hospital as their preferred place of care, others can spend a lifetime in the community hospital awaiting assessments and placement to care homes or to return home.**

**Aim:** Improving end of life care in Community Hospitals using the Gold Standards Framework Dementia Care Training Programme. Community Hospitals have an important role in the community. Many elderly people are transferred to community hospitals from the acute sector following long stays in an acute ward. Although some would choose the community hospital as their preferred place of care, others can spend a lifetime in the community hospital awaiting assessments and placement to care homes or to return home.

**The programme followed the same format as other GSF Programmes. And the aim was to improve the coordination and planning of care, putting systems in place to ensure:**

1. The Right Place
2. The Right Care
3. The Right Time
4. The Eight Gs
5. Every time

**This Quality Improvement Programme involved 28 community hospitals in the West South of England. The programme is currently being evaluated and the hospitals are preparing for Accreditation in 2013. Further details of both quantitative and qualitative changes will be available.**

**Results:** So far no are showing improvements in communication and collaboration with care homes, primary care teams and acute hospitals.

**Abstract number:** P2-243

**Abstract type:** Poster

**Improving End of Life Care in Acute Hospitals, Using the Gold Standards Framework Acute Hospital Programme**

**Aim:** The aim of the GSF Acute Hospital Programme is to improve the quality of care provided for all people in the final year of life, improve coordination and collaboration within teams and across boundaries of care, and to enable more to live and die at home and decrease hospitalisation. Phase 2 GSF included 8 acute hospitals, ranging from 1-3 wards per hospital. A comparative evaluation was carried out before and after the 9 month intervention of the GSF training programme.

**Method:** An independent evaluation and analysis from eight hospitals participating in Phase 2 GSF included; - Staff Survey - Organisational Survey - After Death/Discharge Analysis (ADA) - Qualitative data from a focus group

**Results:**

- The key results were improvements in staff knowledge and confidence in most areas of end of life care
- Increased identification of patients nearing the end of life
- Increased shared planning discussions
- Improved communication with primary care teams
- There have been modest improvements in use of rapid discharge processes and use of care pathways for the dying
- Some evidence of reduced length of hospital stay

**Conclusion:** The GSF Acute Hospital Programme has enabled hospitals to improve quality of end of life care, at grass roots level, through organisational/cultural change and at some patient level outcomes. The programme aimed to enable hospitals the opportunity to broaden awareness of end of life care, develop and educate all staff, improve cross boundary care communication and to move onto to deepen levels of sustainability through objective accreditation. This enables better integrated cross boundary care.

**Abstract number:** P2-244

**Abstract type:** Poster

**Using Tools and Pathways to improve Generalist End of Life Care in the Community**

**Aims:** To improve the standard of end of life care provided by generalist community nursing services through adapting hospital tools and pathways for patients who are in their last hours or days or whose recovery is uncertain.

**Methods:** - Refinement and implementation of the Liverpool Care Pathway (LCP), a widely recognised pathway for dying patients, across seven generalist community nursing teams in both countries. - A qualitative study was undertaken, including five semi-structured interviews with patients and five focus groups for the family members.

**Results:** The patients' main concerns were of a psychological nature and related to do to day to day activities due to fatigue. Families talked of practical issues, such as problems with providing 24 hour care. Both patients and family members acknowledged the lack of a specialised palliative professional help.

**Conclusion:** For communicating with health professionals was stressed by both patients and family members and the problems that ensued as there was little collaboration amongst service providers.

**Provision of care:** recommendations from this study include the need for more education on palliative care management and advanced communication skills training for health professionals, including improved communication between service providers needs. Increased care would help families to provide care for the patient and the establishment of palliative care teams would provide additional help and increase the quality of patient’s life. The study has encouraged a local charity to continue to develop support by volunteers for patients and their families.

**Conclusion:** The successful implementation of the LCP has opened the door for further development, including the implementation of the AMBER care bundle in both countries. The feasibility study indicates that the AMBER care bundle has the potential to be adapted to improve care in the community for patients whose recovery is uncertain.

**Abstract number:** P2-245

**Abstract type:** Poster

**The Views of Palliative Patients and their Families on their Needs for Palliative Care Services in Medjugorje (County of Croatia)**

**Aim:** This study looked at ascertaining the palliative care needs and views of patients with incurable illness, and their families, within the county of Medjugorje in Croatia and asked them for their ideas about the development of a palliative care service.

**Method:** Qualitative study was undertaken, including five semi-structured interviews with patients and five focus groups for the family members.

**Results:** The patient's main concerns were of a psychological nature and related to do to day to day activities due to fatigue. Families talked of practical issues, such as problems with providing 24 hour care. Both patients and family members acknowledged the lack of a specialised palliative professional help.

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Plan for PC. Argentina does not have a National Plan of PC. 2

- Module 1: identified associations:
  a) advances in the intervention in EoL
  b) expectations of the patient and the family of the LCP,
  c) doubts and fears in the application of the LCP,
  d) the position of awareness in the interventions.

Moreover, the concern of the patient/providing comfort/pain/symptom control in Argentina is low. Furtado was a lack of training in PC, obstacles and resistances from other health professionals are described, the importance of documenting: Spain (33%) vs. Argentina (40%).

Conclusion: The study gives, for the first time in LA context relevant data regarding support to EoL and perceptions in the core of the implementation of the LCP's not commonly used in our situation.

Abstract number: P2-247
Abstract type: Poster

PAMP A Program: The Liverpool Care Pathway (LCP) Implementation in Argentina
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The Liverpool Care Pathway (LCP) was largely recognized in Europe as a guide for the care of the dying, providing high quality end of life care in a variety of settings. Its development in Argentina is based, not only on its institutional framework but also on its cultural context. Argentina is a large South American country that is the first country at Level 4 (approaching integration) in the global map of Palliative Care (PC) development. However, PC services are still quite unable to reach the vast majority of people who might benefit from them. For the last 4 years we have been working in the translation and cultural adaptation for the LCP into the Latin American (LA) cultural context. In 2012 we received two grants from the National Cancer Institute and from the National Ministry of Health. The aim of this presentation is to show the integration of the LCP into the LA context, the best practices in almost 65% of the countries of excellence from de LCP. When we started a pilot and pilot phase in five teaching hospitals and the Pallium (NGO) Home Care. In a retrospective base multidisciplinary education programs for care of the dying (20 sessions), family members interviews (32), staff perceptions surveys on the LCP, (issues 112), and professionals focus groups (14). The process was supervised by the Marie-Cure Palliative Care Institute Liverpool (UK) and the data was analyzed by their website software program. The outcomes show that the goals of excellence of the LCP are reached more than 95% and the awareness of the care of the dying was notably improved in the qualitative analysis. This is the first project focused on the LA care best practices in LA. Our challenge consists on the use of the LCP in our language and cultural context. This requires continuous insight, critical decision making and clinical skills.

Abstract number: P2-248
Abstract type: Poster

Meningioma - Nonmalignant Histological Lesion with Slowly Progressive Severe Clinical Course - A Case Report
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Introduction: Meningiomas are mostly histologically benign tumors. However, some patients can suffer from these tumors who spread to the bone and destroy it, but also they can cause hypostrosis. Case report: The patient was 27-year-old when two meningiomas were diagnosed. The first one in posterior cranial fossa was removed surgically - meningioma WHO gradus II. The second one in the right temporal region was operated three months later. The histological examination confirmed an atypical meningioma WHO gradus II. The patient was treated by radiotherapy one month after surgery. About one year later, the bone flap after craniotomy was removed separately at an interval of one month. Last (the ninth) neurosurgical operation was performed for repeated recurrences of tumour in the right temporal region one year later. At the age of 35 years all treatment options of neurosurgical and oncological therapy were exhausted. About two years later, the family was not able to take a care of the disabled patient who was transferred at hospice in Riyadh after three months of her residence at health resort of chronically ill patients. The patient was treated symptomatically including adjuvant analgesic therapy. Mental support of the patient was necessary as well as the patient’s family. We died at the age of 38 years.

Conclusion: Nonmalignant histological lesions such as meningiomas can present severe clinical course significantly enhanced by long term factor. It is essential to take all-embracing care of a patient including psychotherapy.

Abstract number: P2-249
Abstract type: Poster

"Dying Healthly" - How Alternative Therapies Support Reintegration of Psycho, Social, Spiritual and Biographical Parts in the Dying Process
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Alternative therapies such as creative therapies (e.g. music, art) an aromatherapy, manual therapies (e.g. massage, shiatsu) or mind body therapies (e.g. guided imagery) are widely used in hospice and palliative care. Aim of this study was to explore the significance of alternative therapies for seriously and terminally ill people at the end of life.

Elements of Grounded Theory and Intuitive inquiry served as a methodological framework for this qualitative exploratory study. A total of twenty multi perspective, qualitative interviews were conducted with managers (n=7), complementary practitioners (n=11) and doctors (n=5) in six German inpatient hospices. There were also focus groups (n=6) with multi-professional team members. Interviews and focus groups were tape-recorded, transcribed verbatim and analysed using Grounded Theory methods.

Empirical data shows that alternative therapies do not only have effects on a physical level (e.g. decrease of pain and changed pain perception) but also on psychological, social and spiritual levels. In the course of an illness not only physical, but in particular, emotional, social or spiritual parts of an individual get hurt or become separated. Multidisciplinary palliative care staff report, that alternative therapies play an essential part in re-integrating these separated parts into the individual biography during the dying process.

Even if people die of physical illness, the dying process itself should not be considered as an illness. Instead, dying can be understood as a healthy process (of life), which allows the individual to reintegrate separated parts in the biography. To support the dying in these processes of reintegration it needs therapies respectively therapists, which address and respond to bio-psycho-social and spiritual levels.

The research project was funded by the "Stifterverband für die Deutsche Wissenschaft".

Abstract number: P2-250
Abstract type: Poster

Physiotherapy and Motor Skills in Palliative Care
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Background: The problem of physiotherapy in palliative care is significant and recognized in the scientific literature. Therefore, the current knowledge of this issue is limited. In many hospices in Poland, team members are not able to specify goals to be fulfilled in the course of the rehabilitation undertaken, while physiotherapists face difficulties in clear determination of their role in palliative care.

Objective: 1. The aim of the present study was analysis of functional changes in all aspects of life (motor fitness, social condition, emotional well-being), aimed at advanced stages of malignancy diseases during rehabilitation process included in home assistance.

2. To analyze the physical activity of the terminal illness patients in the range of basic everyday activities-Bathel Index.

Material and methods: The research was performed on group of 20 patients in the terminal phase of cancer, who finished 6 months of physiotherapy. All of them were involved in palliative homecare treatment. The physiotherapy was performed twice a week in the patient’s home, for the duration of 6 months. None of the patients was included in any other rehabilitation programme-distinct outpatient unit, nor was he subject to psychological therapy. Results: The physiotherapy improves the quality of life of the patients throughout increasing the level of functional activities: transfer training -28%II and above 50% in VI months of the rehabilitation programme, bath-133%II months, gait education-38%VI months, stairs-50%II months.

Conclusion: 1. The results indicate that motor rehabilitation improves the quality of patients’ life by increasing the level of functional efficiency, manifested as an improved ability to be self sufficient.

2. In the applied in the Barthel Index is a useful and functional model of grading of typical everyday activities. It is also an effective qualifier of the basic area of therapists’ work.

Abstract number: P2-251
Abstract type: Poster

Palliative Care in Reach of the Vulnerable Psychiatric Patient
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Objective: An explorative research among professionals patients and relatives on palliative care for people with a psychiatric disorder: Investigation of further research needs among patients, relatives and experts in mental health, general health and palliative care.

Design and method: Four groups of clients were formed and of them included in the five parts of the project:

1. Focus groups with different medical professionals to gather information about their experiences in treating patients with a psychiatric disorder.

2. A questionnaire among professionals were they were asked about the amount of patients treated in the past year with a psychiatric disorder and the need for palliative care.

3. Interviews with professionals about their experiences with these patients.

4. Interviews with patients about their experiences in receiving palliative care.

5. Biographical groups with relatives.

Results and conclusions: Offering palliative care for patients with a psychiatric disorder is essential, further research needs to be done for embedding this care in fields of health care. Health professionals are developing different methods and courses e.g. a specialized palliative care unit for psychiatric patients and a manual for providing palliative care for these patients but all of them are in a premature phase. Medical professionals presented clear ideas about the contents of these methods and the obstacles they faced when treating these patients, especially in communication. Professionals and different barriers exist in each and all of these cases which makes treating the patients complex.

Abstract number: P2-252
Abstract type: Poster

The Role of Advance Care Planning in an Inpatient Hospice: Is It Too Late?
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Background: Advance Care Planning (ACP) is a process where future healthcare preferences are discussed based on personal values. Discussions are preferably conducted with patients themselves. Our hypothesis is that it is too late to initiate ACP in hospices, especially for patients whose length of stay is 25 days. Our aim is to study the rate of completion of ACP discussions with these patients, understand the barriers and review the outcomes.

Methodology: This is a prospective observational study carried out between June to October 2012. ACPs were conducted by a trained facilitator with patients who were cognitively intact, with no collusion and were agreeable for discussing their future wishes. For patients who were unable to participate, ACPs were carried out with their surrogates, usually close family members by default. Descriptive statistics and reasons for unsuccessful ACPs were collected.

Results: 169 patients were studied, 50% were cognitively impaired, of which majority (88%) were recent in onset. 36% of patients were cognitively intact. The remaining 14% could not be reached due to controlled symptoms or inability to communicate. 23% of all patients completed their own ACP, of these, a fifth died within 1 week. Other than cognitive impairment, collusion (8%) and uncomplicated symptoms (7%) precluded ACP discussions. 5% had no ACP
even via surrogate due to rapid decline. Only 17% had ACP before admission.
129 patients died during this period and care preferences were noted for 80 (63%) patients, of which 70 (88%) preferences to pass away at home, only 20 out of 13 were achieved.

Conclusion: 57% of patients could have potentially participated in ACP discussions as barriers such as cognitive impairment, uncontrolled symptoms and colliquial preferences (PC) led earlier in disease trajectory. This will reduce surrogate-led discussions and honor patient’s true preferences.

Epidemiology

Abstract number: P:2-253
Abstract type: Poster
The Evaluation of Palliative Patients’ Care in Emergency Services in a Hospital without Palliative Care Center

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Research aims: Emergency departments (ED) are units focused on acute and critical diseases, while the palliative care focuses on increasing the quality of life by relieving pain. Although the role of palliative medicine is gaining increasing momentum, many EDs lack palliative physicians care task with limited skills and training. The aim of the study is to find out the course of cancer patients, in need of palliative care, that were admitted to an ED in a province that had no palliative care units.

Study design and methods: The cancer patients that were admitted to ED of an university hospital, between January 2012 and September 2012, were evaluated. The data were analyzed through SPSS 15.0.

Results: It was seen that total of 125 cancer patients have been admitted to ED between January 2012 and September 2012. The number of patients that was in need of palliative care was 52 (41.6%). The mean age of the patients was 61, there were 32 male and 20 female patients. Considering the cancer types, lung cancer was mostly seen (23%) and the second was the gastric cancer (14%). The mean rate of a number of a patient’s admission to ED in an 8-month period was 8.7. In terms of the complaints of these admissions, the first was the pain (34.4%) and the second was dyspnea (25%).

Discussion: Mote et al. have emphasized that an emergency physician needs to be competent in pain control, in elimination of other possible symptoms, and on main issues of palliative care such as breaking bad news or specifying prognosis. It has become a necessity, especially in those hospitals that have no palliative care teams.

Conclusion: This study shows that the palliative patients constitute an important group of patients, in the admissions to ED in our province. We suggest that emergency physicians’ skills and training should be increased until the hospital has its own palliative care units.

Abstract number: P:2-254
Abstract type: Poster
Prolonged Dwindling; An over Simplification of Dying for Centenarians

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Context & aim: Centenarians are the fastest growing demographic in the world. The number is projected to increase worldwide from 3,700,000 in 2010 to 25,000,000 by 2050. To develop and implement services for the group requires understanding on variations in cause of death by place of death. We aimed to test a classification of cause of death and variations by place of death to inform the provision of end-of-life care services.

Methods: A whole population observational study using death registration data for people aged 100-year and over between 2001-2010 in England. Descriptive analysis of cause of death and contributing causes of death to examine models of dying and comparative analysis of variations by place of death.

Results: Participants 3,581, people age average 100 at time of death and 85 years. Majority widowed (85%) and died in a care home (61%). Many died in hospital (28%); few died at home (9%). Three models of dying conceptualised: 1. Acute death on chronic illness. Main cause of death pneumonia (18%) with contributing chronic circulatory disease e.g. heart failure 2. Chronic cause of death. Main chronic causes of death: cardiovascular disease (15%), dementia (5.6%) and cancer (2.9%) 3. Acute cause of death. e.g. myocardial infarction (2.8%)

Conclusions: The models of dying challenge the prominent trajectory of dying in old of prolonged ‘dwindling’ presenting an over simplification of dying with many dying from an acute event while living with chronic conditions. The model of prolonged ‘dwindling’ is questioned as too simplistic. Greater recognition of acute events in this age group and place of death in care homes indicates service implications for wider provision of advanced (ECG) and advanced care planning and health service support to care homes as the main providers of end-of-life care to centenarians.

Funder: NIHR Health Services and Delivery Research programme (project no. 09/0058/58).

Abstract number: P:2-255
Abstract type: Poster
Identifying Advanced Chronic Patients in Need of Palliative Care in the General Population and Health Care Settings: A Prevalence Study

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Aims: To establish prevalence of advanced chronic patients in need of palliative care in the County of Osona (Spain).

Methods: Cross-sectional and observational prospective cohort study. A total of 2,184 (52% of population) were selected to participate, as well as settings in these areas -general hospital (1), socio-health centre (1), nursing home (1) and primary care (1). The NECPAL-CCGMS-ICO tool was applied to advanced chronic patients; those with ‘surprise question’ positive (SQ+) were identified; patients with SQ+ and, at least, 1 additional positive preoccupation. Increasing considered as NECPAL+ and all of them followed up for survival for 1 year, as well as general mortality occurred in the county.

Statistical analysis: number of observation, median, standard deviation, percentages and OR were calculated. Sensibility, specificity, PPV, NPV and AUC ROC for advanced chronic, SQ+ and NECPAL+ categories will be assessed regarding mortality at 3, 6, 9, and 12 months.

Results: 100% of centres participated. Total population was 49164 (>65±21.4%). Between Nov 17th 2010 and Oct 23rd 2011, 1064 persons (2.06%) were identified as advanced chronic, 750 (14.5%) as SQ+, and 682 (13.3%) as NECPAL+. P+ persons are: medium age 82, 62.5% women, 31.7% show advanced frailty, 22.47% dementia; 12.3% advanced cancer (cancer/non cancer=1/8); 64.7% live at home and 22.1% live at a nursing home. 89.9% show general clinical indicators of somatization (nutritional decline: OR=5.79, functional decline: OR=4.9, admissions>2: OR=5.79, functional decline: OR=4.9, admissions>2:

Conclusions: Despite the complexity of problems, present model criteria could probably reduce even more the burden associated with this disease.

Abstract number: P:2-257
Abstract type: Poster
Are Palliative Care Patient Satisfaction Surveys with Low Response Rates Biased? A Randomised Study

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Aims: It is necessary to ask patients about their experiences of palliative care in order to identify problems, but due to advanced disease the response rate is often low. The aim was to investigate (1) the impact of questionnaire length and of sending reminders on response rate and (2) whether patient surveys of palliative care with low response rate are biased towards higher or lower satisfaction with care. Methods: A randomised controlled trial using FAMCARE-P16 with 10 and 20 items will be sent automatically to 1.000 patients with an average follow-up around 6 months. We will classify responses calculated on certainty of incorrectly filled if patients in the palliative care phase. These patients are entitled to free medical care, and is registers when this is granted following application from their doctor. We were allowed to contact consecutive cancer patients receiving this allowance. We randomised 998 of these patients between (A) a long satisfaction with care questionnaire (16 pages) and (B) a short questionnaire (2 pages) followed by a reminder to non-respondents after two weeks. The validated FAMCARE-P16 patient satisfaction questionnaire was included in both versions, and the proportions of satisfied/disappointed patients (including ‘don’t know’) were compared between arms A and B using Chi-square tests.

Results: The participation in A was 21 % (97 out of the 457 who were alive when contacted) and in B 41% (186/458) in arm B. On the temporal pattern we estimated that the participation would have been approximately 31 % in B without the reminder. There were no significant differences in any of the 16 FAMCARE-P16 items between arms A and B.

Conclusion: Low participation is an almost unavoidable methodological problem in research involving patients at the end of life. The short B questionnaire (2 pages instead of 16) affected participation as much as the reminder (each increased participation with 10% and 7%, respectively). This study suggested that low participation does not lead to strong impression; there were no significant differences in satisfaction between arms A (21 % participants) and B (41% participation).

Abstract number: P:2-258
Abstract type: Poster
A Study of Patients Reported to the Swedish Register of Palliative Care 2009 as Departed in Care But Not Registered in the Swedish Cancer Register

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2Background: The Swedish Cancer Register (SCR), an old and reputable health data register, contributes a large amount of data used in research. The quality of the research using SCR data depends on the completeness and validity of the
register. In Sweden, every health care provider is obligated to report newly detected cases of cancer to the SCR regardless of the diagnostic basis. An unpublished report revealed that 11% of the patients in the Swedish Register of Palliative Care 2008 (SRPC) whose cause of death was cancer were not registered in the SCR. This study is aimed at clarifying whether there is an underreporting of patients with cancer to the SRPC or an over-reporting of cancer as cause of death to the SRPC. In this paper, we present the findings at the distribution of under or over-reporting related to age, sex, type of cancer, diagnostic basis, and department responsible for cancer diagnosis. 

Methods and materials: Of the 10,559 patients whose cause of death was cancer, 1,934 patients (17.2%) were not registered in the SRPC (1958-2009). Medical records of the representative sample of 203 patients were collected and reviewed. Results: The medical records for 193 patients were obtained; of these 83 patients should not be reported to the SCR. Among these, radiologic investigation was the most common basis for diagnosis and there was a significant over-representation of cancer of the pancreas, liver, lung, and bile ducts. Discussion: The study cannot quantify the completeness of the SCR. The findings indicate that 12.5% of patients dying of cancer in palliative care are not reported, that specialized hospital departments diagnose the vast majority of the underlying cancer, and it is of crucial importance to report patients to the SCR based on radiologic findings to have been revised.

Ethics

Abstract number: P2-259
Abstract type: Poster
Palliative Sedation and Organized Palliative Care in Flanders (Belgium): From Palliative Sedation Research to Palliative Sedation Guidelines (and Back)
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Background and aims: Especially in a country in which euthanasia is a distinct possibility, it is of crucial importance that information on and expertise regarding other, less drastic ‘options of last resort’ is widely shared. This paper intends to show how the Flemish Palliative Care Federation through research, education and the development of guidelines has been trying to offer clarity and direction regarding the practice of palliative sedation. Design and methods: Starting from a brief overview of the different (conceptual, ethical, prospecic, clinical, review, questionnaire) internationally published studies on palliative sedation in which the Flemish Palliative Care Federation actively participated (1999-2012), we show how this research led to a better understanding of palliative sedation and to the development, in close cooperation with the different working groups of the Federation, of specific guidelines and books in order to share these insights. Results: Through numerous lectures and workshops (1999-2012) and the development of a shared conceptual framework (2006), guidelines on palliative sedation (2010-2012), a practical summary of the guidelines (2012) and a leaflet on palliative sedation for the general public (2012) essential insights regarding i.a. terminology, the importance of proportionality, and the threefold distinction between euthanasia and palliative sedation (intention, act, result) have been widely shared. Conclusion: Palliative sedation continues to cause a great deal of controversy in many countries, especially because of a lack of expertise and of adequate information, the latter both at the level of the general public and of health care professionals. The research done by the Flemish Palliative Care Federation on guidelines and information sheets developed (English translation available) can offer valuable inspiration to address these issues.

Abstract number: P2-260
Abstract type: Poster
Changes in Opinions and Attitudes towards Advanced Directives (AD) in the Primary Care Staff. 5 Years after the First Survey
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A Domiciliary Palliative Care Team starts a collaborative project with the Primary Care in 2006. Aims: To describe attitudes towards the Advance Directive/AD of the Primary Health Care staff in our area. To describe changes 5 years after. Methods: Descriptive qualitative study. Setting: Urban Primary Care Staff. Subjects: Center’s staff. Who organized 5 focus groups. The chairperson (a palliative medicine specialist) informed about ethics and legal frames as well as the registration process of AD. The chairperson leads the dialogue. The observer registered the main questions about AD. An anonymous survey was given to attendants. We repeated the study 5 years later. Measurements: n’ requested AD, n’ delivered AD, n’ assessed AD, Physician, AD knowledge, Requested AD, Delivery AD, Assessment AD, Usefulness AD, difficulties of General AD, Duration AD, Distribution AD, have you drafted your own AD? Results: N=42 surveys, 69 in 2006. Attendants: Physicians 54% (2006), 51% (2011), Nurse 46% (2006), 49% (2011). Practically all (98%) knew the existence of an AD document, but only 59% knew the complete contents of the AD. The AD knowledge increased in last 5 years with significance (p<0.011). A request of AD was received by 38% of attendants in 2006 and 29% delivered AD document to the patients. There’s a trend of increased demand of AD statistically significant (0.007) in last 5 years. Only 22% of attendants assessed the AD status (AD adapted to 9% in 2006) without statistical significance. Practically all the attendants (98%) thought that AD was useful or very useful in their clinical practice. Conclusions: The attitudes of attendants towards AD (2012) were not statistically different to other relevant experts through a process of snowball recruitment. A lack of expertise and of adequate information, the latter especially in a country in which euthanasia is a distinct possibility, is of crucial importance. A close cooperation with the different working groups of the Federation, of specific guidelines and books in order to share these insights is essential.

Abstract number: P2-261
Abstract type: Poster
The Spread of Palliative Care into the European Continent: A Meeting of Different Care Traditions
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Aim: Palliative care is spreading rapidly across the world but little is known about the socio-cultural factors influencing this process. We explore how the ideas of palliative care are spreading to other countries it led to various processes, palliative care itself was modified. Agreement on less is known about the views of patients’ and carers’ with cancer. When the ideas of palliative care started spreading to other countries it led to various processes, palliative care itself was modified. Agreement on care. However, respondents had little knowledge of the services specifically related to end-of-life care. They formed by media representations and/or current care. They were unaware of potentially beneficial services and were unable to envision the development of DN care as their illnesses progressed; lack of knowledge about DN services governed patients’ and carers’ decisions future care. Discussion: Poststructural discourse analysis techniques were used to data collected in 2010-2011. Results: Twenty-six patients and thirteen carers participated. Lack of knowledge on DN services emerged as a key theme. AnoVA test was used for comparing the different groups. Results: Significant differences were found in the assessment of the ethical issues between different types of nurses. Nursing homes nurses showed higher scores on questions related to respecting the patients’ and carers’ wishes. Family and the other. The on-resuscitation units are more implemented in hospitals than in the other settings of the study. The on-resuscitation units are more implemented in hospitals than in the other settings of the study. Conclusion: In appearance, it seems to be more respect to patients and families wishes in nursing homes, than other clinical settings, but overall, our results show that the principle of autonomy often is not respected.

Abstract number: P2-262
Abstract type: Poster
Knowledge and Ethics: A Poststructural Analysis of Discourse on Patients and Carers Views on Quality Palliative and Supportive District Nursing Care
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Background: Palliative and supportive care (P&SC) services increasingly aim to improve quality of care. District nurses (DNs) (UK community nurses) play a key role in providing P&SC but less is known about the views of patients’ and carers’ with cancer. Design and methods: Qualitative design, using in-depth semi-structured interviews with patients and carers receiving DN care. Patients were interviewed at home, in hospices, caseloads and hospice day centres, where possible they nominated a carer: inclusion criteria: over 18, able to consent, and for patients’ receiving DN care, and requiring P&SC. Interviews were audio recorded and transcribed. Poststructural discourse analysis techniques were used to explore patients’ and carers’ perspectives on the quality of P&SC DN care. The study gained ethics and governance approval. Data were collected in 2010-2011. Results: Twenty-six patients and thirteen carers participated. Lack of knowledge on DN services emerged as a key theme. Patients’ and carers’ knowledge of DN services were entirely formed by media representations and/or current care. They were unaware of potentially beneficial services and were unable to envision the development of DN care as their illnesses progressed; lack of knowledge about DN services governed patients’ and carers’ decision making. Discussion: Poststructural discourse analysis techniques were used to explore patients’ and carers’ perspectives on the quality of P&SC DN care.
Physician Assisted Suicide: Are Health Care Professionals More Liberal when Self-concerned

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Abstract number: P2-268
Abstract type: Poster

Attention Pattern Based on the Dignity of the Patients: Agreement Degree of Doctors in Specialized Training

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The dignity of the patients is an intangible concept and difficult to define. Chochinov has reported different arguments defined by patients that delimits what influences an individual’s sense of dignity. The patients who showed a fully agreement with the different arguments of dignity ranged between 87 and 50%.

Objective: Describe the degree of agreement of doctors in specialized training about values comprising the concept of dignity.

Method: Structured survey concerning 22 values of the dignity inventory, given to residents of our university hospital. The degree of agreement on these 22 values was asked, using a scale of Lik, in two different ways: first as the importance from the personal point of view and second as the degree of implementation in clinical daily practice.

This survey was conducted in 2009 and 2012 after implementing a training program in bioethics.

Results: A total of 29 and 55 residents took the survey in 2009 and 2012 respectively. The maximum degree of agreement regarding personal importance and point of view of the 22 values of dignity was ranged between 82 and 7% in 2009, and between 93 and 27% in 2012 (p < 0.05). The maximum degree of agreement for these solutions, the 22 values in clinical daily practice ranged from 46 to 0% in 2009, and between 87 and 16% in 2012 (p < 0.05).

Conclusions: Medical residents have assessed the importance of the 22 arguments about dignity lower than the data provided by patients themselves. Some personal values identified by doctors entraining were applied with difficulty in daily practice. There is a trend of increase in the degree of agreement in the last survey. The data we confirm the importance of formation programs in bioethics during the period of specialized training. In the final presentation, the itemized data on the 22 specific survey questions will be presented.
Providing Palliative Care at Home: How Are our future. We are conducting formal family meetings and 52% thought that 2011) found that only 20% of staff felt very confident in palliative care units (presented at EAPC Congress, Lisbon, Portugal). Of formal family meetings in the palliative care setting. It is hoped that this will help to address the education need identified by staff and increase both staff confidence and competence in carrying out this very important intervention.

Abstract number: P2-273
Abstract type: Poster
Family Involvement in Hospital Care for Patients with Life-Threatening Illness: Lessons Learned from a Country with an Extended Family Structure - A Cross-Sectional Study

Background: Family involvement can contribute to the quality of life of a patient with a cancer. As this is already part of the Indonesian culture, studying family involvement in caring for a person with cancer in this country can provide important information for other countries.

Methods: To determine which problems of patients with cancer were assessed and addressed during hospitalization in Indonesia and by whom.

Results: One hundred and nineteen hospitalized patients with cancer and 142 nurses participated. The patients stated that their capacity to perform activities of daily living (ADL), their physical and psychological problems were very often assessed (>84%) and addressed (>90%). ADL were most often assessed by a nurse (88%), followed by physical (73%), spiritual (56%), social (54%) and psychological (50%), and autonomy problems (49%). Physical problems were also often assessed by a doctor (77%); non-physical problems such as family involvement in caring was high, especially for problems with ADL (89%) and financial problems (89%). Nurses mentioned that they only assessed non-physical problems if there were any, and they informed the doctors if they mentioned them spontaneously. Furthermore, all almost nurses stated that they addressed physical problems (96%), ADL (96%) and psychological (90%) problems.

Conclusions: Nurses as well as the family have prominent roles in cancer care in Indonesian hospitals. The extended family structure plays a role by the prominent influence of family in daily hospital care. More information is needed on patient satisfaction with care and on family caregiver burden.

Abstract number: P2-274
Abstract type: Poster
Development of an E-learning Programme for Formal Family Meetings in Palliative Care

Background: Several studies have demonstrated the benefit of formal family meetings in the palliative care setting. It is imperative that professionals are competent in conducting formal family meetings. A survey of staff in 2 specialist palliative care units presented at EAPEC Congress, Lisbon, Portugal, 2011 found that only 20% of staff felt very confident in conducting formal family meetings and 52% thought that staff training was necessary for improving professionalism and skills.

Objective: A collaborative working group from the two collaborating hospice teams in the UK have started developing an e-learning programme for formal family meetings in palliative care.

Methods: Feedback from a pilot workshop in November 2011 highlighted the need to split the training programme into 2 parts: an e-learning programme outlining the principles of planning and conducting a formal family meeting and a staff workshop on communication skills training. The structure of the e-learning programme was decided based on agreed learning outcomes and a review of resources and e-learning courses. The content was based on a comprehensive literature search and evidence-based guidelines.

Results: The e-learning programme comprises 5 sections: the role of each discipline in formal family meetings; the role of the chairperson pre meeting planning; the structure of the meeting; post meeting debriefing and follow up. Each section contains a podcast and a video clip, followed by a quiz to ensure that the participant has understood the concepts.

Conclusions: The e-learning programme will be used to train palliative care staff in the development of formal family meetings. It is hoped that this will help to address the education need identified by staff and increase both staff confidence and competence in carrying out this very important intervention.
social support, experience loneliness, depression and increased rate of HIV transmission.

A case study of an HIV-positive male child aged 11 years old who was diagnosed with AIDS when he was 3 years old, his father abandoned him after discovering his HIV status. The child has been suffering from multiple skin infections, chest infections and general body weakness. Currently, he is living with his grandmother.

Through Family-Centered Care which enabled the involvement of the whole family, care and treatment plans were established. These included home visits, psychosocial support, return to schooling and enrolment in an antiretroviral therapy program. Currently, the child’s health has significantly improved; he has returned to school and has attended grieving sessions about being at home than the literature suggested. This study demonstrates the impact on carers and family members caring for those caring for dying patients at home, affecting both the caring process and bereavement, highlighting the need for a comprehensive carer assessment.

Poster abstracts:

**Poster abstracts**

**How Can We Support Parents to Adult Children with a Severity Ill Disease?**

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**Abstract:**

Aims: There are much research about being a parent to an under aged child but very little of being a parent to an adult child. This study is about how parents cope with the role and situation which involves caring for grown up children who may have great needs.

Methods: Qualitative interview study with a quantitative part. Thirty parents will be included in the study. They are sent an information letter and a consent blank. Those who consent to participate will be offered an in-depth interview with the interval at 0, 9 and 18 month including two questionnaires about support and sense of coherence. The interviews will be analysed by content analysis and the questionnaires with descriptive statistics.

Results: The study will begin in November 2012 and the first analyses will be presented at the 8th International Conference in March 2013 of the parents experiences of having a seriously ill child, their involvement in the situation and the support they need. Learned: This study will help to give knowledge of how it is to be a parent to an adult child both in existential, practical and social dimensions.

**Poster abstracts**

**Cancer Patients in Homecare Settings: The Profile of Greek Caregivers**

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**Introduction:** The role of family is very important and act as a strong support system for the cancer patient in Greece. In many cases, the relatives have assumed all the responsibilities and decision making on behalf of the patient and often interfere in ethical issues such as truth telling and informed consent.

**Aims:** Describe the caregiver’s profile of cancer patients in Greece.

**Methods:** The sample comprised 95 family caregivers of people with cancer attending two regional hospitals as inpatients for active treatment or visiting hospital’s pain management clinics, or representing patients for consultation and prescription of analogues. Eligible participants were the main family caregivers of patients with cancer who meet the inclusion criteria and who attended the above-mentioned appointment in the palliative care delivery to children with cancer, and participant observation, which contributed to understand the sociocultural context of the phenomenon observed and organized according to Seidell’s proposal and analyzed according to the foundations of interpretative anthropology.

**Results:** It was observed that the role of religion is important for the parents to understand and elaborate their grief, and that religious belief permeates the families’ experiences as the supporting pillar for parents and children. Religion was a supporting pillar for parents and children. Religion was a sustainable strategy for families with cancer in palliative care, allowing them to elaborate a meaning for the suffering inherent in the death of their child. We observed that the parents were able to tolerate the suffering, possibly because they associated this process with religious resources capable of giving meaning to their emotional experiences. Some of these experiences are similar, but the contact with death was singular and influenced by plans, rules and instructions that ordered their daily life. Even though carers believe that religion is an in-depth and profound source of comfort, the different religious views have been ignored, while the study results were relevant for palliative care delivery to children as, by apprehending the meanings that religious belief provides to the suffering of their “loved ones”, we identified aspects that can guide the planning of this care, based on the principles of palliative care, reinforcing the need for individual, multiprofessional and interdisciplinary care, based on the families’ experience during the process of death, dying and grief.

**Poster abstracts**

**Bereaved Caregiver’s Experience of Caring for Patients Dying at Home**

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**Aims:** The aim of the study was to understand the impact of caring for a dying patient at home on carers, by exploring the experience of bereaved caregivers.

**Methods:** Purpose sampling was used to identify the bereaved caregivers. All the bereaved caregivers who were interviewed were under the umbrella of, and identified by the local hospice bereavement service. In each case, the patient had died 6 to 7 months prior to the interview. The participants were interviewed using semi-structured interviews and the phenomenological approach was used to provide an insight into the living experience of the carers. The Heideggerian hermeneutical interpretation allowed the lived world of the patients to be understood, and described, with the researcher’s experience, values and beliefs acknowledged. Results: 8 bereaved caregivers were identified and interviewed. 6 female and 2 male (between 35 and 60). The study showed the familiarity of the home environment created a real sense of normality, dignity, autonomy and control for both the carer and the patient. 5 common themes were identified:

1. Special times; focusing on closeness of the relationships, acceptance of suffering and the comfort of the familiar home environment.
2. Care all consuming; resulting in exhaustion, frustration, resentment, guilt and loss of relationships.
3. Conflict; raising issues of autonomy and control, lack of open communication, impact of changes to home environment, involvement of agencies and financial burden.
4. Clockwatching;描述s of a rollercoaster experience and periods of "listening to every breath".
5. Coping mechanisms and strategies; influenced by patient and carer personalites, and acceptance of death. Participants’ responses were more positive and emphasic about being at home than the literature suggested.

**Conclusion:** This study suggests the need for a better preparation of caregivers of caring for dying patients at home, affecting both the caring process and bereavement, highlighting the need for a comprehensive carer assessment.

**Poster abstracts**

**Inheritant School for Carers: Training for Family Members Is Crucial in End of Life Care**


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**Aims:** To identify training needs for those caring for palliative care patients at home and to put into service an educational training program aimed at helping the patient’s own family, through a travelling carers school.

**Methodology:** Qualitative study through conversation techniques, as such as having facilitated and focus discussion groups, so that content analysis can help us know people’s subjective views and perceptions.

**Unit Study:** Those family members caring for a relative with palliative care needs. Sampling through convenience, with voluntary character.

**Results:** Those caring for people with palliative care needs have family ties with the patient. Oncological pathology is more prevalent than non oncological pathology Among caregivers, patience is identified as their greatest asset and emotional control techniques as top priority, specially in situations of pain and distress. They identify as equally important training needs to provide emotional support, return to schooling and enrolment in the patient’s basic care needs (personal hygiene, getting them to use the toilet, etc.) specially in the bed bound.

Even though carers believe that religion is an in-depth and profound source of comfort, the different religious views have been ignored, while the study results were relevant for palliative care delivery to children as, by apprehending the meanings that religious belief provides to the suffering of their “loved ones”, we identified aspects that can guide the planning of this care, based on the principles of palliative care, reinforcing the need for individual, multiprofessional and interdisciplinary care, based on the families’ experience during the process of death, dying and grief.

**Poster abstracts**

**Families’ Experiences of Assassisted Suicide in Switzerland: A Qualitative Study**

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**Background:** In Switzerland, helping with Assisted Suicide under certain conditions is not prosecuted. Family involvement in assisted suicide and experiences of bereavement afterwards have not received much attention, and the results from the few published studies are rather contradictory.

**Aims of the study:** To explore family experience in decision making prior to assisted suicide and to examine their ways of coping during the bereavement period.

**Methods:** A qualitative pilot interview study was conducted on a small group of relatives of eight patients who chose to assist suicide between January 2007 and May 2009 in Southern Switzerland. The principles of Grounded Theory analysis were used in both collection and analysis.

**Results:** The majority of family members faced moral dilemmas during the decision making phase. Their main concern was breaking the taboo shall not kill rule, by helping the patient, regardless whether they were in general agreement with it. Respect of the patient’s autonomy helped relatives overcome this dilemma. During the decision making phase two types of involvement of the
interviewed were identified as "passive" and "active". Passive when relatives were in disagreement or the decision making challenged them at a moral level. Active when assisted suicide is a relative and the relative contributed to the legal procedures. The relatives reported feelings of isolation during and after assisted suicide. Family members and social stigma and tended not to disclose assisted suicide after the death because of this.

Conclusions: Bereaved families are confronted with moral dilemmas, isolation and secrecy in the management of assisted suicide in Southern Switzerland. These features may undermine and not adequately addressed by the health care professionals. Management of assisted suicide requests should consider requirements of families need, in addition to those of the patient.

Abstract number: P2-283
Abstract type: Poster

Approaching the family in Palliative Care Research - A Case Study Facing Methodological Challenges

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Aims: Better understanding family caregivers’ perspectives has become a widely recognized research area in palliative care, especially in the home care setting. Some methodological challenges remain to be unolved: in most studies data are collected on one family member, identified as the “main caregiver” Following such an approach the characteristics of families as complex networks run a risk of being disregarded.

Methods: This problem arose in an ethnographic study on recognizing dying in palliative home care. Observational data of trajectories (n=16) were supplemented by additional interviews with all bereaved family members.

Results: We found major differences in the perspectives on palliative care of the different members of the family, according to their systemic perspective offered insight into the fragile balance of emotional involvement as well as personalities. It became apparent that the different perspectives complemented each other.

Conclusion and recommendations: We recommend further research exploring Irish caregivers’ experience and a need to develop this service prompted the study.

Methodology: A descriptive, qualitative approach was utilised. Following ethical approval six purposively sampled family caregivers’ were interviewed. Data was analysed using Braun and Clarke’s (2006) thematric analysis framework.

Findings: Participants’ described the referral and transition to palliative care as a "heavy weight" of responsibility with the staff of the palliative day care unit.

Background: An emphasis on home care for patients with advanced disease (DoH&C 2001) has meant that family caregivers’ are taking on the dual role of patient care and the "heavy weight" of responsibility.

Aim: This presentation focuses on a theme identified within a study to describe family caregivers’ experiences of supports received in an Irish palliative care day centre. The presentation discusses participants descriptions of how initial referral and first attendance at day care bought fears and anxieties.

Findings: Participants described the referral and transition to palliative care as a "heavy weight" of responsibility with the staff of the palliative day care unit. Participants reported a more "hospital" atmosphere and were afraid of seeing a lot of very sick people. They worried about the reactions of their loved one. Once they had arrived they welcomed the homely environment of day care and participants were relieved and glad to be able to share the “heavy weight” of responsibility with the staff of the palliative day care unit.

Conclusion and recommendations: Referral to palliative day centre caused initial fear and anxiety for participants. However, following the first visit the support provided was valued by participants. Participants suggested additional ways to ease transition into the service might include, meeting a staff member beforehand, or having an opportunity for family member to visit day centre in advance.

Abstract number: P2-285
Abstract type: Poster

Initial Referral to Palliative Day Care Brings Fear and Anxiety to Family Caregivers: Findings from an Irish Qualitative Descriptive Study

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Aim: This presentation focuses on a theme identified within a study to describe family caregivers’ experiences of supports received in an Irish palliative care day centre. The presentation discusses participants descriptions of how initial referral and first attendance at day care bought fears and anxieties.

Findings: Participants described the referral and transition to palliative care as a “heavy weight” of responsibility with the staff of the palliative day care unit. Participants reported a more “hospital” atmosphere and were afraid of seeing a lot of very sick people. They worried about the reactions of their loved one. Once they had arrived they welcomed the homely environment of day care and participants were relieved and glad to be able to share the “heavy weight” of responsibility with the staff of the palliative day care unit.

Conclusion and recommendations: Referral to palliative day centre caused initial fear and anxiety for participants. However, following the first visit the support provided was valued by participants. Participants suggested additional ways to ease transition into the service might include, meeting a staff member beforehand, or having an opportunity for family member to visit day centre in advance.

Abstract number: P2-286
Abstract type: Poster

Respite for Parents Caring for a Child with Incurable Illness

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Background: Family remains in our society the main care provider of children suffering from incurable illness, struggling to insure that all effort is done for achieving the longest possible life for the child and the best quality. A systematic perspective offered insight into the fragile balance between hope and fears within the family, represented by different members of the family, according to their emotional involvement as well as personalities. It became obvious that no one single interview would have revealed all the perspectives covering the others. Instead the different perspectives complemented each other.

Conclusions: The results raise important issues for future research in family caregivers in palliative care. To consider the family as a complex system affords sensitive research designs, which might be put forward best in collaborative interdisciplinary research groups.

Abstract number: P2-284
Abstract type: Poster

Respite for Family Members/Relatives and Caregivers during 2010-2012 LASKA Irena, KOLECI Gorica, GEZOLLARI Entela, STAFA Eda

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Goal: The presentation of the trainings held to provide useful information to children, family caregivers and/or caregivers of patients of Mary Potter Palliative Care Center.

Methods: 1. Interviews with family members/caregivers of patients prior to the training.

Results: A need assessment on the importance of these trainings was conducted through a face to face interview, which were analysed with SPSS 13.0.

Results: Data were collected from 101 subjects, parents or a child with incurable illness. Respondent rate was 100%. In 97% of cases the main carer was one of the parents. 66,34 % of the parents are involved in the care of their children between 13 and 24 hours/day, 11,38% are involved between 9 and 12 hours/day. The time for self-care is reduced, thus for 61,39% of the patients 1 hour/day in the maximum time for self-care, 55,66% of the parents affirmed that they felt neglected due to lack of time for self-care.

Conclusions: In 97% of cases the main carer was one of the parents. 66,34 % of the parents are involved in the care of their children between 13 and 24 hours/day, 11,38% are involved between 9 and 12 hours/day. The time for self-care is reduced, thus for 61,39% of the patients 1 hour/day in the maximum time for self-care, 55,66% of the parents affirmed that they felt neglected due to lack of time for self-care in medicine.

Keywords: Patient, family member, caregiver of patient, trainings.

Abstract number: P2-287
Abstract type: Poster

Older Parents’ Experiences during a Serious Illness Trajectory and after the Death of an Adult Child: A Qualitative Study

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Increased life expectancy enhances the likelihood that older people face a serious illness in an adult child and even will outlive their child. We aimed to explore the lived experience of these parents and the underlying processes that are at work.

A qualitative study using narrative interviews was used to elicit accounts of 20 parents (>70 years). Data were analysed with use of NVivo9, based on the principles of grounded theory.

The cancer diagnosis in their adult child exposes parents to a multitude of intense feelings which are often contained in the presence of their sick child, in order not to stimulate the others’ suffering. Most parents want to resume their parental responsibilities by means of being there, which can take many forms and intensities. The exercised form of parenting is influenced by several factors i.e. their relationship history, the degree of care dependency and the marital status of the adult child. Envisaged parenting is complicated by their uncertainty of what is appropriate in the situation where the partner of the adult child is deceased. The death of an adult child is a life-altering event for older parents. Feelings of survivor’s guilt and self-blame coexist with an increased awareness of their own impending death. A consistent theme is the older parents’ holding on to their memories and continued encounters with their deceased child. They have a need to talk about the deceased child and his/her life but do not always have the opportunity to do so. Aged parents carry deep burdens from the prospect of losing their adult child. There is also evidence that they want to stay involved, but need to reconstitute their parent role. Mutual protection is an important phenomenon in this context wherein health care providers could play a role by stimulating open communication between both the adult child and the older parents.

Abstract number: P2-288
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Older Parents’ Experiences Following a Serious Illness Trajectory of an Adult Child: A Review of the Literature and Recommendations for Future Research

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Given the increasing life expectancy, the likelihood increases that health care providers are confronted with older people having an adult child with a life-limiting illness. This literature review aims to (1) explore the experiences of older parents in relation with their role and position as a parent of an adult child with a life-limiting illness. Literature review aims to (2) detect gaps in the existing literature and to make recommendations for future research. Studies were identified by searches of electronic databases including, Web of Science, MEDLINE, CINAHL and Google Scholar. In total, 29 published studies were included. Four studies describe the experiences of older people having an adult child with cancer, or having an adult child who died from cancer. From the moment the cancer diagnosis is disclosed, parents are confronted with a ravaging of the parental nurturing which clashes with the autonomy of the

Keywords: Patient, family member, caregiver of patient, trainings.
Medico-Social Studies

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Biographical Disruption - A Descriptor for the Experience of Advanced Colorectal Cancer?
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Aim: Biographical disruption is thought to occur in response to suffering imposed by illness, when fundamental assumptions of everyday life and their relationships are disrupted and restricted. The aim is to explore what extent these with advanced colorectal cancer (CRC) describe biographical disruption, if they conduct biographical work to manage their sense of self; and how this changes over time.

Methods: The study adopted a qualitative longitudinal design, employing in-depth interviews with 16 participants with advanced colorectal cancer. Narrative data was transcribed and analyzed thematically. Interviews were conducted at home, and in the participant's own home hospice program. The mean number of interviews was 9 (range: 5-13 interviews).

Results: Most participants described biographical disruption, with different ways of describing a threat to their sense of self. However, biographical work was carried out in both groups. Participants in the former group were attempting to restore a sense of the self in the latter group were working to maintain it. In the earlier interviews participants used the 'you' voice to assign themselves a collective identity. In later interviews, they wanted to define an after death identity.

Conclusions: The findings suggest that biographical disruption should not be used as a standard framework for describing the experience of illness. One way to facilitate biographical work could be to focus on managing their legacy and negotiating how they were going to be remembered after their deaths. Further research should explore the benefits of an early intervention to support people with CRC to plan for the future.

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Abstract number: P-291
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Lung cancer: A longitudinal interview study with patients participating in the FRAGMATIC trial
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Research aims: Advanced lung cancer patients are under-represented in oncology trials and very little is understood about their experiences of clinical trials. FRAGMATIC is the largest lung cancer study in the world and is investigating the effects of Fragmin (a self-injected anti-coagulant) in patients with lung cancer.

This poster describes the FRAGMATIC trial, which is a qualitative sub-study of the FRAGMATIC trial. The study aims to explore patients’ experiences of participating in the FRAGMATIC trial and of living with advanced cancer.

Study design and methods: Twenty semi-structured interviews were carried out with 10 patients over three time points. Patients were assigned to one of two conditions: (n=6) or control (n=4) of the FRAGMATIC trial. The data were analysed using Interpretive Phenomenological Analysis methodology.

Results: This paper reports on key themes relating to patient coping and adaptation. Patients described their efforts at symptom management and lifestyle changes, gave examples of how they rationalized and re-appraised their symptoms and demonstrated the use of fatalistic coping strategies as well as strategies pursued to give patients feelings of agency and control over their lives.

Conclusions: This study provides new data on how advanced lung cancer patients manage to make sense of their illness and the key resources which help them to do so. The findings have implications for palliative care practice and in the social and psychological literature on coping and practical implications are identified for health and social care providers.

Poster sessions – set 2

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was placed in a central place at the exhibition, for documenting reflections if so desired. The English language was followed with a question about country of residence. This question was then placed in a small chest, similar to one shown in the exhibition for storing memorings.

513 responses to this question were obtained from 48 countries. Most responses came from Sweden, followed by the US, France, Germany and Italy. Respondents described their work as hospital-based in 96%, as university-based in 5%, as hospice-based in 4% and as other in 5%. The majority of respondents were clinicians (85%), followed by researchers (10%) and nurses (5%).

The practice of administering continuous deep sedation (CDS) or terminal sedation at the end of life has generated significant controversy, not least for its perceived life abbreviating effects. Although concerns about the potential life-shortening effects of CDS have abated as a result of shifting to scrutinizing its wider effects upon a patient’s quality of life, the iatrogenic induction of sedation for the treatment of intractable pain or delirium is usually still related to a lack of other options for palliative care. Here, the need for long-term specialized Palliative Care in home-care setting is evident.

Conclusions: Development of palliative care poses many challenges: it is a multidisciplinary field and there is lot of work still to do to reach perfection.

Abstract number: P-299
Abstract type: Poster

Bureaucratic Challenges for the Palliative Care System
Abstract number: P-296
Abstract type: Poster

Organisation of Services
Abstract number: P-295
Abstract type: Poster

Continuous Deep Sedation at the End of-Life and the Question of Personhood - A Ring Theory Approach to Better Understanding the Personhood of Palliative Care Patients
Abstract number: P-297
Abstract type: Poster

What Characterizes Patients with the Need for Long-term Specialized Palliative Care at Home?
Abstract number: P-300
Abstract type: Poster
Community palliative care services have been established in Ireland to provide support to patients with life limiting illness in places of care outside the hospital setting. Delivery of such care requires interaction between the community palliative care service and General Practitioners (GPs), as primary medical carers of the patient. There is limited knowledge of how GPs make use of and their satisfaction with the service provided. This study addressed these questions by examining GP use of and satisfaction with one community palliative care service. Reasons for non-referral if applicable were also explored.

A postal questionnaire, modified from an earlier study was used as the research tool. The questionnaire was distributed to the GPs (n=316) working in the same geographical area as served by the community palliative care service previously studied. Completed questionnaires were returned anonymously by study participants. Data analysis was undertaken using SPSS (Statistical Package for the Social Sciences). Fisher's exact test was used to examine for association between the variables identified. A significance level of P<0.05 was set for all analyses.

A response rate of 37% was obtained, which was low. Study results indicated that GPs had positive views of the service and its aspects among the respondents. All were aware of the study site service and the majority had referred patients to the service during two years. Less than 4 in 5 GPs felt their patients with palliative care needs could be managed without the support of the service. Reasons for non-referral were based on perceptions of the service and usually due to patient factors. The majority of GPs described their role as working alongside the service. Areas for improvement were highlighted by respondents, such as increased GP participation in treatment decisions, which should be addressed. 97% of respondents asserted however they would recommend the service to a colleague.

### Abstract number: P2-302

### Abstract type: Poster

### General Practitioners Use of and Satisfaction with a Community Palliative Care Service

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**Aim:** To support the recommendations of the End of Life Care (EoLC) Strategy of 2008, additional funding was provided to Primary Care Trusts (PCTs) in England in 2009-2010 (338 million) and 2010-2011 (1.198 million). Variability allocation of this funding between individual PCTs may be associated with inequities in service provision. The aim of this study is to review the allocation of this funding across London, UK, in order to identify variations and issues requiring further exploration.

**Methods:** Data was requested from 31 PCTs in greater London for 2010-2011 to obtain a breakdown of expenditure on EoLC. As this data was not readily available in all cases, requests were sent using the Freedom of Information Act.

**Results:** 29 PCTs responded to the information request. Documented expenditure on EoLC by individual PCTs varied widely. Figure 1 illustrates expenditure on (1) clinical services and (2) other relevant projects/networks.

Several PCTs included care funded by the state in the figures, with no detail regarding what proportion was directed at existing versus new services. For example, one PCT demonstrated a range of investment into clinical services, bereavement support, and education, whilst data from another PCT revealed that 16% of investment was provided to local hospices, with the remainder directed to “patients receiving palliative care”, no other services were mentioned.

**Conclusions:** Our results demonstrate variations in funding for EoLC. Data regarding funding allocation should be readily available to enable comparative analysis. The value of the Freedom of Information Act to facilitate this study was clear, but this route is not readily available to all. Further work is needed to standardise data for PCTs for EoLC. Maintaining accountability for budget holders is vital, and the challenges of this will be discussed in the context of national work reviewing the funding of palliative care services and development of Clinical Commissioning Groups.

### Abstract number: P2-305

### Abstract type: Poster

### Artificial Feeding Decisions - A Model for Palliative Medicine Involvement in Complex Decision Making

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**Background:** In our country palliative care (PC) system is underdeveloped. In February 2007 we have established first palliative care unit (PCU) in our region with 6 beds. Aim: Five years after establishment of PCU we decided to carry out a survey on our work. Methods: We have reviewed charts of all patients (pts) admitted to PCU since February 2007 till end of January 2012. We collected information as age, sex, type of cancer, place of admission (ICU, OR, GP, hospice, nursing home), level of hospitalization, prevalence of in-hospital or home death, place of discharge.

Results: In total, five years of PCU we have admitted 706 pts in 899 hospitalizations. 81% were hospitalized at PCU only once. There were 348 (49.3%) males and 358 (50.7%) females, an average age was 65 (29-95) years. All patients had cancer: 34% pts gastrointestinal, 13% breast, 13%
Background: In the UK much of a Palliative Care Team’s (PHTC) clinical activity depends upon how their skills are utilised by consultant colleagues from other specialties. Regular team consultations are intended to place to assess the successes of current models and identify areas of unmet need.

Aims: To assess the views of hospital consultants on their own provision of palliative care and on the HPTC and its developing role in a 600 bed district general hospital.

Method: Consultants were asked to complete an anonymous questionnaire abstracting their views in 3 areas:

1. Their own palliative care skills
2. Their opinion on current provision of specialist palliative care services
3. Views on the future direction of palliative care services

Results: 73% response rate. 54% (32 questionnaires) were valid for analysis. 46% medical / 54% surgical specialty split. When rating their overall confidence in providing palliative care -

• 72% - some confidence
• 25% - confident
• 3% - very confident

Consultants felt greatest weaknesses were managing dyspnoea, spiritual and psychological distress. Responders reported high level of satisfaction with the HPTC and with initial approach at regional critical care. There were varying attitudes to opportunities for joint working. All responders felt the HPTC had a role in non-malignant conditions but different levels of agreement were held in relation to specific conditions. Consultants admitted experiencing difficulties in determining when patients with non-malignant conditions had reached the end of life.

Conclusions: This study provides a broader view of palliative care from a selection of experienced consultants from different specialties. It will provide the support for the ongoing evaluation of the UK model of specialist hospital palliative care and its extension into non-malignant conditions indicating potential future palliative care requirements within an acute hospital setting.

Abstract number: P2-308
Abstract type: Poster

Motor Neurone Disease: Providing Specialist Palliative Care Support for Patients and their Carers

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Abstract number: P2-309
Abstract type: Poster

Developing Networking: Palliative Day Clinic as an Interface Between In- and Outpatient Services

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In 2010 we started project of complementing Palliative Care Day Clinic within PC department (7-bed inpatient unit and 24/7 outpatient service) in a regional hospital. The idea grew out of requirements of patients, we saw a lack of home care setting as well as in PC consultation hour. The goal was to broaden multiprofessional spectrum of End-of-Life home care including rapid managing of care in case of symptom escalation to enable more patients staying at home.

The present aim was to examine efficacy of the PC Day Clinic, especially regarding number of admission or readmission to hospital as well as possibility of consolidation of in- and outpatient network.

We analysed 320 in- and 365 outpatients we cared since 2010 grouping in those who used Day Clinic or not. We examined number of reasons for admissions from home PC setting to hospital.

Results: Within patient group who didn’t draw on resources of day clinic we make no change of clinic admissions compared with previous years. Contrary to this, in the Day Clinic group number of advanced ill patients who could avoid admission due to home under good symptom control, became 9% in 2010 and 15% in 2011 more.

Conclusions:
1. Day Clinic proves to be effective structure to optimise and extend home care in advanced ill patients
2. We noticed significant reduce of clinic admissions within PC patient group who made use of day clinic.
3. Excess bed capacity accruing from less clinic admissions within PC patient group who make use of day clinic.
4. Better care planning and escalation of care giving them time-out during Day Clinic setting helped to prevent burn-out and make family care more stable.
5. As interface service, PC Day Clinic enables better continuity and flexibility of care for patients, optimise network services and affect mutual understanding and team spirit between in- and outpatient services.

This appears to be significant step to provide a model of all-round palliative care.

Abstract number: P2-310
Abstract type: Poster

The Myth of Psychological Empowerment: Impact on Nurses’ Commitment and Intent to Leave Primary Palliative Home Care Services

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Abstract number: P2-311
Abstract type: Poster

Primary Palliative Care

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Introduction: This is a recognized that an organization’s only true sustainable advantage is its people. Health professionals are key players in providing quality patient care. Their perceptions of the work environment influence their well-being and experience of empowerment. Trust is defined as a willingness to be vulnerable allowing closer attachments in teams. Procedural justice concerns the fairness of formal decision-making policies in organizations.

Empowerment involves an individual’s personal sense of control in the workplace as manifested in four beliefs about the work environment and personal development. STACCATO (Stow Anticipatory Care Planning Assessment Tool) was used to measure the major study variables. Scales revealed adequate psychometric properties.

Results: A series of multiple regression analyses tested the model. As hypothesized, findings indicated that both trust (β = .34, p < .001) and procedural justice (β = .23, p < .001) in the workplace were significantly and positively associated with empowerment. Nurses who perceived their workplace as more empowering were more likely to endorse a number of empowering work behaviors and perceptions. Nurses who perceived their workplace as more empowering were more likely to endorse a number of empowering work behaviors and perceptions.

Conclusions: The study suggests a number of implications for future research. First, facilitating perceptions of trustworthiness in teams is important to empower professionals. Second, managers should show transparency and the fairness of formal decision-making policies in organizations, which are critical to create conditions for empowerment.
The aim was to improve the quality of palliative care for all patients with life-threatening illness who require palliation, to ensure that patients are provided with an offer. The project pilot group was patients with COPD, heart failure and cancer.

Methods: Qualitative methods are used to identify patients, who could be better served by consultation. Innovative methods involving employees were used to create a cooperative model. Journal audit were evaluated to model the offer after six months.

Results: Employees have been involved in the development of initiatives to qualify the palliative care. The nurses have described patients with web-based threatening illness, who could be in need of palliative care. Initiatives were tested and adjusted for the benefit of patients in need of palliative care. A cooperation model was established, which includes symptom screening with the EORTC-QLQ-15-PAL to identify patients, who needed palliative care. A guideline was created for a patient interview, which includes a plan for the future palliative treatment. Electronic correspondence between specialized nurses at the hospital and home care district was established. Journal audit was performed on 79 in-hospital patients and as 18 patients from the community. Results from the journal audit showed that 87% of discharged patients were referred to hospice in an advanced phase with a lack of diagnosis prediction.

Conclusions: The results from this project shows, that involving the employees in development of new initiatives improves the quality of palliative care and give attention to offer palliative care to all patients with life-threatening illness.

Abstract number: P2-314
Abstract type: Poster

Consultation versus Shared Care Roles in Palliative Care Service Delivery: Deriving an Empirically-based Framework

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Objectives: To explore the consultation and shared care roles in palliative care service delivery. To compare the perspectives of the consultant palliative care service provider and the primary care provider on these roles.

Methods: An international, 2-day gathering of health care professionals in Canada, Italy and Denmark. Data collection was performed on 79 in-hospital patients and as 18 patients from the community. Results from the journal audit showed that 87% of discharged patients were referred to hospice in an advanced phase with a lack of diagnosis prediction.

Results: The results from this project shows, that involving the employees in development of new initiatives improves the quality of palliative care and give attention to offer palliative care to all patients with life-threatening illness.

Background: Primary brain tumours (PBT) cause suffering by both unpredictable CNS symptoms and impairment of quality of life. Palliative care for these patients is is also well documented. Therefore, timely palliative care interventions may be beneficial. The aim of this pilot study was to characterise the need for palliative care in this patient group.

Methods: In the neurosurgery outpatient clinic of a large teaching hospital, patients with newly diagnosed or recurrent high grade PBTs were referred to the palliative care team (PCT) as indicated by their neurosurgeon. Each patient was seen by the PCT (physician, social worker) on site immediately after the neurosurgical visit. Duration and content of the consultation were recorded and follow-ups offered as needed.

Results: Between May 2011 and August 2012, 30 patients (16 women, 14 men, age 71 years, range 32-81, 26 Glioblastoma multiforme, 3 Anaplastic astrocytoma, 2Astrocytoma °3) were referred to the PCT. In 10 cases the patients were referred due to tumour burden alone. In 15 patients the PCT was referred due to tumour burden and other burden factors. 10 patients (33%) were eventually referred to the PCT as indicated by their neurosurgeon. Therefore, timely palliative care interventions may be beneficial. The aim of this pilot study was to characterise the need for palliative care in this patient group.

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Corbu S.

Organizational Model of Palliative Services

Aims:

Methods:

Goal:

Conclusions:

The general and specific morbidity and mortality rate for the potential palliative care providers from the area, according to a proportionally to local needs reported were: symptomatic control, support to the family, dealing with the final days and hours, how to communicate and give bad news. All palliative care players were reported that they will ask for the collaboration of the PCT.

Conclusions: The PCT is the main support in a continuous of care in the final phase of life, they need education about the importance of a continuous of care and their implication in providing domiciliary care in terminally ill patients. We emphasized that the PCT need to know the need of formation in Palliative Care, and the need of supportive domiciliary involvement.

Abstract number: P2-319

Abstract type: Poster

Organizational Model of Palliative Services in a District

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Goal: To develop a continuous palliative care model based on populational studies and palliative care needs of the county.

Methods: Demographical and epidemiological data were collected from 2008-2012 by the county healthcare board and palliative care providers from the area, according to a proportionally to local needs reported were: symptomatic control, support to the family, dealing with the final days and hours, how to communicate and give bad news. All palliative care players were reported that they will ask for the collaboration of the PCT.

Results and discussions: Demographic data were process and validated by the Population and Housing Census 2011. The study met and monthly rate for the study years were also take into account to estimate palliative care needs for the district to a figure of 5600 patients annually. A stratification for the development of palliative care services in the area was done with the aim to achieve in 10 years a 60% coverage of the needs. The following model was suggested: training for GP to develop basic palliative care with the aim to cover 27% of the needs, increase specialized palliative care services as follows: 36 inpatient beds, two outpatient clinics that could serve more than 500 patients; four home teams for adults and one for children; a hospital team and one day center; unit private use which can take 10% of the services; hotline for: counseling and coordination.

Results: The model has the advantage of integrating palliative care, and to provide a continuum of palliative care. Funded by a San Diego Hospice & The Institute for Palliative Medicine grant and organized a twinning project.

Abstract number: P2-320

Abstract type: Poster

Understanding Models of Palliative Care Delivery in Sub-Saharan Africa: Learning from Programs in Kenya and Malawi

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Aims: The need for palliative care (PC) has never been greater. It is an integral component of healthcare & from being significantly present in only 5 African countries in 2004, PC is now delivered in nearly 50% of African countries. However less than 5% of people in need receive it. In order to scale-up PC in SSA it is essential to know about how models of PC function. A case study evaluation was undertaken to define the models used, contextualise them, is identify the barriers and facilitators that exist.

Methods: A desk review was undertaken addressing the burden & importance of the disease within the countries, the health systems, the development of PC & models of PC delivery identified 7 sites were visited, (4-Malaw, 3-Jenya). Meetings held with government, PC, community and local health leaders, programme staff were observed at the sites.

Results: 3 models of PC delivery were identified: specialist, district & community model, providing care in hospitals, health centres & community settings. Core components of each model identified alongside place of care, personal & family preferences & differences. Models were influenced by the health system, epidemiology & beliefs about PC and palliative care providers from the area, according to a proportionally to local needs reported were: symptomatic control, support to the family, dealing with the final days and hours, how to communicate and give bad news. All palliative care players were reported that they will ask for the collaboration of the PCT.

Conclusion: PC delivery model in the countries varies in response to their specific underpinning questions. Models cannot develop in isolation & need to be linked through local & national structures, thus strengthening the local provision of care & ensuring the patient is at the centre of the care being provided. Lessons can therefore be learnt for scaling up PC delivery in SSA. Funded by: The Diana Princess of Wales Memorial Fund.

Abstract number: P2-321

Abstract type: Poster

Integrating Palliative Care Into HIV/AIDS Care in a Community Health Centre in India

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Introduction: India has the second most people living with HIV/AIDS (PLHIV) in the world, yet palliative care rarely is available for PLHIV as existing program serve mainly cancer patients.

Aim: To test the feasibility of a replicable model for integrating palliative care into comprehensive HIV/AIDS care in India.

Methods: In 2009, our medical college-based palliative care team launched a project to integrate palliative care into HIV/AIDS care at a community health care centre in Bangalore. The project has three parts; 1. Training - two junior doctors and 6 staff nurses from the Community Health Centre were trained over a period of time in end of life care & palliative care, thereby enabled to provide palliative care with guidance from our team.

2. Service implementation - Once a week, a palliative care speciality nurse visits the out patient clinic and the hospital, thereby enabled to provide palliative care with guidance from our team.

3. Research - Data on demographics and symptoms are collected to assess palliative care needs and to make possible ongoing quality improvement.

Results: A total of 151 palliative care consults were done by the palliative care physicians in 3 years and 3 months for 1253 patients. Amongst them, 707 were males and 546 were females. Cachexia, Insomnia and Pain had the highest symptom prevalence. Symptom prevalence was 43.9% (n=96) at referral and 65.5% (n=113) at discharge.

Conclusion: Because of the high burden of physical symptoms alone among PLHIV attending a Community Health Centre in India, palliative care is essential. With over half (56.4%, n=22) receiving transfusion support. Palliative care services would be most effective, the groups were guided by Help the Hospices and the Charter for Respondent’s of the Worldwide Palliative Care Alliance advice for launching twinning projects. Memos of Understanding were set up and signed in 2012. Both groups focus on educational exchanges, hands on support, promoting models of good practice and sustainable palliative care services as follows: 36 new palliative care beds which can take 10% of the services; hotline for: counseling and coordination.

Abstract number: P2-322

Abstract type: Poster

International Networking to Developing Twinning Partnerships with Hospice Ethiopia

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To build on a project developed by educational and donor support from APCHA, Hospice Africa Uganda and fundraising bodies in the USA and the UK. To work towards developing models of palliative care delivery in Ethiopia and Malawi. To identify potential twinning partnerships.

During P2-12 two groups based within specialist palliative care services (one in the UK, the other in Sweden) initiated twinning programmes with Hospice Ethiopia. The UK group were successful in securing a grant from the International Health Links Funding Scheme which enabled early reciprocal visits. The Swedish group evolved more slowly - health care is expected to be seen to by society, hence a reluctance to embrace charity based support. A shift in public view has occurred during recent decades but to encourage credibility the Swedish group registered as a charity prior to launching their funding.

Recognising early on that organising support across distances would be most effective, the groups were guided by Help the Hospices and the Charter for Respondent’s of the Worldwide Palliative Care Alliance advice for launching twinning projects. Memos of Understanding were set up and signed in 2012. Both groups focus on educational exchanges, hands on support, promoting models of good practice and sustainable palliative care services as follows: 36 new palliative care beds which can take 10% of the services; hotline for: counseling and coordination.

Abstract number: P2-323

Abstract type: Poster

Palliative Care & Haematology: Is it Soley ‘Blood, Toil, Tears & Sweat...? O’Reilly V., Roger C.

North West Hospice, Sligo, Ireland

Haematological patients typically have lower rate of specialist palliative care input & uncertainty around identifying transition to supportive care

Aim: To evaluate local palliative care service provision to patients with advanced haematological disease. To quantify documented symptom burden & palliative care interventions in this group.

Methods: Case notes of 39 referrals to palliative service with haematological diagnoses over 20 months underwent retrospective review with data extraction pertaining to symptom burden & palliative care interventions. Time from referral to death & documentation of place of death.

Results: A diverse range of haematological conditions were identified. 79.6%(n=31) died within timeframe examined.Mean Time from referral to death was 40 days(1-150).

Conclusion: Palliative care is a human right for patients with both Communicable Diseases (CD) and Non Communicable Diseases (NCDs). To date, healthcare in low resource countries has focused on CDs. The prevalence of NCDs will grow to that of more affluent countries in the future. Palliative care is essential to meet this demographic shift and palliative care services (one in the UK, the other in Sweden) were developed to address this challenge. Palliative care is a human right for patients with both Communicable Diseases (CD) and Non Communicable Diseases (NCDs). To date, healthcare in low resource countries has focused on CDs. The prevalence of NCDs will grow to that of more affluent countries in the future. Palliative care is essential to meet this demographic shift and palliative care services (one in the UK, the other in Sweden) were developed to address this challenge.

Abstract number: P2-324

Abstract type: Poster

Barriers and Facilitators to the Delivery of Home-based Palliative Care Services in Beirut

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University of British Columbia, Vancouver

HPC2013-112

1Poster sessions – set 2
Poster sessions

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Aims: Providers of palliative care (PC) face multiple barriers to the provision of their services in any setting. Barriers are especially pronounced when the concept of PC is new to the health care system in which it is being developed and accepted. As the first providers of PC in Lebanon, we faced barriers from both healthcare providers (HCP) and the community. This study aims to analyze the barriers as well as the facilitators that affected the delivery of our services.

Methods: We conducted a retrospective and intraspective analysis of all PC cases in the last 2 years for whom we were asked to reflect on reasons they perceived there was resistance to PC services. We then were asked to reflect on factors that facilitated the delivery of our services.

Results: HCPs were concerned about losing their patients and were not comfortable that patients could gain additional benefits from our services. Communicating regularly with HCPs, involving them in major decisions, and admitting patients to their services all acted as facilitators. Our effective utilization of novel PC approaches to symptom management allowed us to gain their trust. Having nurses and physicians involved within the hospital provided a reminder to HCPs of the availability of PC.

Conclusion: This critical analysis of the barriers and facilitators faced by the PC service provided valuable experiences and reflect on learned lessons. Our study provides valuable information to others who are struggling to establish PC in a setting where it did not previously exist.

Abstract number: P2-326
Abstract type: Poster

A Collaboration and Consultation Project to Support Palliative Care Patients in the Community

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Aim: Innovative solutions were recommended to support palliative care patients in the community setting. A real evaluation was carried out within the Edmonton Zone to support the patient and family in the decision to remain at home, or facilitate the patient move to a palliative care hospice unit. One strategy was to limit transfers to Emergency Departments (EDs) where feasible and when appropriate. Focus was on unexpected events or symptom crises that precipitated a need for palliative care or emergency medical services (EMS). Method: Preliminary data on utilization of EDs and EMS was obtained. Consenting patients and caregivers were examined. Partners and stakeholders across rural and urban community settings developed management strategies to decrease transfers to EDs. A PC identification tool and registration approach for palliative patients, both cancer and non-cancer, was utilized for the project. An evaluation process was designed to collect information on patients, families, health care professionals and EDs. Results: We will report on the diverse challenges and opportunities encountered during the implementation of a tool designed to prevent unnecessary ED admissions to EDs, which most often are not optimal choices from patient and family perspectives. Management strategies were comprehensive and included EDs and non-cancer populations, symptoms and events, and settings. It was recognized that a cultural shift was required, with opportunities for PC and ED teams to expand their current practice and collaborative partnerships. Priorities included ongoing communication with families, appropriate care by the appropriate providers, and optimization of services and resources. We will provide preliminary data on the fiscal and utilization impact of the project. Conclusion: Partnerships between EMS and Palliative Care Teams can optimize care for the palliative patient in the home setting, and reduce utilization of EDs and acute care beds. Identification and registration of palliative care patients facilitate care.

Abstract number: P2-327
Abstract type: Poster

Cost Efficiency of Palliative Care

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Introduction: Although the palliative care need coverage in Romania is low, developing palliative care services is a real challenge due to an not stable legal framework, lack of human resources and also financial support. Aim: To evaluate the reimbursed costs for patients who died in hospice inpatient unit and to compare these costs with costs of traditional care in an oncology ward from a public hospital. Materials and methods: A retrospective study based on patients files. A sample of 77 patients who died in hospice inpatient units until 2012 was taken. The cost analyses included daily costs per patient reimbursed by Health Insurance House, but also real palliative care daily costs per patient. Cost data provided in hospice inpatient unit were identified. After this analysis, a comparison was carried out between reimbursed costs for palliative care in hospice inpatient unit and costs for traditional care provided in oncology ward from a public hospital, generated in a previous research. Results: The mean self-reported costs for palliative care were: diagnosis (p=0.05), presence of metastases (p=0.05), nursing interventions (p=0.05) and average number of daily available palliative care services (p=0.05). The mean total costs included medication, clinical investigations, hospitalization (staff and utilities) and meals. Comparing these costs among palliative care and traditional care the differences were highly significant (p=0.01) for three of categories mentioned above, except for clinical investigations (p=0.02). The reimbursed cost per day/patient for palliative care was 58% less than traditional care cost. Even the Health Insurance House would reimburse the real cost of palliative care, the saving would be of 42%.
Conclusion: Including palliative care in public hospitals will provide considerable savings, up to 42% even if the real costs of palliative care is reimbursed.

Abstract number: P2-328
Abstract type: Poster

Volunteers in Palliative Care: The Review of the Center for Palliative Care/Medicine

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Introduction: Volunteering in hospice and palliative care is an important issue in holistic approach to the patients with life-limiting diseases. In Croatia, volunteering has been the only kind of palliative care service for many years now. The unique thing is that there are health workers volunteers and non-health workers volunteers. Health workers volunteers are physicians, nurses and social workers who perform hospice home visits free of charge, in their free time.

We want to present the Center for Palliative care and medicine (CPSM), established in 2009. All members are the pioneers in palliative care in Croatia, with prof.Julic. Center for palliative care and medicine is also international, national and regional level. The priorities are to advocate for hospice care for all those who need hospice/palliative care. And to show excellence in palliative care education, in hospice/palliative care, hospice home care in local community.

Providing of volunteers of Centre are home hospice care for patients with life-limiting diseases and their families need support. Many physical, emotional, social, spiritual problems require a holistic approach through multi-professional teams. Volunteers are an important part of multi-professional teams. They "add today life", alleviate the isolation that severe diseases bring, make it easier for families to move forward. Volunteers can make a difference to patients and families at a very difficult time in their lives: they help more people to die in their own home, their place of choice.

Abstract number: P2-329
Abstract type: Poster

Evaluation of the Implementation of Palliative Care in German Nursing Homes

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Research aims: In Aachen, Germany, a palliative care model program has been initiated and managed by the "Sanktfranziskus-Hospital" to implement palliative care in nursing homes. This process is quantitatively evaluated for the first time in Germany. The nursing homes are provided with a specific tailored training program of seminars over a period of 2-4 years.

Study design and methods: In November 2010 (T1) a pre-test used as needs assessment analysis was performed using the new and validated Bonn Palliative Care Knowledge Test (BPW) to assess knowledge of palliative care (23 items) and specific self-efficacy (15 items) in nurses. The BPW test was designed especially to the demands of palliative care in nursing homes. After implementation of the training program (6 seminar, 9 months November 2011 November 2012). Dependent t-tests were calculated. Results: In six nursing homes 129(T1) and 131(T2) nurses participated (average professional experience: 3.10 years). In the pre-test (T1), the nurses’ knowledge was low, with only 52.8% correct answers. In T1, specific self-efficacy reached a mean of 1.84 (p<.01) and mean score of 46.8%. The mean value of knowledge increased from 2.48 to 2.44 (not significant, p>0.3). The mean value of self-efficacy decreased from 1.68 to 1.65 (not significant, p=.31). Knowledge of nurses not participating in the training program also increased not significantly (p=.13).

Conclusion: A tendency of increased knowledge was not a tendency of increased knowledge was not a
needed to reach significant improvement. This will be tested by repetition in November 2012.

Abstract number: P2-330
Abstract type: Poster

Volunteering - An Indicator of Future Success?  
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This session will consider the results of a systematic review of the literature exploring the relationship between volunteering and the sustainability of UK independent hospices; from a strategic perspective. Volunteers have played a vital role in the founding and on-going development of UK hospices. Volunteers in both adult and children’s hospice services undertake a diverse range of roles, from the governance of the organisation to social, emotional and practical support to patients and families to involvement in income generation and retail. Volunteers play a key role in making strong links with local communities in which hospices are situated.

Aim:  The purpose of the literature review was to consider volunteering from a strategic perspective and to:  
- Conceptualize the relationship between volunteers and hospice sustainability  
- Explore the current trends in volunteering in UK and their impact on hospices  
- Consider the role of volunteers in the development of hospices

Method:  Searching a range of databases, the literature review was carried out in the last days of June and inclusion of exclusion criteria. Papers were reviewed and common themes identified and collated and critically analysed.  

Conclusion: Volunteering is identified as an important factor in hospice sustainability.

Abstract number: P2-331
Abstract type: Poster

A Living Community Presence: Bringing Volunteers into the Heart of “Care of the Dying”  
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Volunteering as we knew it, contributed substantially to the development of Hospice-Care Palliative Care worldwide. OPCARE9 was an EU 7th Framework funded Cooperation and Support Action Project involving 9 countries in establishing the evidence base in care of the dying. The Volunteer Workgroup of OPCARE9 systematically reviewed the available literature of the involvement of non-professional personnel in death, dying and bereavement in different countries (paper in press). It became clear that the scientifically accessible literature was mainly published in the English language, thus excluding most volunteering developments published in the native languages of the participating countries. A Thematic Review based on publications from these countries was, therefore, also undertaken (paper in press).

Goal: Design, implement and evaluate a curriculum and service, to enable the development of a Core Curriculum for Care of the Dying Volunteer.

Rationale: Whilst the evidence from the reviews was limited, it was clearly possible to identify exciting curricular developments in Germany, Italy and the Netherlands. From these, a new approach, focusing on education and training for volunteers to support patients in the last days of life was developed.

Results: Strong leadership and management allied to a robust research design were found to be crucial to facilitate the delivery of this new service in a clinical context. As a result, a Care of the Dying Volunteer Service (CODY) is currently being implemented into 6 wards of an acute hospital trust in the UK.

Conclusion: This presentation reviews the innovative interaction between management, research and education to enable the development of a new service for care of the Dying (during the last hours and days of life) in the hospital context.

Abstract number: P2-332
Abstract type: Poster

Lung Cancer and COPD Patients’ Experience of Emergency Admission: A Qualitative Critical Incident Study  
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Introduction: Emergency admissions (EA) are increasing and are particularly common as death approaches. This has public health and quality of care implications. Despite interventions to reduce EA, few initiatives have been effective. Studies have explored patients’ experience of EA, COPD patients are thought to receive fewer community services than lung cancer (LC) patients. This study explored the reasons for EA in patients with LC or COPD.

Method: Patients with previously diagnosed incurable LC or COPD in the last days of life were invited to participate in semi-structured interviews soon after EA. Each participant was asked to nominate a care and community and hospital health care services (HCP) they had contact with. Interviews were audio-recorded and transcribed. Transcripts were explored and the ‘chronology’ of the patient and carers’ description of the EA process. HCP responses were compared and organized into categories. Thematic analysis of transcripts is nearing completion, enabling depth understanding of issues surrounding EA from patient, carer and HCP perspectives.

Results: 24 LC and 15 COPD patients were interviewed at 3 hospitals in one region; 20 carers and 50 HCPs were also interviewed. 14/24 LC patients died within 3 months of interview; 2/15 COPD patients died. Most COPD patients were admitted with acute shortness of breath (SOB) via an emergency ambulance call; fewer were admitted by community HCPs. LC patients experience was more varied and complex, with pain and SOB common, but also admission for clinical investigation when respiratory deterioration apparent. LC patients did not have more community HCP involvement than COPD patients. No EA was considered inappropriate by participants.

Conclusion: Exploring patients’ experiences of EA enables understanding of the complexity of the process. LC patients, even close to death might not receive enhanced services in comparison to COPD patients. EA in many patients might be appropriate management.

Funder: Macmillan Cancer Support

Abstract number: P2-336
Abstract type: Poster

The Implementation of Palliative Care in Kazakhstan: Ten Years After the Laws on Patient Rights Palliative Care and Euthanasia  
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In 2002 three laws were published in Belgium, which are currently being implemented into 6 wards of an acute hospital trust in the UK.

Rationale: Palliative Care of the Dying Volunteering.

Goal: To investigate the prospects of the further development of palliative care in Kazakhstan.

Method: During teaching sessions on palliative care using the Palliative Care Toolkit, developed by Help the Hospices and the World Federation of Palliative Care, students were asked to consider their role in the next years, participants in three secondary and tertiary hospitals in Abudeloua,  

Religion - mentioned by 41 participants (43%).

"My relationship and peace with God“ “spiritual comfort“ Self esteem - mentioned by 24 participants (23%).

“Happiness“ “Peace within“

Conclusion: The issues that health care professionals in Nigeria see in the future that are most important to their quality of life were primarily of religion, finances, family, health and self-esteem. Religion was the highest rated area and this is in keeping with a country where religion - both Christianity and Islam - are practised widely - the estimated religious attendance at least once a week is 89% of the adult population. Financial issues may be important to them - as patients will be required to pay for all care from consultation to investigations, surgical procedures, beds and medications.

The results give an indication of the areas of concern for the population of Nigeria and the importance of considering these in developing socio-economic and cultural issues in the palliative care of patients and families.

Abstract number: P2-337
Abstract type: Poster

The Prospects of the Development of Palliative Care in Kazakhstan  
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Background: In Kazakhstan, a number of laws and regulations define and approve the main trends of development of palliative care (PC) at the national level. Topics include: professional training of PC specialists; the provision of PC at home, psychological aspects of PC; PC for children; access to opioid medication for the treatment of cancer pain; and providing care for HIV/AIDS patients.

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Results: Currently, PC is provided by hospices in six regions, which is inadequate for such a vast territory with a relatively low density of population. In many polyclinics, large and medium-sized cities, and villages, PC have been introduced, but their responsibilities have not been clearly defined. Inconsistencies and a lack of balance in inpatient PC bring to drug addiction/confine the rights of both patients and medical workers. As a result, the patient or their family is often waiting for a long time to receive care from their home to obtain opioid medication.

Conclusion: According to traditional social and cultural values and beliefs, the majority of patients with a terminal illness prefer to stay at home. Palliative care should therefore be home-based and provided at the level of local polyclinics by the accepted model of care should also involve public organizations via stipulation of government orders for providing care for terminally-ill patients, and through the development of a volunteer movement.

Abstract number: P-348
Abstract type: Poster

**Effectiveness and Limitations of the Hospice Multidisciplinary Team**

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Background and aims: The effective working multidisciplinary team in hospice is the basic principle for complex and multidisciplinary care as it is suitable for the patient and his family. In Slovakia, there are 11 hospices and hospice care units (5 free standing, 3 operating together with social services and 3 existing within the medical facility). Less than 10 are palliative care units within the hospitals. Despite the fact that every hospice and palliative care unit has its own team, or teams, those teams can be working independently in the multidisciplinary teams, there are several specific limitations to have them properly working. The main aim of this study is to find possible solutions or eliminating those limitations. Specific objectives are to identify personal, technical and financial limitations and to prepare the practical tool - manual to help to achieve maximum efficiency, effectiveness and economy (3Es).

Methods: The non empirical study is based on practical experiences of the article authors (manager, psychologist, physician) with setting, managing and supervising the multidisciplinary meetings and therefore not communicating and co-operating towards the patient and his family goodess. They resigned because of too many limitations. The outcome of this study – the manual could help the hospice top management and team leaders to analyse and identify their specific personal, technical and financial limitations and to eliminate them to achieve the maximum level of 3Es.

Abstract number: P-339
Abstract type: Poster

**The Plan of Care in Palliative Medicine: An Analysis of Daily Inter-disciplinary Team**

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Introduction: Our inter disciplinary team (IDT) meets daily to discuss the plan of care for each patient in the inpatient unit. The IDT consists of physicians, nurses, social workers, nutritionists, chaplains, therapists, and case managers. The primary objective of the IDT was to identify discharge planning priorities and the plan of care discussed by the IDT. We also aimed to identify discharge trends for future research.

Methods: This was a retrospective analysis of a quality improvement project. The daily IDT reports daily for 40 consecutive days were derived from 106 consecutive admissions using a preprinted template. No patients were excluded. The IDT report included care processes and outcomes for each patient. IDT members discussed care for each patient multiple times per person. Data included key issues with care plan, actions/interventions/consults, goals of care, and discharge plan. Data was analyzed by: 1) text: demographics, inclusion/exclusion, patient outcomes, and discharge status (inpatient/outpatient); 2) spreadsheet: demographics, organizational and medical information for each patient. Results: Data included 493 IDT reports for 106 patients. 53% were male. Median age (range): 65 (15-101) years. Pain management was the most common (34%) recorded key issue; gastrointestinal 15%; cardiovascular/pulmonary 12%; Pain (31%) was the most prevalent symptom. It was managed by every member of the team (100%). 69% of patients had 4 or more interventional techniques (41%). Daily Plan of Care: 1) symptom management (62%); 2) pain control (48%); 3) discharge plan (37%); 4) family conference (19%). 31% had some form of imaging/testing. 24% were on palliative anti-tumor treatment. Most were discharged either to home (50%) or hospice (32%).

Conclusions: 1) The daily IDT allowed quantification of daily clinical plans and patient issues; 2) IDT reports reflected the acuity and complexity of acute care palliative medicine; 3) IDT provided an individualized plan of care to address medical and psychosocial needs.

Abstract number: P-340
Abstract type: Poster

**Barriers to and Facilitators for Achieving Best Clinical Practice in Palliative Care and Dementia Care**

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Introduction: It is unclear which factors influence the effectiveness of implementation strategies in palliative care and dementia care. This hampers the actual translation of evidence into clinical practice. Particularly in this multidisciplinary field, where improvement in the organisation encounters challenges beyond the usual problems of implementation. The purpose of this study, therefore, was to explore barriers and facilitators for implementing strategies to improve the organisation of palliative cancer and dementia care in Europe.

Methods: A qualitative study design, consisting of semi-structured (focus group) interviews was used. The focus group interviews were guided by an interview guide. A codebook was established after conducting pilot interviews. Analysis of the data was conducted using the content analysis approach, whereby a framework was used to develop themes.

Results: 36 individual and 9 focus group interviews were conducted in five European countries with purposely selected health care professionals. Although a large variety of barriers and facilitators were noticed, factors influencing personal conditions (such as motivation and experience), structure (such as staffing levels) as well as missing culture of care were found to be common barriers. The majority of the barriers and facilitators were noticed for improving the organisation of palliative cancer and dementia care in Europe.

Discussion: All respondents believe palliative care requires a more complex organisation, barriers and facilitators to change the organisation do not seem to differ from those in non-complex organisations. The following strategies will be used to develop tailored strategies to improve the organisation of palliative care during an intervention study of the IMPACT project.

Abstract number: P-341
Abstract type: Poster

**Development of Hospice and Palliative Care Culture in Northern Friesland, Germany: Implementing the Wilhelminen Hospice in Niebüll**

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Aim: The need of inpatient hospice care in Northern Friesland, a rural, large-area region in the northwest of Germany, had been controversial assessed. Nevertheless the local hospice movement fostered the development of a hospice. Since January 2011 the hospice is opened and operating and offers place for seven guests’ care. This pilot study was undertaken to support the participatory objectives: to evaluate the need of inpatient hospice care, to document the development process with its challenges and potentials, to analyze transfer options in regions with similar frame conditions, to initiate diffusion of hospice culture in the community, to support team building.

Methods: The multiperspective action research process includes following steps: Interdisciplinary workshops and conclaves with the team; analysing workshops with the executive committee and the co-operation partners; a palliative care symposium; an open house day for the public and conversations with guests and relatives.

Results: The need of inpatient hospice care in Northern Friesland is given. The feedback of guests and relatives is overwhelmingly positive. Main challenges on team level are: clarifying roles and responsibilities, the flow of information inside of the house and with co-operation partners, psychosocial complex caring situations, many deceased guests in short time interval, non-transparent management decisions and lack of appreciating culture in communication. The co-operation partners and the public appraise the hospice as a friendly, open house, “in the centre of community life”.

Conclusion: The long lasting voluntary hospice tradition in the region, as well as the hospice in Niebüll, has an essential impact on its positive public’s acceptance and its integration in the local community. Nevertheless establishing a hospice needs high attention for developing organizational and management (hospice)culture as a continuous process.

Funded by: The German Cancer Aid.
Aim: The increasing longevity has been one of the most remarkable changes for people with disabilities, although this change is occurring remarkably slower than that of the general population. Due to the increasing longevity, people with disabilities are likely to die over a prolonged period of time because incurable, chronic illnesses occur more frequently with old age. Therefore there is a growing need for high quality palliative care for people with disabilities living in residential homes.

The study analyses the situation in Switzerland on provision of palliative care for people with disabilities, living in residential homes, and on their participation in palliative care and end-of-life decisions.

Methods: A cross-sectional online survey, conducted from October to December 2012 with 480 directors of residential homes for people with disabilities in Switzerland provides data on following questions: How many residential homes allow residents to die within the residential home? How many residential homes have written policies on palliative care and end-of-life decisions? What is the content of these written policies on end-of-life care policies and what are the implementation strategies? Which aspects of palliative and end-of-life care are assessed in residential homes for quality assurance purposes? Do people with disabilities take part in end-of-life decisions and does the implementation of written policies on palliative care affect self-determination in end-of-life decisions and participation? How will the public be designed and distributed via the regional palliative networks. Finally, a specialized training is currently developed to train caregivers in the guideline.

In sum, great steps are taken and continue to be taken with regard to policy and practice on palliative sedation by means of good medical practice and profound ethical debate. Understandable good practice requires a well-trained care team in palliative care planning, and secondly, to enable stakeholders to move forward and take action in the right direction.

Best Practice of Palliative Sedation

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Although its application is accepted in palliative care as one of the options of last resort, palliative sedation is very often less than optimal practiced. First, there is the question of definition, not just theoretical: a lot of so called palliative sedation is just sedative treatment but something else, if not bad care. Second, palliative sedation turns out to be not a too easy technique. Good practice requires a well-trained team with skills in communication, a clear view on indication, a realistic expectancy of the sedative process, and a vast experience with the technical effective (e.g. intensive observation of the patient). Third, problems might occur in the case of prolonged dying.

In response to these three major problems, the PCFG and its regional networks palliative care started a project wherein several tools were developed. First, a good conceptual framework (‘begrenzenkader’) with clear definitions was elaborated for all end of life decisions including palliative sedation (Broekstra et al., 2006). Consequently a guideline for palliative sedation (Broekstra et al., 2012) was published (www.pallail.be). This guideline focuses on the ethical aspects, the decision-making, the communication and the technical procedure of palliative sedation. Thirdly, materials such as a comprehensive folding-chart for caregivers and a folder for the public were designed and distributed via the regional partners, the palliative networks. Finally, a specialized training is currently developed to train caregivers in the guideline.

In sum, great steps are taken and continue to be taken with regard to policy and practice on palliative sedation by means of good medical practice and profound ethical debate. Understandable good practice requires a well-trained care team in palliative care planning, and secondly, to enable stakeholders to move forward and take action in the right direction.
Abstract number: P-352
Abstract type: Poster

Towards a Public Health Model for Palliative Care

Hasselaar J., Centeno C., Engel W., Visser K.

Methods: A palliative care public health model is drawn combining publicly available data of the EU-27 countries. Parameters, the Atlas project score for palliative care services and the CDR (N-25) standard of care for patients with terminal cancer die at home. The research aimed to identify the responsible health providers and non/mis-identification of the responsible health providers and non/mis-provision of care. The Atlas score correlated positively to the CDR (P=0.50; P< .05) and negatively to the CDR (R=0.56; P< .05) within a country.

Background: In the 75% of the new cancer patients become terminal cancer patients die at home. Eighty percent of drugs for PC care are available and reimbursed, but physicians have little knowledge to prescribe them, especially morphine. Patients and their relatives face medical problems with medication access, identifying the responsible health providers and non/mis-information on the benefits of palliative care services. Conclusion(s): It is anticipated that the short term likely impact of the research priorities identification study will be research undertaken and evidence basis development in the prioritised areas of palliative care practice.

Abstract number: P-355
Abstract type: Poster

Is an Atlas the Way to Monitor and Report on the Status of Palliative Care in a Region?

Parrasón T., Centeno C., Kerckx R., Escheischa J., Monti C., Rocaford J., De Lima L.

Methods: The research methodology was used. The secondary data analysis was used for qualitative and active researchers was performed to compare the results of the examination of 248 peer-reviewed articles. These were further examined in terms of the different criteria and included a search of standard bibliographic databases, websites of key hospice and palliative care sites to pay for hospice care, and to extend the statutes of AHPC (for example collaborative work with EAPC and due to that it will be necessary to modify and extend the statutes of AHPC (for example collaborative work with EAPC) and due to that it will be necessary to modify and extend the statutes of AHPC and due to that it will be necessary to modify and extend the statutes of AHPC. The aim of this project was to determine the type and nature of palliative care research conducted on the island of Ireland over the last decade (2002-2012). This forms part of a wider-scale study to identify research priorities in palliative care for Ireland and Northern Ireland.

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while at the national level it varies between 14.6 and 0.23 (Costa Rica and Honduras respectively). Palliative Medicine is recognized as a sub-speciality in 4 countries, with 103 hospitals in 10. Belgium percent of medical schools offer PC in the undergraduate level. Eleven countries reported having a national PC Association. There is ongoing collaboration between countries with partners in USA, Spain, UK and Canada.

Conclusion: Palliative Medicine in LA describes vast differences among the countries and also similarities but above all, highlighted that the availability of PC in LA is very limited. This project also demonstrates that the LAAs is a adequate resource to promote and evaluate PC development and that the methodology applied for the EAPC Atlas of PC in LA can be adapted and applied in other regions of the world. Further studies are needed to evaluate the use and impact of this information to improve national health policies and patient care.

Abstract number: P2-356
Abstract type: Poster

Palliative Care for All Programme - Progress and Plans

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Background: The HSE/IHF Palliative Care for All Report (2008) identified that there is a significant gap in PC infrastructure common to the development of palliative care for all life limiting diseases as well as specific recommendations to support the implementation of appropriate levels of Palliative care for people with COPD, Dementia and Heart Failure. Since 2009 the IHF Palliative Care for All Programme sought to implement and oversee the recommendations of this report.

Aims: A review has commenced to determine what extent the recommendations from this report have been achieved. Particular consideration will be given to the impact of 3 Action Research Projects, to determine their potential for sustainability and translational learning nationally. This review will assist in signposting the next phase of this Programme.

Methods: Information generated from the projects will be used to ensure meaningful engagement with all stakeholders and objective appraisal of literature. As well as documentary review, and conference evaluation, qualitative interviews, review of quantitative data and appraisal of recent relevant policy documentation.

Results: It is anticipated that when completed the review will outline a positive shift amongst many health care professionals and disease specialists towards the recognition of the relevance and role of appropriate levels of palliative care for people with diseases other than cancer. However, it is expected that staff will request further education and guidance to support the implementation of this approach.

Conclusion: Any potential for measures that have taken place in targeted sites, it is expected that this review will recommend that the Programme will benefit from a joint strategy providing a platform for narrative change that is required. This should extend to addressing the palliative care needs of those with end stage kidney disease associated with non-malignant disease and those with multi-morbidities.

Abstract number: P2-357
Abstract type: Poster

Public Advocacy Activities for the Palliative Care System Creating and the Palliative Care State Policy Shaping in Ukraine

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Since 1990 demographic situation in Ukraine indicates ageing of the population. Today the number of people aged 60 and older is over 22%, and aged 75 years and over is nearly 7%. Cancer and other serious chronic noncommunicable diseases associated with aging, and HIV/AIDS, hepatitis C, etc. is an essedate in the number of people who need palliative care (PC).

The number of deaths in Ukraine in 2011 was over 660,000; among the women, 305,000; men 355,000. In 2013, 8.9% of deaths of men and 9.8% - of women. The data of NGO ‘AU-Ukrainian League of Palliative and Hospice Care’ (League) Experts shows that since 2009 the number of patients and their families who need PC is about 2 million people annually, and adequate PC in specialized facilities can be provided only from 0.5% to 10% of them, depending on the region and place of residence: city or countryside.

This situation leads to a great relevance of accessible and quality PC System development, which requires an active participation of the whole society. Therefore, NGO’s intensified advocacy to the government and the parliament of Ukraine to shape State Policy on PC System creating and developing, as a strong cause to build a dynamic and humane society. League’s Working Group has worked out a draft of National Strategy for the Creation and Development of PC System by 2022. It was signed by the Presidents of the First National Palliative Care Congress in September 26-27, 2012, and it was given to the Government of Ukraine. League’s Experts elaborate a Palliative Care Development State Program by 2020; draft a Bill of the Cabinet of Ministers of Ukraine to improve the availability of opioid analgesics for PC patients; directions of Ministry of Health and Ministry of Social Policy of Ukraine, National Standards for PC, clinical protocols and guidelines for PC professionals. So, public, stakeholders and government’s effort consolidation is needed to improve PC Policy in Ukraine.

Psychology & communication

Abstract number: P2-358
Abstract type: Poster

Tailoring Legacy Building Activities to the Lebanese Setting

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Aims: Legacy building activities can relieve existential suffering and help patients and their families to construct different memories. Palliative care providers can encourage and guide patients and their families to participate in such activities for their emotional and spiritual well-being. Acceptance of this process is strongly dependent on cultural norms and beliefs related to death and dying. This study was conducted by providers of home-based palliative care services in Lebanon. We were interested in providing legacy building activities to our patients as part of the package of palliative care services they receive. We wanted to assess the feasibility of such activities in our setting where there are many taboos pertaining to end of life matters.

Methods: We used an qualitative approach which included in depth interviews with caregivers of patients who had died within the year prior to the initiation of the study and focus groups with health care professionals who work in nursing homes, genitourinary units, and oncology units. Data were thematically analyzed.

Results: The main themes that emerged were related to family readiness (end of life conversations, talk spent with patient, religious issues, truth telling, reminiscence, family coherence); choice of activities (age-appropriate activity, tailoring activity to patient interests, culturally sensitive activities); role of a facilitator (support with facilitator, skills of facilitator, benefits to facilitator).

Conclusion: This process allowed us to gain an understanding of the cultural issues related to legacy building. A legacy building manual was developed and tailored to fit the values, needs and preferences of our community based on the different themes that emerged. Future efforts will focus on pilot testing of this manual. Others can use this approach to develop contextualized material when considering a new intervention in their setting.

Abstract number: P2-359
Abstract type: Poster

Managing Uncertainty in Non-malignant Conditions: The Experiences of Young Adults and their Parents

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Background: Traditionally renal medicine has been disease focused; recently there has been a paradigm shift towards a care focus. The renal population is increasingly elderly, frail and co-morbid necessitating a discourse approach, particularly regarding end of life. The role of the professionals feel unprepared for such discussions, particularly given the often long established relationship with patients.

Aims: To develop a renal specific advanced communication training programme to address the needs of renal professionals and their patients.

Methods: A multi-professional team was sought to identify issues in end of life communication and to develop a training programme. This team (consulted individually and in a focus group) included: renal and renal palliative care clinicians, nurses, patient representatives, social workers, psychologists, communication skills trainers from a local hospice, and a linguist. Training was designed in response to their concerns, recommendations and requirements of renal staff, patients and families.

Results: Participants identified the need for:
1. better information about the dying process,
2. more awareness of the patient perspective,
3. hands-on communication practice in a safe environment,
4. skills to manage challenging discussions,
5. follow up to discuss experiences.

A training programme was developed accordingly.

Conclusions: The multi-professional approach has enabled the development of a highly-focused advanced communication training programme, training on cancer models, but tailored to renal medicine. This training has been rolled out locally to nurses and consultants, and is being formally evaluated to assess staff satisfaction, changes in practice, and impact on patient outcomes, with a view to rolling out nationally. This work highlights the need for renal specific communication training regarding end of life issues. Funding: This work is a key component in a project led by NHS Kidney Care.

Abstract number: P2-360
Abstract type: Poster

Determinants of Hope in Patients Receiving Home Based Palliative Care

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Background: Hope is a multidimensional and dynamic construct different from one person to another. As the disease takes its course, the patient’s and their families’ desires to get better to more spiritual forms towards the end of their life.

Aims: To identify factors that maintain hope for patients with advanced cancer.
Abstract number: P2-364

Poster type: Abstract

**Simply Willing and Able! What is the Impact of a Simple Model of Communication Skills?**

**Groves K.1, Boldy C.1, Jack B.1, O’Brien M.1, Markey K.2, Whelan A.1, Kirton J.1**

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**Background:** The End of Life Care Strategy (UK, 2008) recommended the roll out of core communications skills to the entire end of life workforce enabling each individual to be able to respond to patients with difficult/unanswerable questions & deal with difficult topics. A ‘Simple Skills Secret’, model was developed that could be learnt, remembered & used by staff working in all roles, settings and at all levels. It enabled safe conversation where neither information nor authority to provide answers to questions existed, encapsulating the essence of communication skills training around active listening, encouraging, summarising, without having to ‘fix’ or offer solutions & assist the person to come to a conclusion.

**Method:** A mixed methods evaluation of the impact, included pre & post course testing of confidence & willingness to have conversations with the distressed, & semi-structured telephone interviews with participants 6-8 weeks post course. 149 of 133 staff trained, completed both questionnaires. Using a purposive sampling approach, 14 participants agreed to follow up qualitative interviews. Results: Improvement in both willingness & confidence for all categories was statistically significant; overall confidence score; t(148) = 15.607, p= 0.005; overall willingness score, t(148) = -10.878, p<0.005 (with the greatest improvement in confidence in communicating with carers (pre-course mean 6.171; post course mean 8.171). There was no statistical significant difference for 6 months follow-up.

**Conclusion:** The model appears to increase the willingness of staff, in dealing with situations which, if handled appropriately can lead to increased patient and carer satisfaction. Other strategies that appear to increase the willingness to undertake these conversations, which could lead to earlier intervention & minimise distress.

Abstract number: P2-365

Poster type: Abstract

**Information in Specialized Palliative Care - What Are the Topics of Palliative Care Teams, when Consulting Patients at Home?**

**Jansky M., Ovaska-Boakye S., Lindena G., Nauck F.**

**University Medical Center Göttingen, Palliative Medicine, Göttingen, Germany**

**Aims:** In terminal illness, information may help patients and informal caregivers (ICG) to control critical clinical and psychosocial situations. It is especially relevant for patients at home and their ICGs. Research on their informative needs is mostly based on interviews. We analyzed discussions held during round Table No.1 meetings of a palliative care teams (PCT) to give to patients, ICGs and other involved health-care professionals (HCP).

**Method:** During the testing phase of an electronic-patient-record (EPR), patient data was documented by ambulatory specialized PCTs. We analyzed free-text entries on conversations about severe diseases and death with patients and loved ones. We also collected the data during their periodical data collection exercise (EPR), patient data was documented by ambulatory specialized PCTs. We analyzed free-text entries on conversations about severe diseases and death with patients and loved ones.

**Results:** A wide range of topics were addressed. In the care process, PCTs act as a general source of information, not only for topics concerning specialized care. Planning care and the appropriateness of behavior and action of both in the face of escalating suffering. In the light of Maslow's hierarchical need, the behavior of the patient was found to be just right. It is beyond doubt that the number of patients and their routine is affected by the sea of changes in the life of the patient. Emotions were safely expressed until the loggerhead that arose from the information. This is in conformity with the patient's way of dealing with the awareness cycle. The nurse on her part could have arranged for the outgoing involving family members or friends to be told about the news. This would not have been possible. But it did not happen. The breach in the new relationship led to return of suffering for the patient and stress for the nurse as she was released from duty, fearing for the socio-cultural implications cycle. To generate self awareness, we need to put ourselves in the patient's shoes. A golden rule of the bed is: how we can offer emotionally and spiritually. Palliative Care embodies human understanding but with limitations. We need to create a space in our own minds, where we can learn to give up and receive unconditioned love for hospice care to sustain.

**Abstract number: P2-366

Poster type: Abstract

**Strategies to Support the Staff in Difficult Conversations**

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**Background:** Earlier research shows that health care professionals find it difficult to talk about severe diseases and death with patients and loved ones. **Aim:** The aim of the study was to investigate which strategies health care professionals can use to facilitate these conversations. **Method:** The study had a qualitative design using in-depth interviews with staff at palliative and oncology wards at an university hospital. **Result:** The professionals used different strategies when talking to patients and loved ones. One strategy was to structure the conversation according to 1/ Introduction, 2/ Finding out what the patient and loved ones already knew, 3/ Discuss the actual problem and finally 4/ Planning for the future. Another strategy was to use language symbols for uncertainty, give hope to the patient and loved ones. The hope often involved a reference of a secure care, giving the patient an opportunity to live the remaining life as good as possible until death. **Conclusion:** A model for how to perform challenging conversations about severe diseases and death with patients and loved ones. As a result for healthcare professionals and increase feelings of security and decrease feelings of anxiety for patients and loved ones.

Abstract number: P2-367

Poster type: Abstract

**Death and Dying in the Czech Republic - Results of a Representative National Survey**

**Louria M.1, Slama O.2, Benová L.2, Page S.1, Borely S.1, Spankova M.1**

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**Aim:** The objective of this survey was to investigate public opinion on death and dying in the Czech Republic. **Methods:** As part of a larger study conducted with a representative sample of Czech adult population on communication about death, dying, fear of death, and place of death preferences, this paper used CAWI (Computer Assisted Web Interviewing) and CAPI (Computer Assisted Personal Interviewing) methods. Data were collected between May and June 2012. **Result:** 1095 respondents aged 15 years and older were surveyed (response rate 100%). Most of respondents (77%) think that death and dying are not discussed enough in public, especially in the media. 78% of respondents consider that the fear of dying (66%), not discussing this issue in families (59%), lack of interest in the media community (54%), socialization (42%) and public health education (28%) to be the most common difficulties with the fear of death. **Conclusion:** Most respondents indicated a desire to die at home (51%), take time for loneliness, psychological suffering (24%) and will worry about death after 13%). Respondents indicated a preference to die at home (58%), hospice (58%), hospital (55%) and long-term health care facilities (31%).
A Picture Paints a Thousand Words...

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Background: Conceptually, each single in patient within this purpose built specialist palliative care facility is an extension of the patient’s own home and patients are encouraged to ‘personally space’ by displaying photographs, mementos etc. Each room contains a blank white board for patients and family members to use as they see fit. This ‘room’ was inspired by the rich tapestry of messages and imagery found on these boards.

Aims: To describe the varied use of the boards as patients and families choose what and how they wished to reveal of themselves and their shared lived experiences; an opportunity that enabled them to say ‘this is who I am’.

Methods: This qualitative, descriptive study was undertaken over a nine-month period (September 2011 - June 2012). On receipt of verbal consent by the patient and/or family, ten selected boards were photographed and images reviewed.

Results: The display of photographs featured strongly. The themes varied but commonly included family events such as weddings, anniversaries, birthdays and holidays. Some patients included photographs of deceased relatives, work related activities particularly if their career was a source of pride to them, images of pets, religious images also featured strongly as did favourite paintings, usually of settings with some particular significance. Many visitors drew conclusions with regards to aspects of the patient’s life and grandchildren were particularly adept at displaying their talents.

Conclusion: The display of photographs, messages and drawings on the board provide a conduit for people to reveal specific aspects of their lived and ongoing experiences. They enable healthcare professionals to gain a greater understanding of the patient in the unique context of his / her life. The patient is encouraged to say ‘this is who I am’ and we are called to listen.

Abstract number: P2-371
Abstract type: Poster

Self Management in Cancer Patients Receiving Palliative Chemotherapy: Strengths and Weaknesses in Nursing Support

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Background: Self management is an important issue for cancer patients. It helps to control the consequences of the disease and its treatment, to learn to live with cancer, and thereby to maintain or even increase quality of life. For advanced cancer patients making their own decisions is of psychological importance, it gives a feeling of mastering and control.

The department of Medical Oncology of a University Hospital in the Netherlands studied this Self management which that self management is of great importance for its patients. However, it is not clear to which extent patients receive nurse support on this issue in daily practice.

Aims: To determine how and into which extent nurses support self management of cancer patients treated with palliative chemotherapy.

Method: A strengths and weaknesses analysis of this topic according to the ‘3-phase model’ (before, during and after treatment), which consists of ‘tools’ for supporting self management. Selfmanagement is defined as ‘the individual’s ability to manage symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with a chronic condition?’

Results: 3-phase model

Poster sessions

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"Don’t Blame the Middle Man": The Experiences of Translators Breaking Bad News to Oncology Patients

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Background: Healthcare professionals find breaking bad news difficult and upsetting. Increasing cultural diversity has led to an increasing number of patients whose first language differs to that of the healthcare provider, with more patients requiring a translator to facilitate communication. Hospitals often ask non-clinical translators to facilitate breaking bad news, however, the experiences of translators with a specialist oncology centre.

Methods: Qualitative interviews were audiotaped and transcribed verbatim. Thematic analysis was undertaken to identify major themes and subthemes.

Results: Five participants were recruited. Major themes included emotional pathways, translation challenges and translator support needs. Sub-themes included the significant emotional impact of translating distressing information, feeling guilty for divulging distressing news, being the focus of patients’ distress or anger and feeling in conflict with the patient or family. Participants also identified the challenges of accurately conveying information in a culturally congruent format and the need for formal briefing, debriefing and support. However, patients felt a strong sense of advocacy for the patients and found encounters with death and dying emotionally draining. Participants sometimes felt rushed and did not always get sufficient time to convey information. They felt strongly that there should...
**Poster sessions**

be access to counseling and more time provided to prepare and debrief after such communications.  

**Conclusions:** The increasing use of translators in the care of patients who are non-English speaking is one way to make more lay people being subject to similar emotional pressures faced by clinical staff, yet without the necessary formal training and support mechanisms for clinicians. This study highlights the training and support needs of non-clinical staff as identifying a unique set of communication challenges faced by translators.

**Abstract number:** P2-374  
**Abstract type:** Poster  
**A Patient-centered Approach to Giving Bad News**  
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Contact address: halinacusz@yahoo.com  
**Background:** Giving the bad news might be challenging and requiring special communication skills.  
**Methods:** A literature search reveals that much attention has been given to this topic. The typical guidance on managing this patient encounter usually takes a direct approach: give the bad news in person, provide a private setting, utilize feeling reflections, avoid overwhelming the patient with information and ensure the patient is safe to drive home. Many authors suggest that physicians advise patients to create a “false sense of relief” and “call to arms” in the face of the fear of dying. The physician feels the patient’s role is to accept the bad news and “learn to live.” The physician’s role is to “listen to the patient who has time to die.” We want to highlight the patient’s perspective and the challenges they face in communicating bad news.  
**Results:** In our medical education faculty and residency clinic we use a Patient-Centered Approach to Giving Bad News.  
**Conclusion:** The authors think that their approach might contribute to the current understanding of how to give bad news by successfully marrying the informational aspect with the patient-centered approach.  

**Abstract number:** P2-375  
**Abstract type:** Poster  
**“Do Everything”: What It Means for You**  
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Contact address: halinacusz@yahoo.com  
**Background:** When the patient and/or family want “to do everything” and they request treatments which physicians or institution count as an inappropriate, there is the potential for conflict.  
**Objective:** To explore why understanding the meaning of “Do everything” is important in palliative care.  
**Case study:** A 53 year old African American female presented with a right breast mass of 1 year duration, eventually diagnosed as a metastatic poorly differentiated adenocarcinoma. Sternal metastases resulted in paraplegia; due to excruciating pain she was heavily medicated. Her sister and brother wanted “To do everything” and the patient was shortly referred to the palliative care service. A meeting was called in to assist in conflict resolution. At the meeting the family insisted on heroic measures. The bioethics committee recommended to withhold active treatment. Her sister and brother wanted “To do everything” and the patient was shortly referred to the palliative care service. A meeting was called in to assist in conflict resolution. At the meeting the family insisted on heroic measures. The bioethics committee recommended to withhold active treatment. The patient died shortly after the meeting because of complications. Due to excruciating pain she was heavily medicated.  
**Conclusion:** The discussion on outcome indicators in palliative care (PC) was the focus on the evaluation of their children’s symptoms during the palliative phase. Care was assessed on a 5-point Likert scale (1=disagree, 5=agree).  
**Results:** Parental and patient support was high; 34% of patients wanted continuity of care (4.3±0.6) and parental involvement (4.6±0.7) during the palliative phase. Fatigue (75%), pain (74%), anxiety (52%) and anger (48%) were the most frequently reported physical and psychological symptoms of the child. Higher ratings of communication (β=9.39, p<0.01), trust and anxiety (β=9.42, p<0.01), pain (β=9.33, p<0.01), anxiety (β=9.21, p<0.01) and parental support were associated with lower levels of long-term parental grief. The severity of the child’s symptoms (β=9.33, p<0.01), anxiety about the future (β=4.83, p<0.01), anxiety (β=4.99, p<0.01) and uncontrolled pain (β=6.52, p<0.01) were associated with higher levels of long-term parental grief. Multivariate models combining domains of care and symptoms showed a significant influence of both care and symptom management on long-term parental grief.  
**Conclusion:** Palliative care, especially communication, continuity of care, and adequate symptom management in children dying of cancer are predictive for long-term parental grief levels.  

**Abstract number:** P2-377  
**Abstract type:** Poster  
**Abstract withdrawn**

**Research Methodology**

**Abstract number:** P2-378  
**Abstract type:** Poster  
**Searching for Dignity**  
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**Objective:** The discussion on outcome indicators in palliative care (PC) was the focus on the evaluation of the construct of “dignity.” A systematic review on the use of dignity in English language PC literature is planned to learn whether the term is rated as content validity. As a first step a search filter with sufficient sensitivity and precision had to be developed.  
**Design/methods:** A predefined set of 19 sentinel papers was used to test sensitivity on each step of the search filter development. The search was conducted in EMBASE and MEDLINE. A first iteration of basing the filter on MeSH terms was dismissed despite a high sensitivity (90%) due to lack of precision. Combining several text-word terms successively raised the sensitivity and enabled a more precise search.  
**Results:** A search filter combining the text word terms “palliative”, “humane”, “terminal”, euthanasia, end of life, death, dying, terminal care and truncated term “dignit*” resulted in the highest sensitivity. In the combined search from EMBASE and MEDLINE 95% of the reference articles was found and 21,306 publications retrieved. The database was cleared of doublings (946, articles without abstract (801), wrong topic (84). In the analysis of the remaining 858 abstracts another 189 articles were excluded due to lack of relevance. 669 references were considered relevant for further analysis. 7.4% of the papers were published between 1975 and 1989, 22.6% in the 90s, and 70.0% since 2010.  
**Conclusion:** Sensitivity and precision of the search filter was considered to be adequate. The increase in number of publications in recent years suggests a rising awareness for dignity and the need of an in-depth analysis of the understanding of dignity in PC literature. Funded by the German Cancer Aid (grant no. 108726)  

**Abstract number:** P2-379  
**Abstract type:** Poster  
**How is the Role of the Volunteer with Direct Contact with Patients and Families in Specialist Palliative Care Understood? A Thematic Meta-synthesis of Qualitative Literature**  
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**Aims:** Volunteers make a major contribution to palliative patient care, and qualitative studies have been undertaken to explore their involvement. With the aim of making connections between existing studies to derive new meanings and advance theories, we undertook a meta-synthesis of these qualitative studies. We sought to discover how the role of volunteers with direct contact with patients in specialist palliative care is understood by volunteers, patients and families.  
**Method:** We used systematic review techniques to search for relevant literature that explored the role of the volunteer. We searched electronic citation databases, scanned reference lists of included studies, and undertook handsearches of selected journals to find studies which met our inclusion criteria. We extracted data using a pre-existing coding framework. This was used by an audit panel of volunteers, volunteer managers and a group of researchers in palliative care. We undertook a thematic synthesis of the data collected.  
**Findings:** We found 12 relevant studies undertaken in both hospice and home-supported settings, with volunteers, volunteer coordinators, patients and families. The synthesis will be completed in 2012. It will identify key themes that will provide an understanding in how the volunteer role is understood through relationships with paid staff, patients and families. The findings may help volunteers to decide how to support volunteers in the day-to-day palliative care environment which, in turn, may help to improve outcomes for patients and families. We will synthesise research findings using a novel meta-synthesis method, thematic synthesis.  
**Conclusion:** We expect to discover how the volunteer role is understood will help inform the provision and delivery of voluntary services to the patient and family, broadening the scope of the literature that supports how the volunteer role is understood. We seek to synthesise qualitative research systematically, extending methodological techniques to help answer difficult research questions. Funded by: The Dimbles Marie Curie Cancer Care Research Fund.  

**Abstract number:** P2-380  
**Abstract type:** Poster  
**How Qualitative Longitudinal Research Can Help to Understand Existential Loss at the End of Life**  
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**Aims:** To describe how qualitative longitudinal research can highlight the experience of loss in frailty for older adults approaching death.  
**Method:** Qualitative longitudinal study comprising up to three interviews with frail older adults and informal carers over 12 to 18 months. These were compiled as case studies using Vose conceptual analysis. The stories of two participants who died during the study are described to illustrate the benefit of the longitudinal approach.  
**Results:** Mr M suffered from severe osteoarthritis, pain, unhappiness, social isolation and alienation from the world. Initial interviews offered insight into how self discipline and independence were fundamental to his sense of meaning and purpose. Later interviews showed the deep impact of being unable to live by these core values and led to existential loss, increased despair and frustration. Dynamic changes in the different dimensions of need occurred during the physical decline. Mr M’s sense of meaning and purpose was based on an existential sense of unhappiness, alienation in her surroundings and existential loss. Having first lost the power to control her world with her physical self she maintained her sense of autonomy verbally. Once this was lost her sense of existential despair was
Two received palliative chemotherapy with remission of their progressive. 5 of the 7 (71%) never received oncologic presentation to HAU, and these were static or only slowly with endemic KS. The rest were young adults (age range 28-37) who do not fit the epidemiological forms of KS as described in literature after clinical team discussions highlighted departure from the expected patterns for this tumour. Methods: Retrospective chart review and data base search revealed 11 HIV negative patients seen between 2003 and 2011 with histologically confirmed KS. Results: 5 patients (2 women, 3 men, 51 years; 5 children, 12-16 years) had KS with the rest were 1 female, 1 male, 18-60 years) in HIV negative patients. 4 of the 5 patients with KS aged over 5 years before presentation to HAU and these were static or only slowly progressing. 5 of the 71 (71%) never received oncologic chemotherapy and are still alive. Two received palliative chemotherapy with remission of their lesion. Conclusion: This study highlights a peculiar presentation of chemo sensitive KS which is not well epidemiologically described. It occurs in immune competent African young adults with no predilection for sex. Larger studied are required to adequately describe this form of KS.

Abstract number: P2-382
Abstract type: Poster

Enhancing Oral Representations in Palliative Care: Using Timelines with lung Cancer Patients and their Families and Friends

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Aims: To identify benefits of using visual techniques in interviews with patients with advanced lung cancer and those who accompanied them to diagnosis giving crystallisation of insights. Methods: A component of a study seeking to develop an intervention to support patients with lung cancer to share the news of their diagnosis. Undertaking the process of receiving and sharing bad news was key to identifying the place and time for potential interventions to support patients and their families. Methods: In-depth interviews included use of a visual timeline to elicit information from participants. The timeline comprised a horizontal axis on an A3 sheet with news received plotted above the line and news shared below the line. Participants indicated on the timeline when and where they received the news and whether they shared news with whom and when they shared this news and when. Results: The timeline had methodological and empirical benefits. Methodology as a tool also facilitated the emotional management of these intense interviews by temporarily breaking eye contact between the researcher and interviewee and providing a change of focus. Empirically the timeline was invaluable: it identified receiving (and subsequent sharing) of bad news as a sequence of events rather than the solitary instance of the ‘breaking bad news’ consultation frequently referred to in the literature. Conclusion: Visual timelines are useful methods such as a timeline can enhance both the process and outcome of data collection in sensitive interview situations. The changed focus of the interview enabled by the tool helped individuals recall and convey how they received, and then shared, bad news repeatedly over a period of time: a finding crucial to development of a supportive intervention.

Abstract number: P2-383
Abstract type: Poster

Are Palliative Care Research Samples Biased? Results from Interviews with Experienced Palliative Care Staff

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Aim: There is evidence that palliative care patients wish to be involved in palliative care research but recruitment proves problematic. The purpose of this study was to study the experiences of clinicians and their views about patient recruitment to research studies in palliative care settings.

Method: Researchers and clinicians were recruited from various palliative care settings in the UK (n=12). Participants were interviewed using semi-structured questions during guided questions during June/July 2012 about recruitment experience to both qualitative and quantitative research and included both competent and incompetent patients. The studies had relatively good recruitment rates. Interviews were recorded, transcribed and content analysis performed.

Results: The sample included researchers and clinicians (n=7) and professionals with dual research and clinical roles (n=5). Staff and sometimes relatives, practice ‘gatekeeping’, only asking those who fit their ideal participant criteria. These patients were stereotypically deemed nice, co-operative, chatty and younger. Those who tended not to be trusted were poorly, emotionally, angry or older. Staff saw themselves as protecting vulnerable patients from potential harm from research. However, they recognised that patients wanted to contribute to research and should be asked. They had experienced of patients acting autonomously including those who declined a study or withdrew; showing the final decision to enter a research study should be with the patient.

Conclusions: There appears to be an unwritten code to only include those fitting the ideal research patient stereotype. Education of staff in palliative care settings is crucial to grant staff autonomy including those who declined a study or withdrew. Further research is needed to develop a model of research participation.

Abstract number: P2-384
Abstract type: Poster

Nursing Diagnoses in Palliative Care Home

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Objective: Describe the nursing diagnoses most identified by patients and families during the last week of life. Study design and methods: A descriptive study. The participants were a nursing team of palliative home care, who performed six interviews with the patients collected from twenty two patients and their families through structured observation, particularly from an observation grid constructed on chart Palliative Care for Dignified Dying - International Classification for Nursing Practice (ICNPI)® Catalogue. This grid included all nursing diagnoses provided by the International Classification for Palliative Care for Dignified Dying - International Classification for Nursing Practice (ICNPI)® Catalogue. This grid included all nursing diagnoses provided by the International Classification for Palliative Care for Dignified Dying - International Classification for Nursing Practice (ICNPI)® Catalogue. The data collection was performed during days 1 and 31 August 2012. To data processing was created a database in Excel, with the possibility of nursing diagnoses researches. Results: The nurses diagnoses often identified in palliative home care team were: “Fatigue,” “Cachexy,” “Nausea due to the medication regime, lack of” “Edema,” “Skin integrity, compromised,” “Family process, compromised” and “Family coping, compromised.” Therefore four of the prevalent nursing diagnoses correspond to physiological needs and the remaining three correspond to needs of security, as defined by Maslow’s hierarchy adapted to palliative care. Conclusions: Nursing diagnosis activity is relevant to health information systems, specifically to nursing information systems. The nursing diagnosis gives visibility to nursing care and in this case the activity on palliative home care.

Abstract number: P2-385
Abstract type: Poster

Non-Cancer

Recognition of Atrial Fibrillation in a Hospice Inpatient Setting

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Objective: To review the medical assessment of atrial fibrillation (AF) in an admission record of an established AF relevant database if AF has any potential relevance in a palliative care inpatient population. Setting: 28-bedded independent charitable hospice in southeast England. Subjects: Retrospective data were collected on 83 consecutive hospice inpatients aged 65 years and over during a six week period in 2011. Main outcome measures: Documentation in the medical admission record of, establishment of AF, relevant drug therapy, heart rate and rhythm from examination and the proposed management of AF. Results: AF was noted in 17% of patients, with clinical examination suggesting a prevalence of up to 27%. Heart rate was documented in 38% of patients, of these 84% had a normal heart rate. Heart rhythm was documented in 35% of patients, of these 59% had an irregular pulse. Overall 20% patients were taking rate-limiting medication. Conclusion: AF is uncommon, identified in up to 27% of the hospice inpatient population aged over 65 years. This is several times higher than the 3-9% seen in comparable general or acute hospital admission populations. When documented, the majority of patients (59%), had an irregular pulse, however the clinical significance is not clear. An examination of pulse was done in less than 40% of patients, it appears that assessment of heart rate and rhythm on admission could be improved. Since AF represents a potentially treatable condition, studies to examine the symptomatic burden of AF in the hospice setting are warranted.

Abstract number: P2-386
Abstract type: Poster

Use of the Liverpool Care Pathway in End-of-Life Care Following Acute Stroke: The Role of Families

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Background: The Liverpool Care Pathway (LCP) is widely recommended to ensure best practice in caring for the dying, it is increasingly used in stroke units to manage end-of-life care following stroke. Cognitive and communication problems are common in severe stroke, families may be poor information-givers. Aim: We investigated the role of families in decisions concerning end of life care, with specific regard to the LCP. Methods: Ethics and clinical governance approvals were granted. In four Scottish acute stroke units, carers for 100 consecutive stroke patients were invited to complete a face-to-face semi-structured interviews conducted with healthcare professionals and bereaved relatives. Descriptive statistical analysis of data from the carer questionnaire was performed via SPSS 19. Multivariate was used to support thematic analysis of transcribed interviews recording, using constant comparison to develop refined grounded theory of decision-making. Findings from the carer review and interviews were triangulated to strengthen trustworthy conclusion.

Results: Of the 100 consecutive deaths, families were contactable in 96 cases. The LCP was used in 59 of the 100 deaths. Healthcare professionals and families for information about patients’ wishes. Some relatives felt responsible for making decisions and reported ‘signing up’ to the LCP, Family opposition to the LCP could trigger staff to use LCP principles e.g. anticipatory...
Prescribing, without adopting formal LCP paperwork.
Families often organised religious care or provided hands-on care. Families sourced information by negotiating meetings with staff, accessing medical information, using informal social networks, and searching the internet.
Conclusion: The LCP is often used in end of life care after family views influence whether it is formally adopted.

Funding source: Chert, Heart & Stroke Scotland

Abstract number: P2-387
Abstract type: Poster

End Stage Liver Disease (ESLD) in the Last 12 Months of Life - A Retrospective Case Note Review of End of Life Experience of Patients Known to a Tertiary Unit

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Background: Liver disease is a growing global public health problem and 5th largest cause of death in the UK, however health policy for this patient group primarily centres on prevention. To examine care for those with ESLD and end stage liver disease (ESLD). There is little research into gaps in health care provision or delivery for this group in the last year of life.

Method: Retrospective review of purposively selected case notes (30 patients) with ESLD referred to a Tertiary Liver unit between 1/1/2011 and 31/3/2011. Using a structured proforma on demographics, ESLD cause, symptoms and service use in the last 12 months of life.

Results: Preliminary analysis of 14 patients with a predominant diagnosis of alcoholic liver disease (43% female, 57% male) revealed many physical, behavioural and psychological symptoms, plus numerous medical investigations and complex interventions. There was a high in patient hospital admission rate, and median length of stay of 10 days. Communication with families about investigations and complex interventions. There was a high level of distress were 'shortness of breath' (90%), 'feeling drowsy/tired' (93%), 'poor appetite' (95%), 15 patients with different types of liver disease were referred to SPC over one year. The majority (54%) were male, 71% coloured, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% wereEDinburgh, United Kingdom

Abstract number: P2-390
Abstract type: Poster

Differences in Specialist Palliative Care Service Utilisation Between Dementia and Cancer Patients

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Aims: To compare specialist palliative care service utilisation between dementia and cancer patients.

Methods: A retrospective examination of electronic patient records was undertaken of all patients with a primary diagnosis of dementia referred to a specialist palliative care (SPC) service between 1st June 2010 and 31st May 2011. A random sample of cancer patients referred during the same time interval, matched for age and place of residence, were used for comparison. Service utilisation data was collected from referral to 1st March 2012.

Results: 50 patients with a primary diagnosis of dementia were referred to SPC. The majority (90%) were female, 57% male) revealed many physical, behavioural and psychological symptoms and more complex disease and preferences for future care were very limited. Referrals were made to specialist palliative care, but only within the last few days of life. All patients died in hospital.

Discussion: Patients with ESLD in the last year of life have repeated lengthy hospital admissions, many medical investigations and interventions. They are often unaware of the severity of their condition. Specialist palliative care is received late when the patient is not always able to communicate the symptoms and how to access and support. The liver team should address complex unmet needs earlier, communicate their wishes and too sick to transfer. The liver disease should be assessed and palliative care is offered.

Funding: Marie Curie care funding.

Abstract number: P2-388
Abstract type: Poster

The Experience and Provision of End of Life Care for People with Advanced Liver Disease who Are Homeless

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Aim: To identify which clinical symptoms or behaviours people with advanced alcoholic liver that are homeless and living in UK shelters exhibit as they approach the end of life. To examine which health care services they receive at the end of life.

Methods: Patient and carer participant qualitative study using semi-structured interviews. Data was collected from hospital and community health care professionals, shelter staff, people with advanced liver disease and families. Interviews were transcribed and further explored with data sent to experts in liver disease and palliative care.

Results: A high level of distress were 'shortness of breath' (90%), 'feeling drowsy/tired' (93%), 'poor appetite' (95%), 15 patients with different types of liver disease were referred to SPC over one year.

Discussion: To better understand the experiences, goals and needs of patients with advanced liver disease and their families. Palliative care services traditionally focused on patients with cancer and more recently on other types of organ failure, but those with advanced liver disease are relatively neglected.

Aims: To better understand the experiences, goals and needs of patients with advanced liver disease and their families. Palliative care services traditionally focused on patients with cancer and more recently on other types of organ failure, but those with advanced liver disease are relatively neglected.

Conclusion: Patients referred to SPC over one year. The majority (54%) were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58. 60% were male, 71% colored, 25% completed high school, and 28% included in the study, with a mean age of 58.
abstract number: p2-396
abstract type: poster
symptom burden and palliative care needs of people with advanced dementia

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aims: people dying with advanced dementia (advd) often have poorly managed psychological symptoms and suboptimal care. this uk pilot study tests the feasibility of recruitment and study measures in people with advd who can be involved in the design of the research. as such, the study has the potential to shape and improve care for people with dementia.

methods: patients were followed by the palliative care service at the hospital through two ways: by request consultation or by the attending physician. or triage systems. all patients who had been referred were sent by the palliative performance scale (pps) with cutpoint of 20 points. the reason for referral included symptomatic management of pain, breathlessness, anxiety, and depression in 60% of cases. 33% of patients were on opioids at referral with this number increasing to 67% at the end of the study period. for benzodiazepines, 37% of patients were prescribed these at time of referral, increasing to 80% at end of study period. only 33% of patients had any record that advanced care planning had been discussed and only 53% had a record of resuscitation status. the average time from referral to death was 14 weeks (range 1-43 weeks).

conclusion: palliative care of COPD patients is mainly due to an increase in opioid use, but were markedly benzodiazepine-prescribing. Advanced care planning and DNACPR discussions were not documented in the majority of cases.

abstract number: p2-397
abstract type: poster

Collaboration between Respiratory and Palliative Care Specialists: Developing Interventions for People with Advanced Respiratory Disease

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Aims: the aim of this multisite, multidisciplinary research project was to design, implement and evaluate palliative care responses for people with advanced respiratory disease.

Methods: A participatory action research methodology was chosen as its emphasis is on collaboration, action and reflection. This research was located across an acute hospital and hospice care setting. The original participants were the steering group members including clinical nurse specialists and physicians from respiratory and palliative care teams. Other key stakeholders were included as the project developed e.g. physiotherapists, nurses from relevant wards, patients and families. A mixed methods methodology was employed including audits, quantitative surveys, interviews with patients and families, expert focus groups and evidence reviews.

Results: Four of the interventions are highlighted.

(1) Education: 93% of respiratory staff expressed a desire for palliative care education and 50% of those attended full day workshops on developing end of life awareness and communication skills. There was also reciprocal education and training from the respiratory unit with hospice personnel.

(2) Multi-disciplinary Team Meetings: organised on a monthly basis, they provided a format for brief discussions of patient cases.

(3) Communication: this involves regular meetings and presentations at local, national and international levels.

(4) Patient Care Pathway: the collaborative working relationships that developed between hospital and hospice sites facilitated the development of a patient care pathway tool for people with advanced respiratory disease.

Conclusions: As action research takes place within the theory-practice gap, it has facilitated respiratory and palliative care teams to collaborate on bringing about change within real working environments. Furthermore, it has allowed for the generation of a new practice based knowledge of respiratory palliative care to emerge.

Abstract number: p2-399
abstract type: poster

ALS: Amyotrophic Lateral Sclerosis: Characterizing the Patients Assisted by a Palliative Care Team in a University Hospital in Pontevedra Region

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Introduction: Amyotrophic Lateral Sclerosis (ALS) is the most frequent motor neuron disease, causing high degree of disability and overburden for caregivers.

Aim: To characterize patients with ALS followed by the palliative care service (PCS) of a university hospital between 6/Nov/2008 and 15/Oct/2012.

Method: Retrospective analysis of the clinical process of movement and 12% at rest on the PAINAD scale. Difficulty swallowing and weight loss were the commonest symptoms (58% & 44%), most needed assistance with eating. Analgesia was prescribed in 52% (usual range 11-55, lower scores—higher quality of life). Mean Symptom Management in End of life was score was 33 (range 20-45, higher scores—greater comfort).

Conclusions: There is no possibility to meet ethics standards and recruit people with ADVd to a pilot study. Data collection using validated instruments was feasible. Participants were frail with high risk of pressure sores, agitation and difficulties swallowing. Comfort scores varied from 0 to 100. Mean total symptom score was 11.8 ± 0.6 in the United States and 13 ± 5.3 in the United Kingdom.

We evaluated 131 patients between the period of May until March 2012. 38 patients were in the ICU, 28 PD and 10 CG. Among all patients were only 6 patients with cancer, others were mostly patients with neurological failure. There was no difference in age (PG 78.67 ± 12.99 and CG 69.2 ± 15.3 p = 0.11). There was no difference between the groups entering the study (sex and screening and consultation request (p = 0.29). 15 patients of Palliative Care Group died (PG 15/131, 11.5 ± 10.7 p = 0.05) and duration of hospitalization of outcome: PG 14.17 ± 24.2 days and CG 2.1 p = 0.004.

Conclusion: The insertion of Palliative Care in the ICU was associated with a shorter stay in the ICU and in hospital, without changing mortality.

Postersessions — Ret 2
Abstract number: P2-399
Abstract type: Poster

Aim: The aim of this study was to assess awareness about palliative care among Dialysis Nurses.

Methods: We developed a questionnaire of 30 items that measured the knowledge of nurses about palliative care. A total of 100 nursing staff were included in this study.

Results: The overall awareness about palliative care was 34.3%. A positive attitude towards palliative care was found in 73.5% of the respondents.

Conclusion: We recommend that in situ training programs for nurses should be developed to increase awareness about palliative care.

Acknowledgments: This study was supported by the Department of Nephrology, VU University Medical Center.

Poster sessions
Are Patients Being Admitted from Nursing Homes to Secondary Care for End of Life Care?  

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Abstract number: P2-405  

Abstract type: Poster  

Are Patients Being Admitted from Nursing Homes to Secondary Care for End of Life Care?  

Aims: Palliative care has potentially a lot to offer to patients in the acute phase after a severe stroke, but its deliberations and decisions towards palliative care are limited in this phase. Therefore the aim of this study is to describe the experiences of relatives of stroke patients with the care provided in the acute and the ethical dilemma’s with relatives have to face.  

Study design & method: A qualitative study using semi-structured interviews was conducted with relatives of stroke patients aged 18 years and older at a severe stroke or in the acute phase. The interviews took place 2-6 months after the stroke, were transcribed verbatim and subjected to qualitative analysis.  

Results: Preliminary results show that communication about prognosis and/or its uncertainty is at times limited, leading to gap in the care provided. Relatives of patients with a severe stroke and a poor prognosis in the acute phase after a severe stroke between health care personnel and relatives of patients may prevent relatives from making choices towards palliative care.  

Preliminary results suggest that limited communication about the “dignity” of palliative care care in the acute phase after severe stroke between health care personnel and relatives of patients may prevent relatives from making choices towards palliative care.

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Aims: Increasingly, care for people with dementia is being used to be an important role for palliative care. The translational research project aims at increasing community pharmacists’ knowledge and skills regarding dementia care, building competency of pharmacists as providers, and setting up community-based projects involving people with dementia and their carers as professional, thereby increasing well-being of people with dementia and their carers and fostering destigmatisation.  

Study design: The project is based on the principles of participatory research, meaning equal collaboration between researcher and practice, participation of people with dementia, informal and professional care providers in all processes and in knowledge generation, and realizing the project in repetitive loops of action, reflection and evaluation.  

Methods: This included focus groups, workshops, networking activities, and a literature review.  

Results: Partnership building, clarifying aims and goals and reaching interested community pharmacies are the most important steps in the initial phase of the project. People with dementia and their carers expect information on medicines, referral and emotional support from community pharmacists. Community pharmacies are mainly focused on medication management, however, issues like fostering early diagnosis and providing referral and communication with people with dementia and networking with self-help groups and other services are also believed to be highly relevant.  

Conclusion: Community pharmacies are an important health care setting for people with dementia and their carers especially from socially marginalized groups. However, overcoming community pharmacists’ uncertainty of pain on dementia in favor of resource orientation and aiming at well-being and dignity as important outcomes, implementing cognitive services and networks among care providers pose some challenges which should be overcome by working collaboratively towards shared goals.
of the programme. This included detail of phone calls, emails and visits: the time taken and what they did.

Pain management was a key element in end-of-life care provision by the "Brückenprojekt Dresden" has proved to be very helpful. The after-care provision by the “Brückenprojekt Dresden” has been developed together with bereaved parents’ support is twofold: the individual support of the family for one year after the death of the child and the yearly weekends for bereaved parents for an emotional and practical support.

Introduction: Palliative care for children (PCC) does not always end with the death of the child. Rather, the support of the bereaved families is imperative. However, the integrating facilitation from the supporting PCC team has proved to be very helpful. The after-care provision by the “Brückenprojekt Dresden” has been developed together with bereaved parents’ support is twofold: the individual support of the family for one year after the death of the child and the yearly weekends for bereaved parents for an emotional and practical support.

Designs, methods and statistics: In a retrospective study, the after-care of “Brückenprojekt Dresden” during the years 2008-2012 (n=44) was investigated.

Results: 77% of the families opted for individual support. Contacts were mainly over the phone (68%), but also personal meetings at their home or at the funeral (27%) were very significant. Topics for conversations apart from how they felt, were siblings, remembering the child, looking back at the care, return to work, linking with external help providers and counselling. Regarding intensity and frequency a broad spectrum shows the individuality of the families. Participation numbers for weekends for bereaved families showed a big increase (2009-2012: 142%).

The parents benefit enormously from meeting other parents. The weekends include joint activities, art therapy, activities for siblings and a ritual in memory of the deceased children. Care for the surviving family members should be part of the work of a PPC team. Because of the diversity of issues, this after-care has to be arranged through professionals from different areas of expertise and the whole team. As grieving and inclusion of families in a supportive social environment are very individual, standardised forms for after-care are not possible. Some fixed components (e.g. active support for one year after the child’s death, contact arrangements, birthday card, weekends for bereaved parents) were developed together with bereaved parents.

Use of a Social Networking System as a Communication Tool in Home Care

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Purpose: Children’s home care involves a number of professionals, and communication/information sharing are regulated between them. In a social networking system (SNS) for real-time transmission and sufficient communication may lead to confusion among staff, and differences in awareness based on patient OKE. We used a local social networking system (SNS) for real-time transmission of information and to hold online conferences when required. The problems and advantages of SNS are discussed.

Methods: The local SNS used a member-only network service, access to which can be restricted by the community administration. We used this SNS to record information and to hold conferences. The subjects were terminal childhood
cancer and severely handicapped patients taken care of at home. The medical personnel in the community consisted of a home-care visiting nursing service, hospital, home care doctors, medical social workers, and local public-health nurses. In some cases, communities included family and schoolteachers.

Regarding the stable conditions, we could know the everyday state of the patient from the home-care visits and discussions about the condition of the patient, which were held online with the home-care doctor to decide on treatment, and the staff were notified in a timely manner. In the community including family, the family members were also able to express their concerns.

Conclusion: Information can be exchanged through the SNS via mobile phone or computer, with the use of the website as an additional tool for the service. Involving family are also effective for family members to express their feelings, and staff were able to correspond from their professional standpoint. This allowed staff to provide guidance and support. The website was developed by improving the recording of information and additional functions, we expect this to be a tool that will become easier to use in the future.

Abstract number: P2-418
Abstract type: Poster

Improving Practice in Children’s Pain Management

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Introduction: Our knowledge of children’s pain has increased in recent years. Despite the availability of evidence, management of pain in children is often suboptimal. The paediatric palliative care team (PPCT) was created within the hematology and oncology unit in 1996. In 2006, its objectives were redefined to include children and adolescents (between 12 and 18 years of age), male and female, with different diagnoses (leukemia, non-Hodgkin Lymphoma, bone tumors and central nervous system) and in the several phases of the diagnostic-therapeutic process (diagnosis, therapeutic, relapse, palliative care and survival), attended at the Hospital dos Clínicos, Brazil; 14 relatives (two fathers, nine mothers, and three siblings), besides 25 health team members (eight physicians, five nurses, six nursing auxiliaries, two social workers, one psychologist, one nutritionist and one occupational therapist). The interview was used for data collection. The discussion of data was guided by the dialogic life-death in the context of care to adolescents within the PPCT.

Results: In the context of this study, the adolescents do not clearly express their health care needs to them. If the physician in their own and their relatives’ reports though, in submission to situations of intense suffering during the treatment, as a form of distancing death, as well as in feelings of concern with and fear of relapse, which even adolescents who had already finished treatment expressed. It was observed that in the way the adolescents experience time and faces death and the possibility that the family will lose a loved one may not be in accordance with the care the health team offers, considering structural, organizational and affective aspects.

Conclusion: It is not enough for the team just to rationally manage the suffering and seek therapeutic devices, in line with predefined moments in the disease. Instead, a contextualized and sensitive understanding of each situation is needed.

Abstract number: P2-420
Abstract type: Poster

I ‘Just Want him to Be Comfortable’... - A Conceptual Analysis of Comfort at End of Life in Paediatric Palliative Care

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The death of a child is a unique and individual event. Care pathways may be followed but each event requires a nursing team to respond intuitively to the needs of that child and their family effectively. If our aim is at end of life in paediatric palliative care, how do we as practitioners recognize it? How is death identified when it is imminent and is it avoidable? How can we as practitioners interpret what is comfort, and to what extent is it family driven? The aims of this study were to explore the concept of comfort in palliative care, specifically in relation to children and their families.

Methods: A literature review was undertaken, and a qualitative study with interviews with families and health professionals in Ireland and the United Kingdom was undertaken.

Results: The main findings were that comfort encompasses physical, psychological, and social aspects of care. Levels of comfort differ between patients and families, and comfort can be defined as the absence of pain or distress.

Conclusion: The study found that comfort in palliative care is experienced differently by children and their families. Comfort is a complex concept that involves understanding the unique experiences of each individual. The results of this study suggest that comfort in palliative care should be defined and measured in a way that is meaningful to the patients and families involved.

Abstract number: P2-421
Abstract type: Poster

Communicating Bad News in Clinical Palliative Care Practice: A Pediatric Nursing Contribution

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Introduction: Communication is an essential component in palliative care. Transmitting bad news is an extremely sensitive and complex aspect that needs preparation and sensitization from health professionals, besides specific knowledge and attitudes. In view of the incapability of the disease and the transfer from the doctor to patient, it is important to reflect on how bad news is communicated to children, adolescents and their family members.

Aim: To understand the experience of mothers and fathers of children and adolescents with cancer in palliative care when bad news is communicated.

Methods: A descriptive and exploratory study with qualitative data analysis was undertaken. Empirical material was collected through a focus group with the parents of children and adolescents with cancer who were informed about the transition to palliative care.

Results: The parents reported that the moment when the transition to palliative care is communicated is marked by great pain and is often difficult to understand; they reported preferring that this new information be communicated by a physician who has a bond with the family and patient and emphasize the importance of the psychologist and nurses presence at this moment. They mention that understanding the situation takes some time and, based on this understanding, they start to develop coping strategies and their own explanations, always seeking comfort and happiness.

Conclusion: By understanding how the communication process of bad news takes place, this intervention can systematically be incorporated with a view to the protection of health care that responds to children, adolescents and parents’ real needs. In view of communication of bad news, these study results can contribute to the development of strategies for children and adolescents with cancer and their parents, as well as for the health team.

Abstract number: P2-422
Abstract type: Poster

Building Capacity in Children’s Palliative Care through e-learning: The IPCON Experience

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The Development of Paediatric Palliative Care in Norway and National Guidelines

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Until 2009, Paediatric Palliative Care for children with life limiting (LLC) and life treating conditions in Norway had no attention. In three years, this field has now received considerable attention from national and international bodies within the Norwegian society; this has lead to activity in several areas. The founding of the first organizations working for PPC and advocating for this, has marked important steps in the development. In December 2011, the Committee on Health and Care Services acknowledged the need for improving the response for children in need of PPC and a unanimously Storting decided that Norway should develop national guidelines for children with palliative care needs.

Abstract number: P2-423
Abstract type: Poster

The Development of Paediatric Palliative Care in Norway and National Guidelines

Pedersen N.
Yes to Palliative Units and Care for Children, Kristiansand, Norway

Poster sessions

– set 2

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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Poster sessions – set 2

13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013

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Poster sessions

“The Pump Was Good because it Meant I Could Be at Home”: Patient Controlled Analgesia (PCA) in Paediatric Palliative Care, Experiences of Children and Young People (CYP), Parents, and Health Care Professionals (HCP)

Rajapakse D., Kelly P., Boggi T., Koh M., Rasdell E., Craig F., Fuller K., Rajapakse H., Howard K., Bluebond-Langner M.

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Abstract number: P-424
Abstract type: Poster

The Impact of Paediatric Respite on Families of Children with Life-limiting Conditions

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Abstract number: P-427
Abstract type: Poster

Providing Respite Care for Children with Life-limiting Conditions - The Information Needs of Parents. Findings of Case Study Research in the Republic of Ireland

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Abstract number: P-426
Abstract type: Poster

Children's Hospice Assocation Scotland (CHAS), Robin House, Balloch, United Kingdom

Background and aim: Children’s Hospice Association Scotland (CHAS) provides the sole children’s hospice services in Scotland to children, young people with life-limiting and conditions and their families. CHAS provides vital care and support through its two hospices, Rachael House and Robin House and a home care service. Sibling support is an important aspect of care and Robin House has developed the ‘4G’ Group following the findings from two studies and the desire to support siblings at a deeper level. The aim of the group was clearly defined:

- To offer a structured sibling support group, meeting with the same children regularly over a period of six months
- To ensure that the sessions were positive and enjoyable for those attending them

In 2013, a random sample of thirty two siblings and parents were asked about the way that CHAS provides its services, and the desire to see a support group. The group met seven times during the first year and was offered again for a further six months.

FINDINGS AND OUTCOME: The siblings were enthusiastic about the group and reflected that they had found it helpful. They wanted people to know about what they had achieved. Participants’ self esteem and confidence grew and was recognised by both parents and staff. Feedback was overwhelmingly positive and siblings have continued to refer to it on subsequent stays at the hospice. The 4G Group recognised the needs of siblings and valued their individuality. Introducing the group at Robin House helped in their development. It is recommended that this support is extended at Robin House, and is shared with others who are involved in the care of the children, adolescents and their families.

Hospice House for Children and Adolescents: The French Experiment

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In France, children and adolescents have long been forgotten in palliative care organization. In 2008, a national hospice program was set up to improve the quality of palliative care and specific pediatric palliative care was defined so as to enable the development of an organizational structure and siblings have continued to refer to it on subsequent stays at the hospice. The 4G Group recognised the needs of siblings and valued their individuality. Introducing the group at Robin House helped in their development. It is recommended that this support is extended at Robin House, and is shared with others who are involved in the care of the children, adolescents and their families.

We will describe here two years of management of this hospice with its positive aspects and the mistakes that were made. We will analyse some of the technical aspects of this experiment ranging from the architectural point of view to economic considerations.

An information campaign was focused on pediatric palliative care but we realized how difficult it was for parents to accept this concept and we chose to insist on supportive and palliative care. We will present a short analysis of the parents and the children's willingness regarding end of life care in the French socio-cultural environment. The clinical situations that led to a stay in hospice for the family include a deteriorating family life. In order to help, hospice is a place that helps to cope with the problems that are connected with the child and their family needs. They learnt to time to navigate the system in order to secure the services that they required including respite services. Organisations providing this information varied and information varied according to child’s diagnosis and the parents own preferences. Parents described how the lack of information impacted not only on their child but also had consequences for the whole family. Parents spoke of the need to ensure that other families would have ready access to the information and that they would understand it. We did not experience a disadvantage.

Conclusion: Having a child diagnosed with a life-limiting condition impacts on the whole family. In order to help, hospice is a place that helps to cope with the problems that are connected with the child and their family needs. They learnt to time to navigate the system in order to secure the services that they required including respite services. Organisations providing this information varied and information varied according to child’s diagnosis and the parents own preferences. Parents described how the lack of information impacted not only on their child but also had consequences for the whole family. Parents spoke of the need to ensure that other families would have ready access to the information and that they would understand it. We did not experience a disadvantage.

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Creating policy change sensitive issues around dying, death and bereavement.

Correcting misconceptions, filling information gaps, developing a range of appropriate responses.

Conclusion: advocates for patients - Encouraging patients and families to be

Programmes:

Staying resilient - keep advancing and introducing new development of palliative care beyond cancer awareness of end of life issues; supporting GPs and primary care, identifying alliances at all political levels - developing relationships with advocates within the political system - training in communications and public speaking.

Methods: Targeting the right audiences to promote our issues robust evidence for patients, proxies and health professionals.

Abstract number: P2-430

Abstract type: Poster

Making the Case for Resources and Attention - Advocacy and Communications in Palliative Care

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Inch Hospice Foundation, Dublin, Ireland

Aims: To build support for the future development of a national hospice and bereavement strategy by raising awareness of what hospice care means and the strategic importance of good end-of-life care for the entire health service.

Methods: Making a multi-layered approach to raising awareness and building consensus.

Targeting the correct audience who have the power to make change happen - our champions.

Bringing robust evidence to the table to help them to justify reform and investment.

Demonstrating that our issues affect a significant number of people.

Sharing our experience and knowledge

Costing any proposed solution

Knowing their policy priorities

Staying resilient - keep advancing and introducing new angles to our argument.

Using a mixture of new and existing projects and programmes.

Encouraging patients and families to be self-advocates - using examples and giving people direct and recent future care preferences; organised public events to empower people about their decisions.

Supporting patient professionals to become effective advocates for patients - training in communications and awareness of end of life issues; supporting GPs and primary healthcare workers to deliver palliative care; supporting the development of palliative care beyond cancer.

Engaging directly as advocates within the political system at all political levels - developing relationships with politicians with an interest in hospice issues

Identifying advocates in the public service to promote policy change.

Creating alliances with like-minded organisations to lobby for policy development.

Using media opportunities to tell the story.

Results: To date we have identified knowledge gaps and are searching for any proposed solution will need a mixture of overall and particular material have been

Abstract number: P2-431

Abstract type: Poster

Representations of Assisted Dying in the UK Media

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Euthanasia and assisted suicide are both terms which, under the umbrella term of assisted dying, have caused much debate. Understanding how the media represent assisted dying is crucial because it is often a primary resource where the public can gather information and make sense of social phenomena.

There have been limited studies on the portrayal of assisted dying in the media, with research focusing on narrow themes. The aims of this study were to find out how the reporting of assisted dying differed in the Dutch and British media, to identify the broad themes running through the media's representation of the issue, highlight where assisted dying terminologies had been incorrectly used and verify the hypothesis that these were nation-specific.

A recent unpublished Dutch study which conducted a content analysis on euthanasia in the Dutch press was found, using the same search terms as the Dutch study, in the Nexis database, 187 UK articles were located. The process of thematically coding the data was dynamic in nature and the coding scheme was added to and corrected throughout the analysis making the scheme fluid and effective at capturing arguments and new pages.

The results showed the UK media reported assisted dying neutrally which differed from conclusions of previous research. Incorrect use of assisted dying terminologies were found in 33% of tabloid articles. The Dutch press also contained more 'right to die' arguments than the British, which contained more 'slippery slope' arguments. This reflects the difference of Dutch and British opinions in autonomy and end of life decisions.

The striking difference in conclusions from these countries was that the use of incorrect terminologies and labelling of groups and individuals can lead to confusion amongst the public. This study has the lead visitors to the blog when used as search engines terms.

Abstract number: P2-432

Abstract type: Poster

Use of Social Media in Palliative Care - Evaluation of the EAPC Blog after six Months

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The EAPC board of directors has decided to foster the use of social media in palliative care in the aim to expand its outreach, e.g. towards younger professionals and by persons. It also allows the EAPC to give a rapid response to new developments worldwide. An evaluation of the use of the EAPC blog was performed after six months.

Methods: The social media team was installed and set up a blog at www.eapc.eu and a Facebook page. An evaluation of the use of the EAPC blog was performed after six months.

Results: The social media team was installed and set up a blog at www.eapc.eu and a Facebook page. An evaluation of the use of the EAPC blog was performed after six months.

Abstract number: P2-433

Abstract type: Poster

Personal Resources Explaining Patients’ Wellbeing: A Structural Model on a Multicentre Study in Spain

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Patients’ physical, social, psychological and spiritual needs relieve is essential in the decrease of suffering within palliative care units. From the anthropological model proposed by the SECPAL Spirituality Group, and using a measurement instrument developed to assess the spirituality through three levels: intrapersonal (spiritual), interpersonal (emotional) and transcendent (knowledge). Aim: To study the relationships between this spirituality grade and the emotional wellbeing (absence of anxiety and depression signs) in a sample of patients from Spanish palliative care centers.

Study design and methods: Sample consisted of 121 patients (68% female) from palliative care units and the rest from home care palliative (36%); acute care hospitals (16%) and nursing homes (10%). We perform a cross-sectional study with descriptive analyses, correlations and a structural equations path model including measures of psychological wellbeing, resilience and spirituality.

Results: Have shown high internal consistency of emotional wellbeing similar to other studies (anxiety mean=8.93; SD=2.23, depression mean=6.95; SD=1.04) and, statistically significant and high correlations between spirituality, depression, anxiety and resilience. The data fit the path model properly (χ²/df=18.35, p<0.05; CFI=.92; TLI=.91; RMSEA=.06; 90% CI=[.05; .08]). This finding link from the spirituality grade on depression and anxiety, in a negative way, and a positive relation between spirituality and resilience.

Conclusions: Put all these results in relation to previous literature, providing new evidence on the importance of spirituality for palliative care wellbeing.

Abstract number: P2-434

Abstract type: Poster

Swedish Palliative Network - SPN a National Newsletter and Web Site

Sauters S, Fürst C.J.

Swedish Palliative Network - SPN a National Newsletter and Web Site

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Background: The amount of information in palliative care is growing and there is a need to filter and handle increasing quantity of professional non-scientific information.

Methods: A description of the development of SPN newsletter and web site. A forum for multi professional national exchange was lacking in Sweden and there were no initiatives to start a multi professional palliative care association.

Results: At Stockholm Sjukhem, a newsletter was created with the following intentions: free of charge, no commercial advertisement, short articles or communications, relevance for all palliative care team members and monthly issues of, in page, 3-6 pages. New subscribers directly through e-mail or from lists distributed at major palliative care events in Sweden. In ten years subscriptions have increased from 100-3000. The single edition is consumed in palliative care. Also receives information from professionals and makes contact e.g. with those who publish PhD or master exams in palliative care.

Discussion: The Newsletter is after 10 years and >100 issues, a well known source for information on palliative care in Sweden. We believe that the relatively short and traditional format and the regular and free submissions as well as the mixture of overall and particular material have been important factors for the success. Future challenges include sensitivity to the demands of the readers, even those who do not respond to reader surveys, increased interactivity with the subscribers and of course to continuously be a high priority for the readers.

Abstract number: P2-435

Abstract type: Poster

Spirituality

Posters sessions

– set 2
Poster sessions

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Background: The ‘Opening the Spiritual Gate’ education programme, established in the North West of England, is designed to enhance participation in spiritual care. It uses semi-structured interviews with participants who had undertaken either type of course was undertaken. The interviews established their reasons for choosing this type of learning, their experience of the course, what they felt they had gone well and what had been a challenge, & their overall judgement of the outcome of the course & its impact in practice for them.

Results: Most participants undertook a variety of courses. Six semi-structured interviews were undertaken. The interviews were transcribed and reviewed and coded. Interviews were continued till thematic saturation was reached.

Abstract number: P2-436  
Abstract type: Poster

Issues of Control and Perceived Disruption of the Self: The Main Reasons for Choosing Assisted Suicide, Despite the Provision of Palliative Care  
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Background: Palliative care is often seen as a safeguard against assisted suicide. Recent studies demonstrated that palliative care ranked high in terms of provision and quality indicators, whereas assisted suicide choice and their perceptions of the interactions with health care professionals and palliative care during decision making.

Methods: Four semi-structured interviews and thematic analysis with eleven relatives of eight deceased patients, cared for by a palliative care team, who undertook assisted suicide, between January 2007 and May 2009 in Southern Switzerland.

Results: Interviews suggested that pain and symptom burden were not regarded as reasons to seek assisted suicide, rather existential distress and fear of loss of control were the key determinants. In some cases the general decision making process was slowed due to cancer was made more than 10 years earlier. According to relatives, a need for control over their situation and death circumstances was reported as common. Relating to these responses reported a number of misunderstandings about the nature and purpose of palliative care: fears that morphine would interfere with decision capacity, palliative care seen as useless because it did not influence the illness and other issues. Patients did not regard receipt of palliative care services as influential in preventing their decision to proceed with assisted suicide.

Conclusions: Assisted suicide was preferred by these patients despite provision of palliative care. Existential and psychological fears and control played a key role.

Abstract number: P2-437  
Abstract type: Poster

Spirituality and the Arts - Discovering what Really Matters  
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Abstract number: P2-438  
Abstract type: Poster

Confirmitory Structure of Two Measures of Spirituality in Spanish Palliative Care Units  
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Aim: To present and discuss empirical evidence about the competitive structures regarding two different spirituality measures applied to palliative care practice in Spain.

Design & method: Data from 121 participants from a cross-sectional study are used to assess reliability, criterion and factorial validity of two spirituality measures: GES (8 items) and FACIT-Spa (12 items). Competitive confirmitory structures for GES consists of a three factors structure, inter understanding, intrapersonal and spiritual peace and meaning/peace factors. FACIT models are those reported by Birkenstock. Speaker literature comparing two against three factors based on meaning/peace and faith constructs.

Results: Both measures provide adequate reliability in terms of internal consistency (GES α = 0.72; FACIT-Spa α = 0.80).

From the competitive confirmitory factor analysis, factors are reported and discussed in terms of better fitting options. With respect to factorial validity the best-fitting model for GES was the second order one, with a good model fit (χ2=29.12, df=8, CFI=0.96, RMSEA=0.083). Regarding FACIT, a better comparative fit (established with a lower amount of model AIC of -26.53 compare with -23.78) was obtained using a 3-factor structure (NFI=0.97; χ2=96; df=96; RMSEA=0.070).

Discussion: Current results pointed to an adequate reliability of both measures, clarifying their dimensionalities, with a clearer structure for the GES. It should be borne in mind that this measure was developed to solve a gap in the spirituality measurement and that it is intended to expand spirituality in palliative care taking into account a main trait of Mediterranean culture: the interpersonal resources.

Abstract number: P2-439  
Abstract type: Poster

Soul Searching: Developing a Tool for Spiritual Assessment  
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Background: The recognition of the importance of spirituality has been highlighted in recommendations for palliative care. The UK 2004 National Institute of Clinical Excellence guidance 'Improving Supportive and Palliative Care for Adults with Cancer' suggests spiritual assessment should be an integral part of care, being regularly completed and being the responsibility of the whole team. This study was conducted in a tertiary cancer centre in the United Kingdom with over 1000 new patients each year.

Conclusions: There is no formal assessment of spiritual care needs carried out during the nurse assessment. Identified as one of the key obstacles, was lack in staff's confidence in assessing spiritual needs. Following this a formal spiritual assessment method was piloted.

Objective: To develop and pilot a formal spiritual assessment tool and referral criteria, in order that spiritual needs can be confidently addressed by all health care professionals, leading to improved patient outcomes.

Method: A baseline literature search reviewed a range of assessment methods and referral criteria. A chosen tool was then adapted and piloted by the Royal Gwent Specialist Palliative Care Team and hospice nurses.

Results: All nurses involved in the pilot (n=8) stated the tool helped in structuring the spiritual history and 3 nurses stated they would use this tool again, without any further improvement to it. The remaining 5 nurses felt they were already experienced but said it would be useful for less experienced nurses. Confidence in using the tool was reported as high.

Conclusions: Having a formal assessment method was new to the cancer centre. The introduction of a structured spiritual history tool was helpful to staff and was confidently used without the need to be formally taught. This is a small pilot study with scope for future work. The aim is to introduce an assessment tool that all staff can use during patient assessment.

Abstract number: P2-440  
Abstract type: Poster

Frequency of Spiritual Concerns in a Palliative Care Setting in a Developing Country: Are there Cross-cultural Differences?  
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Aim: To study frequency of spiritual concerns in a palliative care setting in a developing country and compare these with those reported from Western developed countries.

Study design and methods: A qualitative study design was used to acquire information on frequency of spiritual concerns in Hindu cancer patients undergoing palliative care in a hospice. An ethics committee approved the study and written informed consent was taken from all participants. Interviews based on a structured format discussing spiritual concerns were conducted and recorded on a digital voice recorder. The audios were transcribed in English and codes identified. Interviews were continued till theme saturation was reached.

Results: Ten patients (7 female,3 male) were interviewed. Ninety-two spiritual concerns ranged from 6-22, (mean 11.6) per person. The commonest spiritual concerns were benefits of Pooja (religious activities), faith in God(100%); concept of rebirth; reconciliation of own condition, perspective of future; (80%); belief in Karma, and "Why me?" (70%); Spiritual concerns, commonly reported in western literature, related to meaning/peace, longed for but never had. Religious struggle, were reported by none of the subjects. Concerns about angry God, gratitude, good omens, loss of control and reconciliation with others were reported by 10% only.

Conclusion: This study confirms that specific spiritual concerns are common in Hindu society. It identifies strong cross-cultural differences in the key areas of spiritual concern, when compared with western palliative care patients. These findings are important in the development of spiritual care in the development of palliative care but cautions the direct transferability of western models of spirituality within this setting.

Abstract number: P2-441  
Abstract type: Poster

The Impact of Faith and Hope During the Palliative Phase on Long-term Psychological Functioning in Patients who Lost a Child to Cancer  
van den Geest L.M.1, Darlington A.2,3,4, Falkenburg J.L.5,6,7, Michiels E.M.C.8,9, Pieters R.2,3,4, van den Heuvel-Eibrink M.M.9  
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Poster sessions – set 2

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13th World Congress of the European Association for Palliative Care, Prague, Czech Republic, 30 May – 2 June 2013
Paediatric Oncology/Haematology, Rotterdam, Netherlands,
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Southampton, United Kingdom

**Background:** The aims of this study were to investigate
1) faith and hope for parents of a child dying of cancer,
2) the impact on long-term traumatic grief and depression,
and
3) factors that helped parents to cope during the palliative phase.

**Patients and methods:** Eighty-nine parents of 57 children who died of cancer between 2000 and 2004 participated in a retrospective cross-sectional single centre study and completed a set of questionnaires measuring grief and depression, and exploring faith, hope, and factors that helped parents cope.

**Results:** For 19 parents (21%), their faith was very important. The majority of parents had hope for: a meaningful time with their child (n=68,76%); a pain-free death (n=58,65%); and a cure (n=30,34%). Most parents indicated that their child (n=70,79%) helped them to cope during the palliative phase. Approximately 14% (n=12) of parents could be categorised as having traumatic grief and about one quarter of parents (n=22, 25%) showed symptoms of clinical depression. Nine parents (10%) showed symptoms of both traumatic grief as well as clinical depression. Parents’ faith and hope for cure during the palliative phase were not associated with long-term traumatic grief (OR=0.86,p=0.49;OR=1.08,p=0.70) or depression (OR=0.96,p=0.78;OR=1.13,p=0.42).

**Conclusion:** Faith was important only for a minority of parents. The majority of parents had hope. Faith did not protect parents from traumatic grief and depression, while hope for cure did not put parents at increased risk for traumatic grief and depression. For most parents, their child was an important source of coping.
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