Oral abstracts

Friday 8 June

CONNECTING DIVERSITY

10th Congress of the
European Association for Palliative Care

assisted in our approach with both indigenous and non-indigenous patients.

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73. Reporting cancer and dying in the news: a study of Portuguese newspapers and magazines

Barbara Gomes, Marjolein Gysels, Irene Higginson

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Background: The media's role in educating about cancer and dying is poorly understood yet these are leading sources of health information for patients, families and general public.
Aim: To examine the coverage and representations of cancer and dying in the Portuguese print press.
Method: 234 newspapers and magazines (98 with national coverage) were searched for all articles on cancer or dying (9th March-8th May 2006) using 10 keywords. Publication patterns and variations in articles' length and themes were described. A qualitative analysis of a sub-sample explored discourse and reporting strategies employed to reflect media representations.
Results: We identified 351 articles issued in 41 different publications (inc. dailies, women's magazines, business and sports press), with a mean per day of 5 articles on cancer (min=0; max=20; SD=3.5) and 2 on dying (min=0; max=9; SD=1.8). 40% of the articles had <180 words and only 14% had more than 1000 words. 37% reported research (mainly new treatments) and statistics, 27% were on policy developments and 21% on fundraising events. In depth health information (7%) and discussions on death and dying (1%) were rare. *Palliative care* was only mentioned in 11/351 articles.
Conclusion: Discussions of death and dying, descriptions of palliative care services and research on symptom control are almost absent in the Portuguese print media. Ways to improve media coverage and implications for communication in health practice will be discussed.

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74. The Battle for Palliative Care during Wartime

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The recent military conflict in the northern part of Israel had a direct impact on our home based palliative care (PC) services. All patients were offered evacuation to safer areas. Despite the constant threat, many opted to stay at home and required PC provision. For the first time, our team had to provide care while under persistent threat and fear. We were faced with multiple new challenges and dimensions of care for which we were not trained. Travel in the region became dangerous due to unexpected missile attack. Occasionally, military restrictions did not permit travel to patients' homes. Medication accessibility was reduced due to limited pharmacy services and since local hospitals were constantly on standby for possible mass causalities, patients were discharged earlier or not admitted. For patients who were evacuated, remote PC was required. While eager to provide optimal support to patients and families, team members had to confront their own anxieties. Attempting to cope with the nearing death of their loved ones, family members also had to struggle with their own fears and sense of threat. Likewise, patients' fears and concerns increased due to the threat to their loved ones. Additional challenges included PTSD reactions among team members, patients and families. The presentation will highlight the many challenges we faced emphasizing the need to develop additional training and support for PC providers in countries facing similar situations.

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75. Level of unmet need and use of palliative care services in an Australian population

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Despite the existence of palliative care (PC) services in Australia, there is still a very heavy burden of physical and psychological symptoms, lack of awareness of approaching death and low expectations of service delivery. Our paper reports on the first comprehensive population-based Australian study to investigate factors that influence unmet needs of people in the last months of their lives. A retrospective telephone interview of 1,100 family carers of people who died of 10 conditions, considered by experts to be amenable to palliative care, provided information about demographics, symptom severity, functionality, concerns in the time before death and organisational barriers to service delivery. The majority of carers reported that their relative was in pain, two thirds thought he/she suffered in the three months before death, an alarming 17% had bedsores and 22% of carers did not realise that their relative was going to die. With such high levels of unmet need, it is surprising to learn that only 36% of carers said they needed more support from health services. Of those needing help, most wanted information about what might happen to their relative in the future and psychological support for themselves. Even though 86% of carers knew of PC services, less than half of those interviewed accessed PC. Our study provides much needed information about unmet needs of palliative care patients and their carers.

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76. Oral history: A tool for education, research and development in hospice and palliative care

David Clark

Lancaster University, Institute for Health Research, Lancaster, United Kingdom

Background: 'Oral history' is a little used tool in palliative care research but seems to have extensive potential.
Aims: This workshop will introduce participants to a programme of work in oral history relating to the global development of hospice and palliative care that has been underway for the last dozen years under the leadership of Professor David Clark and is now located at the International Observatory on End of Life Care at Lancaster University, UK.
Methods: 1) To outline the current extent and range of the oral history collection that has been assembled 2) To describe the methods of interviewing, recording, verifying, archiving and analysis that are employed 3) To illustrate how the archive can be used for education and research and as a tool for development 4) To introduce participants to three recent exhibitions and associated publications that have been produced from the archive and which will be displayed in the workshop.
Expected outcomes: 1) A raised awareness of oral history as a form of research practice 2) Increased understanding of how oral history has been used to illuminate the development of hospice and palliative care 3) An initial experience of oral history methods 4) Insight into how oral history might be used as a tool for education, research and development in hospice and palliative care.

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77. An oral history of palliative care in Germany and Austria

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Although it is rather short, the history of palliative and hospice care in Germany is essential to understanding the current situation, as well as to shape future developments. This project aims at collecting stories and gaining insight into the history of hospice and palliative care in Germany from the perspective of those who were involved. The project ties into the International Hospice History Project, hosted by the International Observatory on End of Life Care, Lancaster (D. Clark). First results of the ongoing project as much as methodological aspects will be presented. The research approach is oral history, and data generation consists of about 80 qualitative narrative interviews focussed on the biographies of hospice pioneers in Germany and Austria. Sampling characteristics include regions, age, role and the professional background of the pioneers. The interviews were recorded and transcribed verbatim. Analysis follows several coding procedures along central issues. First results show that there is not one history, but rather multiple histories which have shaped the current hospice and palliative care field/landscape in Germany. Not surprisingly, there is a certain amount of tension in the current debate, which reaches back to the roots of the issue, e.g. relating to professions, confessions and civic movements. In light of this, current strategies aimed at standardising the concepts have to be reconsidered.

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78. Opioids - how to rotate

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Cancer patients in pain may not respond to increasing doses of opioids because they develop side effects before achieving acceptable analgesia, or the analgesic response is poor, in spite of rapid dose escalation. Opioid rotation or switching may significantly improve the balance between analgesia and side effects. Although opioids have no known ceiling effect associated with their dosing a more liberal use has resulted in clinical reports of very high opioid doses causing new forms of side effects, the so-called opioid induced neurotoxicity. Oral morphine is widely used and remains the opioid of choice for its familiarity, availability and costs. For that reason most opioid rotation studies go from morphine to alternative opioids. In these cases clinicians should be skilled in using alternative opioids. According to available data, opioid rotation will result in clinical improvement at least in more than 50% of patients with chronic pain presenting a poor response to one opioid. Despite the favourable effects reported with opioid rotation, data are are mainly based on open studies, most of them retrospective or small case series. Unfortunately, in the setting of uncontrolled pain in the presence of side effects it is difficult if not impossible to conduct randomized controlled studies. Opioid rotation is becoming a popular approach, although data on the use of this practice are poor and difficult to determine. Having these circumstances in mind we will also address the pharmacology of opioids, which is mandatory to understand and practice opioid rotation.
Reference: Mercadante S and Bruera E. Opioid switching: A systematic and critical review. Cancer Treat Rev 2006; 32: 304-315.

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79. Emergencies in Palliative Care

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Introduction: Emergency situations (ES) in patients with advanced terminal disease can be extremely distressing for patients, caregivers, and health care personnel. Common emergencies to be addressed may be associated with acute pain, compression syndromes, hypercalcaemia, dyspnoea, seizures, acute urinary and bowel obstructions, massive haemorrhage, and other syndromes due to advanced malignancy.
Results: We surveyed and assessed the quality of physician-delivered care in inpatient hospices in the state of North Rhine Westphalia. About 9% of the physicians felt to have deficits in dealing with ES. 58 of the surveyed physicians (45%) reported to be annually involved in 1-3 ES; 6% in more than 10. 37% of the ES were related to malignant disease, 26% to side effects of drug treatment and 11% were unrelated to the underlying advanced disease. 86% of the physicians reported to have clear standards for ES in their hospices.
Conclusion: The term "emergency" applies to acute and fearsome, possibly life-threatening situations. However, there is no international consensus on a definition of ES in palliative care. Some principles, however, for the management of ES are widely accepted and include respect for the patient's wishes and early documentation of wishes for probable ES. In many cancer patients, these can be anticipated, and patients, carers and professionals can plan ahead to minimise distress. Clinical scenarios will be addressed in this session.

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80. The role of religion in palliative care

Michael Wright

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Permeating the definitions of religion is an acknowledgment of its integral place in human culture: a phenomenon which focuses on that which is sacred and unites believers in a moral community. For a large proportion of the world's population, religion is a vehicle through which individuals encounter the mysteries of their life; their calling to be members of their family and their world; their understanding of suffering, and the ways in which death is confronted and managed. In this scenario, transitions figure prominently, not least the transition from health to illness and life to death. Palliative care inhabits this space and recognises both the context and perspective that religion provides for its devotees, whether they are patients, significant others, health care workers, or members of the wider community. For patients: the juxtaposition of faith and suffering may promote a sense of identity or connect with a code of conduct, a group of values or a spiritual leader. It might also effect a coping strategy or the maintenance of hope - for spiritual re-birth or translation to an after-life - when hope for a cure has passed. For health care workers: religious beliefs have been variously identified as a source of motivation or sense of calling; a prompt towards redemption through good works; or a sharing of the brokenness of humanity in the presence of God. These factors are evident in the daily lives of those caught up in the palliative care experience, who subscribe to different religious traditions, located in disparate regions of the world.

81. The role of religion in palliative care

Piotr Krakowiak

Hospice Foundation, Education, Gdansk, Poland

With the growth and development of palliative care, interest in religion, and spirituality seems to be growing. On the other hand commentators on the history and development of hospice care can appear inclined toward a viewpoint that sees something lost in recent years from the original concept, pronouncing the thesis concerning the secularization of hospice (Clark, 2001). Apart of the historical dimension current research and clinical practice confirm that terminally ill patients and their families often get strength and hope from their religious belief system and their spirituality. During times of illness and crisis people may find that their spiritual needs increase. Attention to religious and spiritual needs can contribute to an increased quality of life.
Spirituality can be defined as whomever or whatever gives one a http://eapc2007-abstract.blaguss-congress.hu/%5C%22http:/cancer-research.umaryland.edu/transcend.htm%5C%22transcendent meaning in life. This is often expressed as religion or relationship with God, but it can also refer to other things: nature, energy, force, and belief in the good of all. Spirituality is important during all phases of one's health and illness, but spiritual and religious factors play an especially prominent role in a patient's experience with terminal illness, the dying process and death (Puchalski, 1999).
Religion is the relationship between an individual and God, characterized by belief in, reverence for, and desire to please that God. Patients with religious faith are less likely to have unmet spiritual concerns if their religious needs are met. In the palliative care setting, a person's faith, no matter how strong or weak, will influence, and be influenced by, everything they experience as death approaches (IAHPC, 2004).

82. A Mew Model and New Resources for Teaching Pediatric Palliative Care

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The Initiative for Pediatric Palliative Care (IPPC), one of the most comprehensive pediatric palliative care programs in the United States, has developed 25-hours of instructional material for physicians, nurses, and other health professionals serving children with grave illnesses and their families (see www.ippcweb.org). The educational strategies were informed by two years of research with families and clinicians and fieldtested in major children's hospitals, including ones affiliated with Harvard Medical School, Johns Hopkins,and the University of Pennsylvania. Spearheaded by Education Development Center, Inc., a nonprofit organization, the program is cosponsored by the National Association of Children's Hospitals and Related Institutions, the New York Academy of Medicine, and the Society of Pediatric Nurses. The membership association of the chairpersons of all pediatric departments in all U.S. medical schools peer-reviewed the materials. The IPPC team developed an innovative training model, in which parents who have experienced the death of a child, serve as co-faculty. Approximately 600 health care professionals have been trained. This session will describe the research base, educational strategies, and training approach, drawing lessons for other institutions wishing to institute pediatric palliative care education. Special attention will be given to the examining the cross-cultural relevance of this approach.

83. PhD education - a European perspective

David Clark

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

Across Europe academic institutions have differing norms and traditions as to what constitutes the degree of PhD. In recent years, new ideas about the 'professional doctorate' have begun to take hold in some of the applied professions (from education to engineering). Such doctorates are designed to equip graduates for high level leadership roles in their chosen profession. They include taught elements as well as research, plus practice-based learning and reflection. They place a high premium on evidence synthesis and knowledge management as well as personal development and resilience. In this session I shall attempt to open up a discussion about the potential for a European professional doctorate in palliative care.

84. See page 71

85. See page 72

86. Beyond Words - making relationships in unique ways

Nigel Hartley, Lars Bjorklund, Peter Strang

ST CHRISTOPHER HOSPICE, London, United Kingdom

Over the years - hospices and Specialist Palliative Care Units have championed a number of supportive therapies and activities for patients and familes under their care. Reasons for this have included the fact that when people are facing death and dying and all that this brings, we need to think creatively as normal channels of communication and expression diminish either due to illness or emotional paralysis. This forum brings together a number of experts in the field to present and discuss a number of ways which have proved useful in supporting patients and families as they face issues around end-of life. Case studies and material will be presented for discussion and participation from the audience will be required in the form of dialogue and debate around the issues raised. there will be a focus on a lack of evidence base around such work and different evaluation paradigms will be suggested and explored for use in the future.

87. Pet dogs a genuine support in existential crises

Peter Strang

Karolinska Institute, Stockholms Sjukhem Foundation, Research and Development Unit, Stockholm, Sweden

Companion animals bring a lot of joy to their owner's and the relationship may be deepened at times of hardship. During this lecture I will describe results from an in-depth interview study with 20 severely in cancer patients in palliative home care. The interviews focused on the support and new relationship with their dog, as they were diagnosed with disseminated cancer. The analysis revealed four main categories: 1) psychosocial support 2) communication 3) motivation, and 4) existential support.The three first categories were expected: most dog owners, healthy or not, normally describe their dogs in words such as friendship, loyalty and an object of love. They communicate with them and the dog is a motivator for walks and constitutes a "door opener" for conversations with new people. However, these terminal cancer patients also described a deepened relationship. To feel needed and acknowledged, despite a severe illness created meaning in a trying situation. When feeling existentially abandoned, their dogs were the best available support, as they were experts on interpreting body language. Certain issues and experiences were too delicate to share even with family members and only their dog was a good and safe enough listener in such situations. The lecture will be exemplified by case reports of how the dog even relieved acute death anxiety.

88. Silence, a language beyond words

Lars Björklund

Sigtuna foundation, , Sigtuna, Sweden

Silence, a language beyond words
A man wanted to see me. He was very ill and wanted very much for me to visit him. When I arrived he hardly said anything. At one occasion I asked him:

- Is it so that you have thoughts and feelings that you don't tell anyone?-Yes, he answered. -Would you like to tell me?-No, I'd like to keep them to myself, was his answer. When I left him he said:-I'd like for you to come back.

Sometimes it is completely silent in the conversation room, and nothing is said, but the silence carries and lifts. It can be hard to have the courage to wait in the silence, and sometimes you have to exert yourself to the utmost to keep your own words in. But then after a while the conversation picks up, and it is as if though there never was a pause. Often it is more important to be quiet than to speak. We can share knowledge without actually having to say it out loud. But we need to meet to state this. We are together, but do not speak of what we already know, and we ask no questions about what we don't know. Certain things in life are very painful to speak of and the words we use can sometimes cause misunderstandings. The silence, on the other hand, can give room for the real story, and the silent understanding can sometimes reach much deeper than all words.

In the story of the very ill man, it turned out that my visit was meaningful even though he didn't want to talk about his innermost thoughts and feelings. There was a pride and strength in him which I was not allowed to take from him. An insight that the most difficult parts of life you are forced to bear alone. No one else can ever carry the burden of my life. Yet, it can be meaningful that someone knows I am carrying this burden myself, someone who shares the very insight and respects my silence and accepts me.

89. Genetic markers for opioid responses - Representing the EPCRC group

Frank Skorpen

Faculty of Medicine, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Trondheim, Norway

The talk will provide an overview of the goals and ongoing activities within WP1.1 of the EPCRC project. The primary aims all to identify genetic markers able to predict opioid responses in pain treatment.

The available evidence of genes and genetic polymorphisms that influence opioid responses is currently too sparse to be useful in practical pain management. An important goal is to identify the majority of genes relevant for opioid responses, as well as genetic variation associated with these genes that may contribute to interindividual variation in opioid responses. Candidate genes are currently being extracted by thorough review of the literature, and experimentally by assessing the changes in global gene expression caused by morphine exposure *in vitro*, using relevant model systems. Our findings so far will be presented. In the next phase, candidate genes will be evaluated with regard to informative genetic markers, using information from publicly available SNP databases and the human HapMap project. In addition, SNPs associated with differences in opioid responses will be identified from whole genome SNP scans (500K Affymetrix SNP arrays), using a "pooled DNA" approach on groups of individuals classified as "responders" and "poor-responders" in large patient Cohorts. A first version "opioid response SNP marker set" will be constructed and tested on patients. Further refinement and validation need to be planned for future clinical controlled studies.

90. Pain assessment: How can the clinical tools be improved? Representing the EPCRC Research Group

Marianne Jensen Hjermstad

Division of Oncology, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Oslo,Norway, Norway

Background. Detailed pain assessment is a prerequisite for optimal pain treatment. This is not routinely performed in practice, because many tools are burdensome to use and the content, format and applicability limit their usefulness in PC, resulting in inadequate pain treatment. There is little international agreement on how to classify and measure pain in clinic and research.
Relevance. The traditional paper- and pencil-based assessment mode is out-dated, and it is time to take advantage of modern computer technology, i.e computer adaptive testing (CAT) or case-based reasoning (CBR). This reduces respondent burden, selects appropriate items to the given situation, incorporates other medical and clinical data with the assessment, provides rapid, more precise estimates and recommendations for treatment based on the data entered.
A comprehensive pain assessment consists of several dimensions other than the patient's subjective feeling and pain intensity: ie. disease and treatment-related variables, demographics, ethnicity, history of abuse, the genetic/inter-individual variability in pain perception for which the understanding is inadequate. Only a few classification systems for cancer pain exist, but a plethora of assessment tools.
Methods. It is time to develop a software solution for pain classification and assessment for practice and research. This can only be achieved through a translational approach, uniting basic scientists, clinicians, PC experts and computer technicians. The content of the software will be derived through literature searches, best practice, clinical studies empirical studies, use of existing tools/classification systems and international consensus.
Status. A first version of the program is tested, the second is ready for empirical testing in 4-6 months. Parallel work is going on in order to generate the optimal software.

91. Guidelines for pain: the main challenges from the EPCRC a 6th EU framework research project

Augusto Caraceni, Alessandra Pigni

National Cancer Institute of Milan, Palliative Care Department, Milan, Italy

The European Palliative Care Research Collaborate is a multicenter consortium funded by the 6th EU framework and includes several projects to improve the assessment and management of cancer pain. The work package on pain guidelines has been considering two main challenges in designing clinical guidelines in cancer pain:
1- Updating the EAPC guidelines on morphine and alternative opioids administration for cancer pain
2- Preparing a set of recommendations that summarize the needs of cancer pain patients world wide starting from the WHO method for cancer pain relief as released in 1986 and (2nd edition) 1990
To accomplish task n. 1 an EPCRC method for developing guidelines has been designed and the workpackage on Pain guidelines prioritized the update of EAPC opiod morphine guideline as the first step in its work plan:
a) The guidelines development will follow an evidence-based and consensus method
b) Three subsequent levels of expert groups have been appointed to cooperate with the different steps of literature reviewing, evidence grading, formulating and assigning strenght to recommendations.
c) key points defining the list of considered recommendations have been identified and will be discussed during the conference to reach wider consensus

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92. Pain in children's cancer - new strategies

Boris Zernikow

Children's Hospital Datteln - Witten/Herdecke University, Vodafone Foundation Institut for Children's Pain Therapy and Pediatric Palliative Care, Datteln, Germany

Parents and medical professionals from European and North-American treatment centres report that many children and adolescents with cancer or other life limiting conditions suffer from insufficient pain control during their end-of-life phase. A contributing factor to this undertreatment may be the lack of pediatric specific drug formulations for many of the strong opioids or the lack of sufficient technical devices like patient controlled analgesia (PCA) pumps. The recently introduced fentanyl transdermal therapeutic system (TTS) with a drug release rate of 12.5 μg/h and the buprenorphine TTS with a drug release rate of 5, 10 or 20 μg/h matches the lower dosing requirements of cancer pain control in children. It is likely that fentanyl and buprenorphine TTS will be used in pediatrics with increasing frequency. We compiled the published evidence on pediatric applications of this drugs formulation in order to help physicians get the most benefit from its use. Results will be presented. In the last week of life the daily opioid dose in some children is highly variable and the use a fentanyl or buprenorphine TTS might be inadequate even if additional fast acting opioids are given. Whether patient-controlled analgesia (PCA) might be a useful therapy option in those patients will be discussed in detail.

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93. The Role of Paediatric Palliative Care in facilitating Resilience in Children infected with HIV in a Resource Poor and Multi-cultural community

Joan Marston, Rebecca Semppe, Olga Mohlahloe

Hospice Palliative Care Association of South Africa, Paediatric Palliative Care, Cape Town, South Africa

Children infected and affected by HIV and AIDS in resource-poor setting in Mangaung, Free State, South Africa, face many diverse problems and require coping skills to make sense of the situation, and grow and develop despite the trauma associated with life-limiting illness, extreme poverty, orphanhood and multiple deaths.

A study carried out with 65 children and primary caregivers identified common factors associated with resilient children. Liaising with the Department of Education, a training programme with multi-lingual materials, was developed for teachers, pastors, primary caregivers, and NGOs working with these children to enable them to identify risk factors and provide a supportive environment to promote resilience and help children cope with present and future trauma, and to enable them to work as part of a multi-disciplinary palliative care team. Culturally - acceptable training was also developed for grandmothers and older siblings caring for these children . Through 3 case studies the impact of a resilience-promoting programme for children and primary caregivers that includes training, support groups, self-esteem strengthening and activities, will be identified.

Preliminary results show that interventions that strengthen the child's inner personality factors can be implemented in a culturally sensitive and acceptable manner, even in extremely resource poor areas.

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94. END-OF-LIFE IN NICU: DIFFERENCES BETWEEN DEATHS OCCURRING NATURALLY AND DEATHS FOLLOWING A MEDICAL DECISION

Denis Oriot

University Medical Center, Neonatal intensive Care, Paris, France

Aim: To compare the populations of neonates for whom death occurred naturally or followed a medical decision of withdrawal. **Methods:** Retrospective study over 3 years of all deceased neonates in NICU. Analysis includes perinatal and parental variables. Two groups are formed: M (death after medical decision) and N (natural death). **Results:** 68 neonates are included, 34 in each group. Gestational age is identical in both groups: M = 29.5 ± 5.2 weeks vs. N = 30.5 ± 5.3 weeks (NS). 12% of neonates receive CPR in delivery room (9% in group M vs. 15% in group N, $p = 0.04$). Periventricular leucomalacia is more frequent in group M ($p = 0.0004$). The first visit of mother ($p = 0.0002$) or father ($p = 0.001$) occurs later in group M than in group N. But in group N, 30% of mothers ($p = 0.003$) and 24% of fathers ($p = 0.002$) have never seen their child before death vs. none in group M. The number of visits of mothers is identical in both groups, but greater in group M for fathers ($p = 0.02$). Almost all parents of group M meet a paediatrician vs. 40% in group N ($p < 0.001$). The age of death is 22.3 ± 5.3 days in group M vs. 9.3 ± 15.6 days in group N ($p = 0.008$). 48% of parents of group M are with their dying child vs. only 9% in group N ($p = 0.01$). **Conclusion:** Parental presence is less important in group N, then decreasing medical and psychological affordable support. This may lead to a difficult mourning process because of lack of information and contact with reality. These results favour reinforcement of support before and after a natural death of a neonate.

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95. The palliative care needs of Australian children who die from cancer and their families.

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Background In Australia, there is increasing recognition of the need for the development of appropriate paediatric palliative care services. The needs of children with life threatening conditions such as cancer and their families are unique and require special consideration to enable the appropriate delivery of multidisciplinary care that aims to relieve suffering and improve quality of life.
Aim To determine the palliative and supportive care needs of families of children experiencing incurable cancer.
Method Two-phase quantitative and qualitative study.
Setting Tertiary paediatric oncology units in four Australian states.
Participants 112 parents
Key study findings Children with life-threatening and/or progressive illnesses prefer to remain at home for care whenever possible. Families are: significantly affected physically, emotionally, mentally, financially; need ongoing multidisciplinary support throughout the trajectory of their child's illness; parents require clear, straightforward information about their child's condition, treatment and long term outcome; require education and practical assistance with caring for their other children; require access to both in-home and residential respite care. Siblings have specific needs and are sometimes burdened with the care of their brother/sister. Improved coordination between community and hospital-based services is required. There is a need for increased leadership to organise inter-agency collaboration, and for a case management approach for families. There is a lack of recognition of the caring role, with many families feeling isolated and "battling on".
Conclusion Core elements have been identified for consideration in the future development of an integrated palliative and supportive care services.

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96. Caring for life: The palliative and supportive care needs of children and families in Western Australia

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Background: Supportive care services for children in Western Australia (WA) are underdeveloped. There is a recognised need to develop evidence-based paediatric palliative care services.
Aim To obtain feedback from families of children receiving palliative and supportive care about their care needs in hospital and in community settings.
Design Two-phase quantitative and qualitative study.
Setting WA.
Participants 134 parents and 20 service providers.
Results Analysis indicated the concept of palliative care is poorly understood by health professionals and by parents. Many families are affected emotionally, financially and physically by the burden of caring for children with life threatening or chronic conditions requiring complex care at home. Parents indicated the need for clear and honest information about their child's condition and prognosis throughout the trajectory of illness and perceived this had been lacking. Families required financial and practical assistance with providing care from their children at home. Parents also wanted more practical resources and information to assist with the management of their child's nutrition and pain, as well as support for their other children. The level of respite (in home and residential) was perceived to be insufficient and inequitable. Parents also required access to, and advice from, multidisciplinary health professionals when caring for their child at home. There was a perceived lack of coordination between community services and the hospital. **Conclusion** Care for children and their families must be coordinated by a multidisciplinary team in consultation with children and their families, and linked and integrated with the treating hospital in collaboration with community services. More inclusive criteria is required for community services including practical aids and respite care. Key elements for care models will be presented.

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97. Dying in old age: how illness trajectories influence place of death

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Background Despite extensive palliative care services large numbers of older people are admitted to hospital to die with minimal access to these services. In reality, little is known about the end-of-life trajectories of older people, and how palliative services could meet their needs. This paper describes the first of a two phase study, funded by Rotherham PCT, which sought to investigate the end-of-life trajectories of older people dying in hospital. **Aims** To describe end-of-life trajectories of older people dying in hospital **Methods** A retrospective case-note review of hospital inpatients aged 65 years and over, who died between October 2004/March 2005, was undertaken. Ethical approval was obtained. 190 case-notes were randomly sampled. Data were coded and entered on to SPSS. Deaths were allocated to one of five 'death trajectories' (Lunney et al 2002). Descriptive and comparative analysis was undertaken to determine patterns and relationships between the different death trajectories.**Results** 54% were over the age of 85. The main diagnoses were Ischaemic Heart Disease, Cerebrovascular disease and Multiple Pathology. 35% were categorised as Frail Older (FO); 28% Organ-System Failure (OSF). 50% lived at home prior to final admission; 35% in care homes. 24% of FO; 45% with OSF died within 7 days of admission. 50% of FO; 37% with OSF died after 1 month. **Discussion**These findings identify that the 'oldest old', considered to be FO or with OSF, are admitted to hospital and die within 1 week or 1 month following admission. This raises issues about the nature of palliative care that older people receive at home and in care homes. **Conclusion** Interventions to reduce these admissions and offer more appropriate end-of-life care are needed and could be targeted at care homes and at care professionals' awareness of end-of-life care trajectories of these two 'types' of older people.

98. Opening the door for older people to explore end of life issues.

Jane Seymour[1], Amanda Clarke[2]

[1] *University of Nottingham, School of Nursing, Nottingham, United Kingdom*
[2] *Sheffield Hallam University, Faculty of Health, Sheffield, United Kingdom*

Aim: to understand the concerns of older people about end-of-life care and assess the utility and acceptability of information materials. **Objectives:** to work in safe environment with older people to explore issues about end-of-life care; to evaluate a booklet developed in a pilot study. **Methods:** a diverse sample of 74 participants was recruited using snowball sampling and invited to attend one of four workshops in the UK. A booklet 'Planning for Choice in End of Life Care' was used in small group work. Fieldnotes were used to record each small group discussion. Framework analysis was used to develop a thematic framework to organise data. Participants evaluated the booklet and the workshop sessions using a self complete questionnaire.
Findings: Participants raised issues in six areas: perspectives on talking about the end-of-life; raising concerns with family members; the importance of spirituality; after death: bereavement and funerals; good and bad care at the end-of-life; concerns and fears about death and dying. 60% returned a questionnaire, and all strongly agreed or agreed that the event was worthwhile. 97% strongly agreed or agreed that their concerns were covered. One person said that an issue of importance to him was not addressed.
Conclusions: this study highlights: the heterogeneity of older people's concerns about end of life care. It suggests that many find it useful to share views. It demonstrates one means of enhancing public understanding in a sensitive field.

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99. End-of-life care for heart failure in Acute Care for Elders Unit: a retrospective case series

Vito Curiale, Camilla Prete, Stefano Trasciatti

E.O. Ospedali Galliera, Dipartimento di Gerontologia e Scienze Motorie - Struttura Complessa di Geriatria, Genova, Italy

Aim: to observe the effects of end-of-life care for terminal heart-failure patients in an Acute Care for Elders (ACE) Unit. Materials and methods. We reviewed 19 consecutive patients who died of heart failure over a 1-year period. We recorded age, length of stay, multimorbidity, communication disability, symptoms, use of cardiovascular, support, palliative or sedation therapies, and their impact. Results. Age 89.63 yrs (mean), hospital stay 12 days, severity and comorbidity indexes (13-item Cumulative Illness Rating Scale) 2.21 and 3.63, communication disability score 3 (0-4). 14 patients had symptoms. All patients received antithrombotics, 13 parenteral hydration, 10 furosemide, 9 vasoactive drugs, 3 ACE inhibitors, 3 beta-blockers, 3 digoxin, 3 nitro-derivates. 11 patients underwent palliative therapy subcutaneously (mean 3.36 days). All received morphine hydrochloride (mean 17.55 mg/day), 9 haloperidol (2.89), 8 scopolamin butylbromide (90), 5 midazolam (8.5), 2 metoclopramide (35). Dyspnoea was controlled in 9 out of 13 patients, pain in 2/2, agitation in 5/6, nausea and vomiting in 2/2 and death rattle in 4/6. 4 patients were terminally sedated with an association of morphine (mean 22.5 mg/day), midazolam (10) and haloperidol (3.5), which was effective in all cases. Conclusions. Low-dose palliative drugs controlled the symptoms in most of the oldest-old patients dying from heart failure in ACE Unit. Terminal sedation was effective and needed a slight increase in doses.

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100. Improving End of Life care in care homes in England: An evaluation

Frances Badger[1], Collette Clifford[1], Keri Thomas[2], Gillian Plumridge[1], Alistair Hewison[1], Karen Shaw[1]

[1] *University of Birmingham, School of Health Sciences, Birmingham, United Kingdom*
[2] *National Clinical lead, NHS End of Life Care Programme, Department of Primary Care and General Practice, Birmingham, United Kingdom*

Background 20% of deaths in England occur in care homes; and good End of Life care is vital. The Gold Standards Framework (Thomas 2003) is used extensively to support optimal primary palliative care in the UK. It has been adapted into the GSFCH Programme which supports care homes. Phase 2 of the GSFCH programme involving 95 homes was evaluated.
Aim. To evaluate the introduction of GSF into care homes.
Methods 1. Quantitative survey data before GSFCH introduction and following the programme. 49 homes completed pre and post surveys. 2. Case studies (10 homes) enabled in-depth qualitative exploration with residents, families and staff of relevant issues.
Results Quantitative data: homes demonstrated significant improvements in the following indicators; Reduced number of residents with hospital admissions; Discussion with residents of plans for resuscitation; Number of homes carrying out advanced care planning; Number of homes with a coordinator for End of life care; Ability to meet residents' spiritual needs. Case study data showed GSFCH improved communications between residents, health practitioners and care home staff. Reasons for homes failing to complete GSFCH and suggested improvements have been identified.
Conclusion GSFCH has potential to improve end of life care for residents and reduce admissions at the end of life. Improvements have been integrated into further phases of GSFCH programme, to secure greater impact and successful implementation

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101. Analysing End of Life care in care homes: After Death Analysis tool

Keri Thomas[1], Frances Badger[2], Collette Clifford[2], Karen Shaw[2], Alistair Hewison[2]

[1] *National Clinical lead, NHS End of Life Care Programme, Department of Primary Care and General Practice, Birmingham, United Kingdom*
[2] *University of Birmingham, Department of Primary Care and General Practice, Birmingham, United Kingdom*

Background Over 400,000 older people live in UK care homes and most die there. The Gold Standard Framework in Care Homes (GSFCH) is a programme used support high quality end of life care. (Thomas 2003). As part of the evaluation of the GSFCH an "After Death Analysis" tool (ADA) was developed to examine the impact of GSFCH on end of life care.
Aims of the ADA were to;
1. Gather quantitative data to provide details of deaths including: location; crisis hospital admissions; and advanced care planning.2. Compare End of Life care pre and post implementation of GSFCH3. Determine the value of using the ADA Tool to audit end of life care.
Methods ADA was completed by nurses who provided data on five deaths before, and five deaths after, completion of GSFCH. Descriptive analyses produced using SPSS.
Results 44 homes completed pre and post GSFCH ADAs. Data revealed positive changes in end of life care following GSFCH implementation, indicating success of GSFCH in improving End of Life care. More residents died in the care home rather than hospital following GSFCH.
Conclusion An accurate picture of end of life care is necessary to ensure care planning and policy are based on detailed information. Further development of the ADA is needed. Initial findings indicate it is a useful method for monitoring end of life care.

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102. Pastoral care of the elderly: do clergy have an attitude problem?

Peter Speck, Marie Mills, Peter Coleman

Southampton University, Health Psychology, Southampton, United Kingdom

Aim: Do knowledge & attitudes to personal ageing influence ability to engage with spiritual needs of elderly people?
Palliative Care: Recent work (Coleman,Mills & Speck 2002/06) indicates many older people with unmet spiritual needs following bereavement or illness, and feel ignored by clergy. Given increased age of patients entering palliative care and in need of spiritual support the ability to engage positively with the elderly is of increasing importance.
Method Anglican clergy completed 3 questionnaires: Knowledge of Ageing (Kline 1990), Attitude to Ageing scale (O'Hanlon 2002/4), Southampton Inventory of Pastoral care-Older People (Speck,Mills 2005). Sub group was interviewed in depth.
Results 141 (76%) returned questionnaires. 84 men and 57 women. Mean age 56 (sd 9.1) Years in ministry = 2-50. Knowledge mean score 63 (sd 9.73) only marginally better than those for general population. Clergy attitudes showed average anxiety (cf O'Hanlon's cross cultural group) for physical aspects of ageing, but more negative for social and psychological effects. Especially for psycho-social transitions associated with personal loss - status, role, housing at retirement. Training received was patchy.
Implications: Adressing mortality, reducing death anxiety, important for health professionals in palliative care. Addressing attitudes to personal ageing may enhance ability of clergy to engage positively with spiritual needs of elderly.

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103. The Gifts of Grief

Nancee Sobonya

Shining Light Production, Oakland, United States

The Gifts of Grief
This 90-minute presentation explores the nature of grief, using the educational documentary *The Gifts of Grief* (produced and directed by the presenter) as a teaching tool to identify the physical, emotional and spiritual affects of grief, the resources that help us through our losses and discover for ourselves the extraordinary opportunities our own losses may reveal.

The Gifts of Grief is a compelling documentary that explores how seven remarkable people embrace their pain, learn to live with their loss and now engage in life with more compassion, courage and awareness. The personal and moving stories include author, Isabel Allende; Reverend Cecil Williams; Zen Monk /Vietnam Veteran, Claude AnShin Thomas; filmmaker, Lee Mun Wah, celebrate and inspire healing and transformation. The film invites us to open to pain and reminds us of the preciousness of life.
OBJECTIVES:
1) To demonstrate and validate that grieving is a natural, healthy process.
2) To identify the physical, emotional and spiritual affects of death and grief.
3) For participants to identify the resources that help them through their losses.
4) For participants to discover gifts emerging from their own losses.

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104. "to care at home: a journey through the experience"

Massimo Melo, Stefania Bullo, Teresa Sellan, Sofia Rasini

A.V.A.P.O., VOLOUNTARY ORGANIZATION, MESTRE-VENICE, Italy

Assisting a terminally ill patient at home is something any one of us might experience. While caring for such patient, family members have to cope with difficulties that may arise in their life for the first time. These critical moments can be overcome with one's own interior strength coupled with the help of the Local Health Service and the social support network. Local volunteer associations can provide such aid; helping families with organizational, social, spiritual, and financial support and, in some cases, with very complex health care which may substitute or act in addition to the care provided by the Local Health Service. This emotional video relates several stories as told by family members, who narrate the painful experience of caring for their ill relative and reveal their approaches to important issues such as receiving a terminal diagnose, communicating with the patient, choosing where to be treated (home vs. hospital), problems related to home caring, maintaining a good quality of life for both the patient and family, ethical and spiritual questions. We feel that conveying these experiences can help promote the possibility of caring at home for terminal patients, as well as advancing a sense of solidarity.

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105. Team working - fulfilling or frustrating

Peter Speck

King's College London, Palliative Care, Policy & Rehabilitation, London, United Kingdom

Effective teamwork within palliative care enables a wide range of skilful people to work together effectively to provide high quality holistic care. Different styles of working have evolved, dictated by vision, funding, availability of skilled people, and changing demands from patients and purchasers of service: the lone worker in the community, a small team within a large acute hospital, the multi-professional association of professionals, and the interdisciplinary specialist team. Key to effectiveness is commitment to a common task, trust and respect for each other's discipline, attention to the interpersonal and inter-team dynamics and an ability to accommodate to changes in demand and from the society and larger organisation to which they relate (Speck 2006). Shared values are important. The experience we have at work will depend to a large extent on how these values blend to form a team culture and match, or clash, with our own personal values. Teamwork can enable people to work toward common goals, pool expertise in the best interests of the patient and the service and provide a forum for problem solving - ethical and otherwise. Teams can share the burden of the work, contain anxiety, and provide space where people can grow and develop.We must increase our understanding of the things that happen within teams in order to develop in healthy and creative ways, to recognise when there are difficulties and have strategies to deal with them. This presentation will explore some of the joys and difficulties associated with team working in the context of palliative care, with particular reference to formation, leadership, authority, power, envy and rivalry.

Ref: Speck P ed. (2006) *Teamwork in Palliative Care: fulfilling or frustrating. OUP*

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106. SOURCES OF STRESS AND REACTIVE BEHAVIOURS IN THE PC TEAM

Oscar Corli [1], Maria Giulia Marini [2], Massimo Pizzuto [3], Giorgia Andreoli [4]

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In 2005 the first National Investigation aimed to evaluate the working quality of life of the PC team has been carried out in 78 Italian centers of palliative care. 344 operators, of both genders (F. 74%, M: 26%), with a mean age of 43,3 years (SD: +/- 10,0), composed by 30 % physicians, 40% nurses, 6% psycologists, 11% volunteers and 13 % other roles, partecipated to the study.The investigation has been leaded by O.I.C.P. (Osservatorio Italiano Cure Palliative: www.oicp.org) e I.S.T.U.D. (Istituto Studi Direzionali) Foundation.The main tools for investigation were:- an expressely set up questionnaire- a description, through methaphores, of the point of view of the interviewed people about the work equipe, and about patients and relatives.- analysis of the burn out degree through the Maslach Burnout Inventory- The free narration, implemented according to the Propp fairy-tales structure, of the creative, emotional and logical features of each own professional experience. The results springed out from this complex of sub-investigations strata allowed the definition of the professional and human picture of the operators in the palliative care team, the equipe working condition, the possible burnout, the positive and negative aspects evaluation referred to the professional experience: and, most important, the reason behind the choice of working and continuing to work in this field.

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107. When the team is limited

Daniela Mosoiu

Hospice, Education and Training, BRASOV, Romania

Palliative care aims to alleviate suffering and to offer comfort by addressing holistic the needs of patients and their relatives. This requires the joint expertise and work of several professionals and team work is recognized as one of the principles of palliative care. When it comes to developing countries and especially when there is the attempt to introduce palliative care into the public health system there are some challenges to face: team work is eventually seen as a consultation among same category of professionals, there is a strong hierarchical system with nurses usually subordinated to the doctors, position for social workers, psychologist are difficult to be accepted as part of the organization chart, there is a low staffing ratio, and volunteers have no place in state hospitals. As results palliative care models have been frequently created by NGO's outside the public health system. Recruitment of staff for these services is another challenge because there is no pool of trained staff available, the job is seen as emotional draining and there are no incentives for personnel working in this field. Frequently there are not defined, inside the countries, the minimum competencies for different staff working in palliative care and standards concerning staffing. Discussion of this challenges and adopted solutions in different countries will be presented

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108. RESUSCITATION IN PALLIATIVE CARE

MADELINE BASS

St Nicholas Hospice, Education and Training, Bury St Edmunds, United Kingdom

"Resuscitation as we know it today only started in 1960, however it is now the only thing which needs consenting against in healthcare today. There are many issues involved in making a resuscitation decision, which does not include asking the patient *when* resuscitation is likely to be futile. Such issues include legal and ethical issues, getting the patient's views if resuscitation may be successful (or asking the family carers what the patient would want, if they are not mentally competent at the time), Human Rights, quality of life, the patient's beliefs and culture, and overall expected success. Each decision is individual for the patient it involves and it is unethical for blanket policies to exist. Approaching such discussions with patients and family carers can be difficult but should be approached sensitively, and allow time for such a discussion to take place as well as allowing the patient time to share their own opinions. Although the National Council for Palliative Care so there is no need to discuss a resuscitation decision with someone for whom it is thought to be futile, the ethics of truth-telling and honesty mean that the overall treatment aims should be discussed so that everyone knows what will be happening.

Education and training is needed amongst manay healthcare staff to be aware that the patient should not be asked whether they want resuscitation if it is going to be futile. Although the resuscitation guidelines state that it is iportant to discuss each decision with the patient if they agree to, discussion should not be interpreted to mena asking he patient. No patient has a right to demand any futile treatment form a docotr, and no doctor is obliged to give it.

The only person who can leglally make the finalr esucitaiton decision if the doctor in charge of that patient's care at that time. This needs to be recorded in order to make it legal: a verbal message is not enough".

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109 . The End of Life Nursing Education Consortium (ELNEC) Salzburg Institute for Nurses in Eastern Europe

Betty Ferrell [1], Nessa Coyle [2], Patrick Coyne [3], Judith Paice [4], Mary Callaway [5]

[1] *City of Hope National Medical Center, Nursing Research and Education, Duarte, United States*
[2] *Memorial Sloan-Kettering Cancer Center, Nursing Research and Education, New York, United States*
[3] *Virginia Commonwealth University, Richmond, United States*
[4] *Northwestern University, Division of Hematology/Oncology, Chicago, United States*
[5] *Open Society Institute, New York, United States*

Research Aims: The ELNEC project (www.aacn.nche.edu/ELNEC) was initiated in 2000 in the United States, and has been very successful effort to improve palliative care through education of nurses. The ELNEC project is a Train-the-Trainers approach and has trained over 3100 nurses to educate their colleagues. .
Sample: In fall 2006 the ELNEC project, held its first international ELNEC Trainers conference in Salzburg Austria supported by the Open Society Institute.
Methods: The course included 39 nurses from 14 eastern European countries. The content of the ELNEC curriculum covers topics including palliative nursing care, pain, symptoms, grief, ethical issues, culture, communication, care at the time of death, and quality improvement
Results: The participants rated the course at 4.9 on a scale of 0= poor to 5= excellent in terms of overall effectiveness. Nurses represented roles in clinical practice and nursing education and each participant developed goals for implementing the education in their countries. Follow up support and evaluation is in progress. This presentation will present key findings regarding this international educational outreach and report on the implementation across these countries.
Conclusions: There are tremendous opportunities for international collaboration in palliative care education. Nurses are vital leaders in improving care for patients and families.

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110. The first Nordic Specialist Course in Palliative Medicine 2003-2005. Final evaluation of the course content and the impact of the course on students and on palliative care in their area.

Tove Vejlgaard [1], Juha Hänninen [2], Carl-Magnus Edenbrandt [5], Valgerdur Sigurdardottir [4], Stein Kaasa [3], Eva Thoren-Todoulos [5], Tiina Saarto [2], Lena Lundorff [1], Dagny Faksvag Haugen [3]

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[2] *The Finnish Association for Palliative Medicine, helsinki, Finland*
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[4] *The Icelandic Association for Palliative Care, Reykjavik, Iceland*
[5] *The Swedish Association for Palliative Medicine, Stockholm, Sweden*

Coordinated specialist palliative care is generally not well developed in the Nordic countries (Denmark, Norway, Sweden, Finland and Iceland), although the situation varies a lot.Palliative medicine has not been recognised as a specialty in any of the countries. In 2002 the first Nordic Specialist Course in Palliative Medicine was established as a joint venture of the Associations for Palliative Medicine in the five Nordic countries. The course content covers the theoretical part of the curriculum for palliative medicine from EAPC and APM, and the course lasts 2 years, consists of 6 modules, and takes place in the different Nordic countries. Only doctors who had obtained a specialty authorisation within a relevant clinical specialty were admitted. Each module was evaluated using Seth Long Course Rating Scale. At the end of the course students were asked to fill in two questionnaires concerning overall evaluation of the course content, their own learning outcomes, the impact the course had had on them as professionals, on their career, their experiences with research, their attitudes to research, and the possible impact on the development of palliative care in their country. Another questionnaire concerning position and career within palliative medicine, research activities and publications was sent to the students 1? years after endning the course.The overall evaluation of the course and the main results from the two surveys will be presented at the conference.

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111. The Association for Palliative Medicine (APM) Consensus Syllabus for Undergraduate palliative medicine

Paul Paes [1], Bee Wee [2]

[1] *Marie Curie Hospice, Palliative Medicine, Newcastle upon Tyne, United Kingdom*
[2] *Sir Michael Sobell House, Palliative Medicine, Oxford, United Kingdom*

Aim of study
The development of the APM undergraduate syllabus for palliative medicine.
Background
The APM produced a previous undergraduate palliative medicine curriculum in 1991. Since then a number of changes have occurred in medical education as well as palliative medicine. This new updated syllabus has been endorsed by the APM for use in undergraduate study.
Method
The syllabus was derived following a Delphi study carried out amongst experts in palliative medicine across Britain and Ireland.
Results
44 participants agreed to take part. 3 rounds of the Delphi study took place. Consensus (75% agreement) was achieved in over 90% of the outcomes. The new syllabus is broken down into the following sections: basic principles, physical care, psycho-social care, culture, language, religious and spiritual issues, ethics and legal frameworks. The learning outcomes identified are divided into those that are essential to achieve during undergraduate study, and those that are desirable.
Conclusions
This paper describes in detail the new APM undergraduate syllabus. The aim of this syllabus is to set out the learning outcomes that all students should achieve. It is left for individual institutions to develop their own distinctive curriculum. In addition learning outcomes are set for those institutions who are able to deliver more than the minimum level, for example through special study options.

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112. Evolution of the Subspecialty of Hospice and Palliative Medicine in the United States: The Role of Accreditation and Certification

Steven Radwany [1], Dale Lupu [2], Dorothy Moga [3]

[1] *Summa Health System, Palliative Care, Akron, United States*
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Hospice and Palliative Medicine was officially recognized as a subspecialty in the United States in 2006. How was official recognition obtained? What role did accreditation of training programs and board certification offered by the ABHPM play in achieving formal recognition?

In the decade leading up to official recognition, board certification by examination was offered by the American Board of Hospice and Palliative Medicine (ABHPM). By early 2006, there were more than 2,100 physicians who had achieved board certification. As formal training programs (fellowships) began to emerge, the need for accreditation of these training programs became apparent. Beginning in 2004, the ABHPM, in cooperation with the professional society, the American Academy of Hospice and Palliative Medicine, began to accredit training programs. A committee, the Palliative Medicine Review committee (PMRC), was appointed to adopt standards based on recommendations from the field and to apply these standards. Three accreditation rounds were held and a total of 32 training programs received accreditation. In 2007, the accreditation process will be taken over by the Accreditation Council for Graduate Medical Education (ACGME), the major US graduate medical education accreditating body.

Both PMRC accreditation and ABHPM board certification played key roles in setting standards for the field and preparing the way for formal recognition of the subspecialty in the US.

113. An Evaluation of an HIV/AIDS Palliative Care Education Strategy in Rural Uganda

Julia Downing[1], Esther Kawuma[2]

[1] *African Palliative Care Association, Kampala, Uganda*
[2] *The Mildmay Centre, Kampala, Uganda*

Aim of Study There is minimal literature on the evaluation of palliative care training in Uganda. The Mildmay Centre conducts a 1-year modular rural HIV/AIDS palliative care training programme through their mobile training teams. The aim of the study was to evaluate this training. **Method** The evaluation was based on a case-study design. Participants were drawn from 4 health facilities within a District in Western Uganda. Sources of data included observation, interviews, FGDs and research diaries. A meta-evaluation was undertaken using The African Evaluation Guidelines. **Results** Impact of the programme was seen at the patient and community, participant, health facility and district levels. An increase in access to care by PLWHAs was seen as stigma was reduced and the attitudes of health workers towards PLWHAs improved. Participants' knowledge and skills acquired through the training was recognised and they were used as trainers in the district. Participants found the training demanding and challenging with regards to working with the district officials, forming multi-disciplinary teams, and implementing their action plans. **Conclusion** Strengths and limitations of the evaluation were identified, along with recommendations for future evaluations. The evaluation demonstrated the programme was impacting on the provision of palliative care at different levels. Further work has been identified for future programmes, research and evaluation

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114. Bridging the gap between oncology and palliative care. Presentation of an interactive educational tool.

Detlef Von Zabern[1], Frank Elsner[2], Jon Loge[3], Marie Fallon[4], Xavier Gomez-Batiste[5], Daniela Mosoiu[6]

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[2]*RWTH Aachen University, scientific, Aachen, Germany*
[3]*University of Oslo, Behavioral Sciences and Health Research, Oslo, Norway*
[4]*Cancer Research UK, Palliative Medicne, Edinburgh, United Kingdom*
[5]*Institut Catala d'Oncologia, Palliative Care Service, Barcelona, Spain*
[6]*Hospice, Palliative Care, BRASOV, Romania*

The workshops on the project "Bridging the Gap Between Oncology and Palliative Care" are designed to give an insight into a broad interactive educational tool which is based on authentic patient films. The project contains nine patient cases with a total of 3,5 hours of film. The textual content comprising over 2000 printed pages has been reviewed by a multidisciplinary international advisory board and is officially recommended by EAPC and IAHPC for education in palliative care. Further educational materials are reviewer interviews and brief guides for use in daily practice. The state of the art educational concept, including didactical tools such as voting system, group work and role plays, has been successfully tested in 15 workshops. In the two sessions during the congress the project as such will be introduced, followed by a description of the educational possibilities and a short glimpse on two out of overall 60 topics. Further use of the course as educational tool and possible modes of cooperation with institutions, scientific societies and others will be discussed at the end of each session.

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115. Wound Care 1 - Practical Approaches to Palliative Wound Care

Frank Ferris, Rosene Pirrello

San Diego Hospice and Palliative Care, Center for Palliative Studies, San Diego, California, United States

Pressure ulcers, malignant and other chronic wounds have a relatively high prevalence in patients with advanced life-threatening illnesses. Both the wound and the sense of being "wounded" can cause considerable suffering for patients, families, caregivers and members of the healthcare team.

During this interactive, hands-on workshop, the presenters will guide participants though the underlying pathophysiology of chronic healable and non-healable wounds. We will use clinical cases to discuss effective approaches to wound assessment and management, including debridement, cleansing, and moist interactive wound dressing for both healable and non-healable wounds.

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116. Family Focused Grief Therapy (FFGT) during Palliative Care & Bereavement : a model of family-centered care to optimize adaptation and coping - June 8, 2007 at 11:00

David Kissane

Memorial Sloan-Kettering Cancer Center, Psychiatry & Behavioral Sciences, New York City, United States

Participants will (1)gain broad understanding of the FFGT model; appreciate role of screening with the FRI to identify at risk families; understand FFGT model of assessment, engagement, focused treatment, consolidation & termination of therapy; (2)understand key strategies in conducting a family meeting; appreciate some of the challenges & limitations of helping families during palliative care & bereavement. This 3-hour experiential workshop provides an overview of FFGT & introduces techniques & strategies for its application. FFGT is designed to support at risk families during advanced cancer, particularly as the family is drawn into caregiving roles with disease progression & the prospect of death. Continuity of care is readily achieved into bereavement. This intervention has goals of optimizing open communication, family cohesion, & conflict resolution while encouraging emotional expression & mutual support. The early part of the workshop will focus on the rationale for FFGT & describe its application. Demonstration videos will illustrate techniques. Role play will take therapists through assessment to practice strategies of family engagement, & will demonstrate the use of linear, circular & strategic questions, the role of affirmation of family strengths & the use of inclusive summaries to promote family motivation towards greater teamwork & mutual care & support.

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119. Solid facts in Paediatric Palliative Care - A new EAPC Taskforce

Franca Benini

University of Padova, Pain and Palliative Care Unit, Padua, Italy

In the last decade palliative care has witnessed an expansion in knowledge and provision of services in many countries worldwide, while palliative care for children has not had the same attention and growth. Due to advances in medical science, life-threatening and life-limiting illnesses in children are on the increase. More emphasis is placed on prolonging life thus allowing potentially terminally-ill children dependent on palliative care to survive. Globally, very few children actually have access to palliative care and as a consequence, they face disease and death without dignity in adult facilities not suitable to their age without appropriate management of symptoms or clinical, psychological, religious, social and organizational support and assistance. In fact the situation is extremely varied throughout Europe where some countries have developed organised centres and reference facilities, while others are currently working on the problem and some still lag behind. Many problems are common, despite all the cultural diversities and the differences in social organisation and availability of resources. Given the complexity of the situation, care for incurable or terminally ill children requires an effort on many fronts: on the health care organizational level in order to gain recognition of the definition of appropriate health care policy, and on the clinical level, for the elaboration of tools, audit and training, in order to address the infinite number of clinical, psychological, ethical and social issues posed by serious chronic illness or the death of a child. The purpose of the EAPC Taskforce: Solid facts in Paediatric Palliative Care is to examine and describe the state of the art and need for palliative care in children through a systematic and comprehensive analysis of scientific evidence, anecdotal experience, suggestions and contributions from leading international experts in different fields of paediatric palliative care in order to formulate recommendations for health care policy. The work of health care planners would be considerably facilitated by having access to such a document. In particular, this Taskforce will be effective where there is an absence of adequate national health care strategy devised to establish costs and to determine problems and needs necessary for the development of appropriate and effective care services.The topics are:1. The definition of palliative care 2. Epidemiological data 3. The needs of children with life-threatening illness and their families 4. The effectiveness of palliative care5. Examples of care practice6. The rights of children with life threatening illnesses and their families – legal services7. Training for care workers 8. Social awareness 9. Research and progress This represents the fundamental basis of concrete proposals for the reform and improvement of existing in Palliative Care practices for infants, children and adolescents, regardless of age, type of pathology, cultural, social and economic background.

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120. Meaning

Lisa Sand

ASIH Långbro Park, Palliative team, Stockholm, Sweden

Meaning"He who has a why to live for can bear almost any how" is an aphorism expressed by Nietzsche, sometimes referred to when discussing the importance of meaning. The question is what this "why" springs out of when life is threatened and previously held belief-systems are challenged by a palliative cancer diagnosis. According to existentialist thinkers suffering could be a springboard both for having a need for meaning and for finding it. Viktor Frankl, the man who developed the existential therapy named Logotherapy, suggested three basic sources of meaning – creative, experiential and attitudinal.

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121. Hope

Michael Wright

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

Hope may be defined as a universal attribute which is characterized by an expectation that is personally meaningful and considered to be possible. Hope arises from a context of uncertainty and is so vital to human well-being that its absence equates to a loss of life's essence, whereas its presence plays an important role in the ability to cope. Despite its significance within palliative care, hope is neither well understood nor well researched. It is often linked to the possibility of a cure, even among patients who are most resigned, and reports suggests that its status changes as physical symptoms fluctuate. Two types of hope have been identified: particularised hope (such as seeing a newly-born grandchild), and generalised hope (a condition of being hopeful). Particularised hope is concerned with doing, and may be influenced by the strength of a person's motivation; generalised hope is concerned with being, and may resonate with an individual's world-view or spiritual beliefs. Health professionals can influence the maintenance of hope or contribute to its loss - a factor identified by patients through their experience of receiving bad news. This perceived relationship between diagnosis and hope has, for some physicians, inhibited truth-telling, which may in turn contribute to the retention of false hope. Important questions need addressing: How does hope enable some people to transcend the adversity of a life-limiting condition? And how can hope be maintained and re-focussed when the possibility of a cure has passed? Meanwhile, an approach to patients which acknowledges the being and doing dimensions of hope, and locates truth-telling within the parameters of supportive care, is likely to maximise any benefits that hope offers to patients.

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122. The existential dimension of faith

Piotr Krakowiak

Hospice Foundation, Social Education about Hospice, Gdansk, Poland

Can religious faith help the dying? Most faiths are reassuring that biological death is not the end of life. Believers are comforted that there is something after death, that their wrong doings can be forgiven and their good deeds be credited. It can be a source of comfort to the dying patient, confident that faith will help those left behind. People with a deep religious faith often find it grows as death approaches.
Can religious faith cause problems for the dying? Religion does not make living or dying easier, though it may make both meaningful. Any of religion system does not provide all the answers people seek. People with unrealistic expectations of their religion are usually disappointed, especially expecting miracles or immediate and sympathetic answers to their prayers. When these are not forthcoming they may blame their religion or their God, directing their disappointment against caregivers or family members.
How should religious issues be handled in palliative care? There should be unreserved respect for an individual's religious beliefs and practices. The patient or family should be asked about religious matters including prayer, diet, and other routines. Sacred practices including prayer, sacraments, the burning of incense, special diets, and many others should be both respected and facilitated. The manner in which individuals practice their religion must be respected. A patient's religious needs should be assessed on an individual basis. Hospice and palliative care team members should facilitate arrangements for their priests and teachers to visit them. Everyone should be reassured

that the rites of their religion and culture will be fully respected after their death (IAHPC, 2004).

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123. Guilt

Peter Strang

Karolinska Institute, Stockholms Sjukhem Foundation, Research and Development Unit, Stockholm, Sweden

According to existential philosophers, freedom, i.e. man's free will to choose is an existential given. Using Sartre's words, "man is doomed to freedom". Freedom means, that people must make their own choices and in that respect people are responsible for their own lives. To choose is associated with existential anxiety, as choices imply "doors being closed". The problem of making choices is not in first place related to the issue that one chooses, but to the fact that every active choice means that all other alternatives are (or should be) left behind. Every person will make bad choices during life, even unethical choices, as the alternatives at the time of the choice may be too burdensome. Such choices create existential guilt if the choice was bad enough, if it deeply hurts oneself or others. When life goes on, the guilt issue is hidden, but at the end of life, the feeling of guilt and the need to solve the guilt issue may arise and guilt may become a great obstacle for good palliative care. In my own experience, broken relations between old parents and adult children, are the main source of existential guilt in everyday care. Certain patients cannot find peace and will not even accept good care, if they feel too guilty, they want to punish themselves. In that way, handling of guilt issues is of great importance in palliative care. During the lecture the guilt issue, related to broken relations will be exemplified by case histories and suggestions of how palliative care staff may come to assist in solving such problems. It is also well-known, that dogs are a motivator for walks and a "door-opener" for conversation with people. However, these terminal cancer patients also described how their relationship with the dog had deepened. To feel needed even if you are severely ill

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124. EPCRC - Session: Cachexia in cancer patients – Classification, what difference does it make?

Florian Strasser

Cantonal Hospital St.Gallen, Oncology & Palliative Medicine, St.Gallen, Switzerland

Understanding of **typical clinical situations** is driven by agreed-on diagnostic criteria, which need to be constantly revised responding to emerging experience and evidence. Cachexia is such a key clinical situation: the majority of patients with advancing, incurable illness suffer from cachexia and its consequences, such as associated eating-related symptoms, impaired physical function, psychosocial and existential distress, and malnutrition-associated complications. Since eating is a central theme of life, family members are affected too and most often play a role in modifying (deteriorating or alleviating) the consequences of cachexia.A useful classification system for cachexia in the palliative care context requires to acknowledge the **peculiarities of palliative care**: a) multidimensional aspects of suffering, b) the unity of care involving family members in care concepts, c) goal-, and suffering-directed (not primarily aetiology directed) diagnostic and therapeutic concepts, and d) fluctuating trajectories of illness from many months until immediately before death. Defined **variables**, including patient-reported information from assessment instruments, objective measurements, and laboratory values, are required to compose a classification system. In cachexia some instruments are already available (i.e., measuring weight, subjective appetite), others are under current consensual (international "cachexia community") development (i.e., measures of body composition [fat, muscle], inflammation, muscle function, upper gastrointestinal dysfunction, appetite -, satiety-, and energy homeostasis -related hormones), and others need to be adapted to (i.e., nutritional intake) or newly developed (i.e., psychosocial and existential distress associated with eating, secondary causes for anorexia and cachexia) for palliative care. For practice-guiding use in everyday palliative care including clinic and research an "EPCRC – Cachexia Classification" requires to be **pragmatic** and **practical**, taking into account key aspects of aetiology and pathogenesis tailored to the palliative care context.

The contribution of professionals involved in clinical care and research (**your impact**) in this important consensual classification development process is highly encouraged.

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125. Cachexia in cancer patients: Inevitable or treatable? Research proposals from the EPCRC.

Lukas Radbruch

Dep Palliative Med, Aachen, Germany

This session will present first reports of the EPCRC cachexia work packages, spanning the bridge from research into genetics to clinical practice guidelines. We will present an overview on the pathophysiology of the cachexia-anorexia syndrome, including a short review on the evidence on genetic risk factors. Classification systems based on etiology and pathophysiology and their potential impact on treatment decisions will be discussed. The scope of a clinical guideline to be prepared by EPCRC will be introduced. The methodological process required for the preparation of guidelines will be explained, including evidence and consensus finding procedures that will be used in EPCRC.

The major part of the session will be devoted to the discussion on potential key questions on diagnosis, assessment and treatment of cachexia. These key questions will be used for the preparation of systematic reviews and consensus procedures. We invite you to join us in this discussion and give your input to the guideline development!

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126. Developing a common language towards consensus based quality palliative care - Why are definitions important?

Irene Higginson

King's College London, London, United Kingdom

A definition is a form of words that states the meaning of a term. In the context of palliative care definitions are important in all aspects of care, ranging from the identification and detection of a symptom, understanding symptom prevalence, to determining what comprises a service, what are the skills and training of staff, what types of problems will they deal with in determining the eligibility criteria for care, and in deciding what outcomes to assess. This presentation will debate examples when different terms are used to mean the same thing and when there are variations in the understanding of the same term.

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127. What is "hospice"?

SHEILA PAYNE

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

http://eapc2007-abstract.blaguss-congress.hu/login_inv.jsp **Background:** Hospices have developed in a diversity of ways. This paper will concentrate use on the term 'hospice' by the public and professionals in the United Kingdom.**Aim:** To explicate the use of the term 'hospice' in contemporary public discourses and in health care practice.**Discussion:** The term 'hospice' refers to:

- a concept or philosophy,
- a building
- a set of end of life care services
- a community of purpose, with often religious, predominantly Christian allegiances
- a team of health care workers, combining professionals and volunteers
- a charitable endeavour.

A public survey conducted in 2006 by Help the Hospices indicated that 72% of people knew the term 'hospice' and identified it as a place where terminally ill people received care. In comparison only 27% knew what 'palliative care' meant. Hospices were closely associated with cancer care, dying and institutional care, and were held in high esteem. The public also knows and supports their local hospice through charitable donations and voluntary labour. From the perspective of health care, the term 'hospice' has been used to refer to a building where a range of services including in-patient, day care, home care and bereavement support are delivered by 'teams' of professional and voluntary workers. **Conclusion:** The congruence and differences in understandings of the term 'hospice' by the public and health care professionals and policy makers will be highlighted.

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128. Developing a Common Language - Towards Consensus-based Quality Palliative Care

Frank Ferris [1], Xavier Gomez-Baptiste [2], Irene Higginson [3], Sheila Payne [4], Urska Lunder [5], Cynthia Goh [6]

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[2] *Institut Catala d'Oncologia, Palliative Care Service, Barcelona, Spain*
[3] *King's College London, Department of Palliative care, Policy and Rehabilitation, London, United Kingdom*
[4] *Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom*
[5] *Palliative Care Development Institute, Ljubljana, Slovenia*
[6] *National Cancer Center, Department of Palliative Medicine, Singapore, Singapore*

Fundamental to the practice of quality palliative care is a common language that is shared and understood by all involved stakeholders, including patients, families, caregivers, healthcare workers, administrators, policy-makers, regulators. Without a common language, considerable confusion and misunderstanding can arise, and the consequences could be problematic, even enhance suffering.

This panel will discuss "why common definitions are important" and suggest consensus-based approaches to developing "common language" using examples from existing national and international strategies.

With time and a carefully constructed consensus-building process, could we develop one common language for hospice palliative care that is accepted and used internationally?

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129. EAPC national association task force

David Praill

Help the Hospices, Research and development, London, United Kingdom

A new EAPC task force was established in Spring 2006 with the aim of surveying national association organizational development and their needs. The group aims to understand the needs of a broad spectrum of national associations across Europe. It aims to survey national association organizational development and find needs according to stages of development be it beginnings, growth, maturity and decline. Based on the outcomes of this survey a training programme will be developed

This session will discuss

- different definitions of national associations
- details of a survey of national association development sent out to provide information for planning of support to national associations

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130. Grieving is a Family Affair

Pam Firth

Isabel Hospice, Family Support, Welwyn Garden City, United Kingdom

Introduction Much research into the effects of bereavement and loss has been focussed on the individual. Indeed the research has been dominated by studies on adult women. However grief affects the whole family and if we see palliative care as providing holistic care to the family as a unit we need to consider what interventions can help. The effects of a death in the family have different meanings for each family member. Each individual has a role and function within the family hierarchy and the family adjustments will vary according to family history, culture as well as the current situation in the family. The story of the death becomes important as the individuals within the family each try to make sense of the process. This is particularly true for children who are often excluded from parts of the story of the death. They are particularly affected by the loss of the role and function of the dead person, especially if it is the parent.

Discussion Ideas from systemic thinking will underpin this presentation which will be illustrated with examples of interventions from the authors own practice. The voices of some of the service users will be reflected in the debate about interventions and these will be families who have had interventions pre and post bereavement. Pam Firth, Head of Family Support, Isabel Hospice, Welwyn Garden City, UK

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131. The cultural determinants of grief

Eszter Biro

Hungarian Hospice Foundation, Psychooncology, Budapest, Hungary

"Pull yourself together!" – so are transmitted the strong cultural expectation of being "strong" and not to mourn long. While the traditional rituals of mourning are vanishing, the psychological problems of loss remain, and to mourn in a cultural context where tears are signs of weakness, is even harder.The psycho-oncological service of Hungarian Hospice Foundation helps the bereaved to find his/her own rituals of grief. After the first interview – as the 1st step of our eight-step protocol – we conclude to a contract on 8 to 16 fifty-minute sessions (one per week). The 2nd step is to establish individual arrangements for regular remembering of the deceased. The 3rd step fosters the communication among family members by giving the patient the task of collecting photos and telling stories about the deceased. The 4th step is to open up the hidden feels of guilt, and to process the ambivalent emotions. The 5th step is the beginning of development of new habits, instead of the old ones, that are not to be practiced anymore. The 6th step is consolidating these new habits by practicing them, and sharing the experiences with family members. Doing so the patient realizes, that life in a changed form continues even after the loss of the loved one, and in the 7th step s/he becomes able to say good bye in a ritualized form. The 8th step summarizes the events and results of the supporting therapy that really helps the patient “to pull him/herself together”.

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132. Decision-making in end-of-life care: a pilot study on the attitudes, knowledge and medical acts of 602 Belgian GPs

Marc Cosyns[1], Myriam Deveugele[1], Jan De maeseneeer[1], Roland Roland[2], Bénédicte Abbadie[2]

[1] *University of gent, General Practice, gent, Belgium*
[2] *Vrije Universiteit Brussel, family medicine, Brussels, Belgium*

Introduction The Federal government of Belgium ordered a study. 1. attitudes of care givers towards EOL care 2. knowledge of the associated laws 3. their communication skills 4. decision-making process and medical acts towards the patient at the end of his/her life.
Methods/interventionA questionnaire, consisting of 3 parts, was developed. The first part contained general questions about the laws and attitudes. The second part was a retrospective survey about communication, decision making and medical acts in EOL care while the third part aimed at a prospective survey. Three settings were studied: GPs, GPs with a coordination function in homes for elderly and physicians in palliative care units. There was also a semi-qualitative research by peer-groups and interdisciplinary teams.
Preliminary results The questionnaire was returned by 602 GPs: 66 % men en 34 % women. Only 14 % of them followed an institutionalized education in palliative care. Less than 50% knows the rules that are important for informed consent in a sufficient way. 63 % of the GPs agree on the fact that palliative care should be integrated in the field of terminal care, while 39% agree with the practice of euthanasia (within the Belgian law) on terminal ill patients. More than 40% of the GPs agree with the practice of terminal sedation, based on their professional autonomy and without the consent of the patient or his representative. Interdisciplinary decision making is registered in 28% of the retrospective cases.

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133. The care givers point of view in the approach of sexual cancerns in palliative cancer patients.

Mario BARMAKI, Aurélie LAURENT, Henri NAHAPETIAN, Murielle RUER, Christelle PLUVIAUX, Marilene FILBET

CENTRE HOSPITALIER LYON SUD, Palliative Care Centre, PIERRE BENITE, France

Goal: This study proposes to explore the approaches of physicians and nurses when confronted to patients with sexual concerns during the palliative phase.
Background: The lack of communication between patients and care givers has been pointed out in many studies, with the patients evaluations and perspectives about sexuality. This issue is considered as fundamental, and its perturbation alters the QOL. 53% of the questioned patients talked about this issue with their partners, and 14% with their referent physician (EAPC Venice 2006).
Methodology: It is a prospective study using a semi directed interview, aiming a population of 20 care givers, recruited in 3 cancer units (oncology, radiotherapy, and palliative care). The interviews are conducted by clinical psychologists.
Results: The analysis of the first interviewed show that sexual concerns are considered as secondary in the approach of cancer disease, specially in the palliative phase. It is difficult for care givers to talk with cancer patients about sexual disorders, fears or apprehensions. We noted a reluctancy for a systematisation of such approaches during evaluations to prevent any depressive reaction. These concerns seem disturbing for both patients and care givers.
Perspectives: The expected end of this study is March 07. We hope to encourage care givers to a wider range of quality of life evaluations, including sexual concerns.

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134. Handling Bad News for People with Learning Disabilities Facing Death

Jacqueline Saunders[1 4], Linda McEnhill[2 3]

[1] *St Nicholas Hospice, Education, Bury St Edmunds, United Kingdom*
[2]*St. Christopher’s Hospice, London, United Kingdom*
[3]*National Network for the Palliative Care of People with Learning Disabilities, Cambridge, United Kingdom*
[4]*Help the Hospices, Education and Training, London, United Kingdom*

Anecdotal reports and small scale research indicates the quality of breaking bad news (BBN) to people with learning disabilities (LD) is below that expected for the ‘ordinary’ population; there is no guidance on how to handle bad news with this vulnerable group. The aim was to create an alternative model of communication by consulting with and being informed by people with LD. LD and hospice staff and people with an LD were invited to contribute to the project. The professionals reflected on BBN models, the contemporary evidence base and their experience of BBN to people with LD. They listened to the accounts of people with LD and kept reflective diaries. The accounts were taped, transcribed and analysed for themes. People with LD said the ways that they had been told the bad news increased their distress. The professionals were shocked at the depth of insight displayed and consequent anguish experienced by the people with LD. In conclusion, fundamental aspects of accepted BBN models can hinder communication with people with LD; collaborative working between LD and palliative care can overcome this and prevent increased psychological distress. Adaptations to the current BBN models are easily included in existing communication training and have transferability for a range of people with cognitive impairments

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135. Family-Oriented Communication in Palliative Care

Iris Cohen Fineberg[1], Steven Asch[2]

[1] *Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom*
[2]*Veterans Administration GLAHS, HSR&SD, Los Angeles, United States*

Aim of study: Effective communication with families is an important component of palliative and end of life care, yet health care professionals receive little training on how to work with families. This study aimed to identify a theoretical model of successful family conferences from videotaped inpatient conferences and to develop an educational program for professionals based on the model.
Method: We recorded 24 family conferences for patients facing serious illness and end of life at two medical centers in the United States. Following each conference, participants took part in an audiotaped interview about their views of what made the conference helpful and/or successful. A multidisciplinary team of qualitative researchers conducted a rigorous qualitative analysis of the videotapes, videotape transcripts, and interview transcripts using Atlas.ti software to facilitate the coding process. A team of clinicians/researchers then designed the interdisciplinary educational program for health care providers.
Result: A theoretical model emerged about optimizing communication among patients, families and health care providers in a family conference. A one-hour educational program for health care professionals was developed to illustrate model components using videotape clips from real family conferences.
Conclusion: Family-oriented communication can be promoted and taught to health care providers using a theory-driven educational program about family conferences.

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136. Patient-Family Communication About End-of-Life Topics: Development & Pilot Testing of a New Measure (PFICQ)

Jennifer Abbey[1], Barry Rosenfeld[1], Hayley Pessin[2]

[1] *Fordham University, Department of Psychology, Bronx, United States*
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Purpose: The goal of this study was to develop and pilot test a measure of patient-family communication about EOL topics, the Patient-Family Illness Communication Questionnaire (PFICQ).
Method: A literature review was conducted to identify salient themes for those at the EOL. Palliative care experts provided feedback on the exhaustiveness of the themes and on the format of the questionnaire. Two subscales emerged, one involving present interest in discussing the topic (a) and the second involving the degree to which it had been previously discussed (b). The last step was to administer the PFICQ to 30 cancer patients receiving inpatient palliative care.
Results: Item-analyses revealed adequate variability on all items. Cronbach’s coefficient alpha indicated adequate levels of reliability for both subscales (a = .923; b = .913). There was no noteworthy improvement in the internal consistency levels of the subscales with the elimination of any items. A low spearman correlation coefficient was documented between the two subscales (r = .162) supporting their discriminant validity.
Conclusion: The results of this study provide preliminary support for a measure of patient-family communication about EOL topics in a palliative care setting. Such validation will ensure that this important area receives adequate research attention moving forward. This measure may also have clinical utility for facilitating conversations between patients and family members.

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137. Body images and communication in psychotherapy and pastoral care

Helle Jensen[1], Steen Nielsen[1]

[1] *bispebjerg hospital, Chaplaincy, Copenhagen, Denmark*
[2]*bispebjerg hospital, Palliative care unit, Copenhagen, Denmark*

The paper will present differences and similarities between psychotherapy and pastoralcare and present a method for interdisiplinary work in palliative care.

Psychology and theology are often presented as incompatible due to their different perspectives on man But in a palliative context it can be important to offer both perspectives instantaniously. For this reason we conduct psychotherapy and pastoral care during the same meeting with the patient. The method we use is inspired philosophically by Kierkegaard and his ability to “translate” psychological and spiritual problems into body images. Inspired by Kierkegaard we use a bodily grounded language for two reasons. The first reason is that body images are universal and need no particular educational nor cultural background to be understood. The second reason is that it offers a “neutral” language because it avoids a psychological and theological language.

We will show how bodily images offers a potantial for an open dialogue, where it becomes possible to alternate focus between a psychological and a theological perspective.

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138. ART THERAPY IN PALLIATIVE CARE Video

Wadih RHONDALI, Marilene FILBET, Aurelie LAURENT, Mario BARMAKI, Isabelle BRABANT

CENTRE HOSPITALIER LYON SUD, Centre for Palliative Medicine, LYON, France

This video movie is taken during the painting workshop in our palliative care.It shows the change in the communication and interaction between the patient and care givers during the session.The video are edited around a case studies .

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139. “Doing good care” - a grounded theory of palliative home nursing care

Anna Sandgren[1], Hans Thulesius[1], Kerstin Petersson[1], Bengt Fridlund[2]

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Lately, in Sweden, more and more people die in nursing homes and own homes and fewer die in hospitals. The community nurses therefore play a central role in palliative homecare. In this classic grounded theory study, the authors analyzed interviews and data related to palliative care in basic home nursing. “Doing good care” emerged in the analysis as a typology of three different caring behavior, Anticipatory care, Momentary care and Stagnated care, by which nurses act on the basis of their desire to do good. When failing in doing good, they experience a feeling of letting the patient down, which can lead to frustration and feelings of powerlessness. Anticipatory care is the optimal caring behavior with the intention of Doing the best all the time and involves Foreseeing trajectories, Creating trust and safety, Collaborating and Prioritizing. Momentary caring, on the other hand, is done through Doing best momentarily and Temporary solutioning. Stagnated caring is done by Doing what is expected, Avoiding changes and Resigning. Depending on the circumstances nurses can hover between the different caring behaviors. Healthcare providers need to increase the status of palliative care and facilitate for nurses to give Anticipatory care by giving recognition, offering education and providing adequate resources.

140. A Cross-sectional, Consecutive Patient Survey of the Views of Cancer Patients and their Relatives towards Randomized Controlled Trials in Palliative Care

Clare White [1], Margaret Charles [2], Janet Hardy [3]

[1] *Royal Victoria Hospital, Palliative Medicine, Belfast, United Kingdom*
[2] *University of Sydney, School of Psychology, Sydney, Australia*
[3] *Mater Misercordiae Hospital, Palliative Care, Brisbane, Australia*

Aim: To determine the willingness of patients and relatives to participate in palliative care research, in particular randomised controlled trials (RCTs), and determine factors that influence participation.
Methods: A questionnaire was developed and modified through focus groups with palliative care stakeholders, patients and relatives. The final questionnaire assessed issues affecting willingness to participate (WTP), trail complexity and inconvenience tolerated using modified Leikart scales. Following ethics approval, consecutive eligible patients and their relatives were asked to participate. Demographic data was collected on all participants. Descriptive statistics were used to assess WTP. Multiple linear regression was performed to determine if demographic and other factors can predict WTP.
Results: 125 patients were screened; 101 patients and 100 relatives completed the questionnaire. 92% of patients and 95% of relatives were interested in participating in simple studies, whereas only 26% of patients and 20% of relatives would consider complicated studies. 83% of patients expressed altruistic views.
Conclusions: Many patients and their relatives are willing to participate in research trials. The level of inconvenience and trial complexity tolerated may aid the development of future studies.

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141. What Are Patients Research Priorities for Palliative Care?

Paul Perkins [1], Sara Booth [2], Sarah Vowler [3], Stephen Barclay [3]

[1] *Sue Ryder Care St. John's Hospice, Moggerhanger, United Kingdom*
[2] *Addenbrooke's Hospital, Palliative Medicine, Cambridge, United Kingdom*
[3] *University of Cambridge, Department of Public Health and Primary Health Care, Cambridge, United Kingdom*

Aims:
To elucidate which areas patients think should be research priorities for palliative care.
Method:
2 stage methodology: Facilitated focus groups to identify themes to be included in a questionnaire. Questionnaire used in 5 different hospices. Inclusion criteria for both stages - advanced cancer with estimated prognosis of <6 months.
Results:
1) 6 focus groups held with a total of 19 patients. 4 themes given high priority for future research: Talking with patients; Help for patients and families; Symptoms; Medication/treatments.
2) 112 questionnaires completed. Median patient age was 65 and time from questionnaire completion to death was 103 days. All topics scored as important but emergency care; pain; services available at home; and doctors understanding patients scored highest.
There were statistical differences:
Women wanted more research around services for patients and alternative therapies than men.
Day Therapy patients rated communication of prognosis as more important than In-patients.
Over 65s rated issues around doctors visiting at home and complementary therapies as more important than under 65s.
No evidence of differences between research priorities for patients with different diagnoses.Patients felt that it was easy to answer questions about research priorities.
Conclusions:
Patients do wish to contribute to the research agenda. When asked they score many issues as important. There are differences of prioritisation depending on gender and care setting.

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142. Self reported mobility in palliative patients: Does wording of items matter?

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Background: Various questionnaires present items about similar subjects in different ways and use different response scales. The PAT-C project aims to develop a computerized questionnaire on functioning and symptoms in palliative patients. Mobility is one scale included. This paper aims to assess how wordings of mobility items affect responses.
Methods: 380 palliative care patients from in- and out-patient units filled in a computerized questionnaire. The order of items was random. Three mobility items on walking length (20m, 100m and 1000m) where asked in two different ways: "Can you walk x m" (yes or no), and "Do you have difficulties in walking x m?" (not at all, a little, some and very much).
Results: The sample (192 women and 188 men), had a mean age of 64±11 years, median Karnofsky score was 70 (20-100). Six% reported that they could not walk 20m, and 20% and 47% could not walk 100m and 1000m. Among those reporting a little, some and very much difficulties walking 1000m, 12%, 20% and 91% respectively, answered no to the question "can you walk 1000m?" 4% of those who said they could not walk 1000m, reported that they had no difficulties doing this. The discrepancies between answers were also present for the 100m items.
Conclusions: Phrasing of items and response scales influence results. Comparisons between studies using different instruments should be performed with caution.

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143. Assessment of the patients' spiritual needs: the influence of investigators' attitudes on patient drop-out rates

Gian Domenico Borasio [1], Martin Fegg [1], Thomas Hagen [1], Traugott Roser [1], Gudrun Linke [1], Carola Riedner [2], Eckhard Frick [3]

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[2] *Oncologist in private practice, Munich, Germany*
[3] *University of Munich, Department of Psychotherapy and Psychosomatics, Munich, Germany*

Background: We developed and tested a semi-structured spiritual assessment interview (SPIR), based on the FICA interview by C. Puchalski.
Subjects and Methods: The study took place in two outpatient and an inpatient setting. After administration of the SPIR, patients and investigators were asked to rate (0-10) the helpfulness and distress of the interview, and the importance of spiritual issues in their lives. Unexpectedly high drop-out rates prompted the hypothesis of investigator bias, therefore a follow-up study evaluated the investigators' (physicians/chaplains) spiritual background and their attitude towards the study.
Results: 70 oncological and palliative care patients were evaluated. The data indicate a low distress (patients 1.0 ±2.2, investigators 1.6 ±1.7), and a high degree of helpfulness (pts. 7.2 ±2.7, inv. 6.6 ±2.4) of the SPIR, as well as an overall high importance of spiritual issues (pts. 6.6 ±2.9, inv. 6.6 ±2.8). For the investigators, a high importance of spirituality and a positive attitude towards the study were significantly correlated with a lower patient drop-out rate ($p<.05$).
Conclusions: The SPIR appears to be a well-accepted method of assessing the patients' spiritual needs. Possible attitudinal barriers need to be proactively discussed with the investigators when planning spiritual care studies in the clinical setting.

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144. Combining Patient & Professional Perspectives Using "Speed Dating"

Jane Maher [1, 2], Alison Donaldson [2], Elizabeth Lank [3], Teresa Young [1], Humaira Jamal [4], Keri Thomas [5], Clare Gwilliam [1], Lorraine Sloan [6]

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Multiple stakeholders are involved in the care of patients with advanced cancer. Since 2005, we have applied the principles of "speed dating" in workshops to generate ideas and bring together diverse perspectives. To date this has involved >400 stakeholders. More recently the method has been refined to bring patient and professional perspectives together to find ways of improving care for patients with bone metastases or late effects of radiotherapy.
Method: 1: A user involvement facilitator works with patients/carers to identify "real life" stories which can be told in 2–4 minutes. 2: Each pair hosts a table with 5–6 "professionals". The latter move from table to table every 12 minutes after discussing each story. A team of facilitator/writers captures ideas and quotations illustrating different perspectives.
3: Resulting insights are used to refine models of care and study protocols.
Results: Patient narratives focus minds of professionals and researchers.
Time pressure accelerates generation of ideas.
Patients and carers speak more than professionals and value the process.
Significant changes in study designs emerge.
Conclusion: This is a useful tool to draw ideas from multiple stakeholders. It is highly valued by patients but requires skilled organisation and facilitation.

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145. The Coordination Centre for Pediatric Palliative Medicine in Munich - a model for the future?

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Aim: The Coordination Centre for Pediatric Palliative Medicine (KKiP) was established in 2004 as a joint project of the Children's University Hospital and the Interdisciplinary Centre for Palliative Medicine of the Ludwig-Maximilians-University Munich. The aim of the project is to improve the quality of life of terminally ill children and their families by coordinating the medical, nursing, psycho-social and spiritual care at home.
Method: Retrospective analysis of the patient documentation.
Results: From 3/04 until 4/06 61 pts. (age 0–35 yrs) were enrolled in the program. 36 pts. (62%) have died so far, 67% at home. The first contact was arranged by hospital staff in 69%, in 27% the family contacted the KKiP. The local pediatrician was involved in 64%. Prenatal counselling was provided in 4 cases. In 9 cases., parents signed an advanced directive for their child. In 70% of the families with siblings parents needed intensive counselling about the siblings' specific problems. Bereavement care was provided in 61% of the families. The median duration of palliative care in children dying at home was 51 days (2 – 275 d).
Discussion: The work of the KKiP was highly accepted by children and families. Most children could die at home. This could be achieved mainly because of a 24/7 availability of a specially trained pediatrician. A network of similar coordination centres could be helpful to reduce the still existing deficit in out-patient palliative care for children in Germany.

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146. SisBroJekt - A German project for healthy siblings of chronically ill children

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Background: In Germany, there are approx. 22,000 siblings of chronically ill children. Healthy siblings tend to be unintentionally neglected which may have negative impact on their physical and mental well-being. Studies demonstrated that healthy siblings show an improved adjustment to challenging family situations if socially supported. A project for siblings of chronically ill children was developed at the children's hospital in Datteln.
Aims: 1) To explore healthy siblings' needs. 2) To provide social support for healthy siblings. 3) To provide evidence for further interventions.
Method: 1) Intervention: Fifteen siblings aged 6 to 11 y of chronically ill children with life-limiting/life-threatening conditions took part in weekly group activities. They were encouraged to focus on their own needs, to express their feelings and bond with other group members. 2) Study: Thirteen children participated in a pre-/post intervention evaluation. Quantitative data was collected from parents (CBCL) and children > 8 y. Focus group interviews with all children generated

qualitative data.
Results: The majority of the children benefited from the project. All parents and children rated the project as helpful.
Conclusion: Although these are preliminary results, quantitative and qualitative data indicate beneficial effects of the intervention for healthy siblings. As such the project will be implemented as continually offered support.

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147. An Ethical Framework for Pediatric End-of-Life Decision Making

Mildred Solomon [1, 2], Cynda Rushton [3], Laura Rieglhaupt [2], Alan Fleischman [4]

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The purpose of this session is to provide health care professionals with a conceptual framework for approaching difficult decisions about the use of life-sustaining treatments for neonates, children and adolescents. The framework calls for an assessment of the benefits and burdens likely to be associated with different care plans. In discussing benefit, the model legitimates the importance of considering the child's longterm prognosis, not just the immediate assistance the proposed treatment can offer. In addition, the model encourages inclusion of quality-of-life considerations, not just strictly physiological benefits. The session will distinguish and provide ethical justification for a range of cases in which treatment is clearly indicated as in the child's best interest, where the benefits are treatment are marginal or uncertain, and where treatment is likely to be nonbeneficial or harmful. The model promotes shared decision making with parents, and it helps clinicians determine the degree of parental discretion that is possible under varying clinical circumstances.

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148. The lived experience of parenting a child with a life limiting condition: A focus on the mental health realm

Alison Rodriguez, Nigel King

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Aim: This paper reports a study that highlights the mental health implications of the lived experiences of parents of children with life-limiting conditions
Background: As medical technology has improved; there has been a marked increase in the numbers of children with life-limiting conditions being managed in the community. Few studies have evaluated the life worlds of the parents of these children; however there have been studies that have reported feelings of isolation and depression amongst mothers.
Method: Semi structured interviews were conducted with ten parents of children with life-limiting conditions and analysed using a phenomenological method.
Findings: The essential meaning of the phenomenon: "the lived experience of parenting a child with a life limiting condition", is understood as a fulltime emotional struggle involving six continuous constituents: inner drive, feeling responsible, psychological affects, threatened self image, social withdrawal, and fear of reaching the bottom line.
Conclusions: Very little attention is focused upon the wider issues that affect parents dealing with caring for a child with a life-limiting condition, not implementing sufficient services on a medical, psychological and social count for children with life-limiting conditions and their families may eventually lead to increased spending through adult mental health services having to pick up the pieces.

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149. Paediatric hospice care: parental feelings, thoughts and remarks

Matthias Schell [1], Maité Castaing [1], Didier Frappaz [1], Thierry Philip [1], Yves Devaux [2]

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[2] *Centre Léon Bérard, Home Care Team, LYON, France*

We have been developing paediatric hospice care for the past 3 years.
Aim: To evaluate parents feelings and the impact of our hospital team on paediatric hospice care.
Methods: We sent an anonymous questionnaires to 33 parents of children deceased of cancer.
Results: 20 parents responded. 10 parents whose child died at home had no regret for their decision. All 10 benefited from a formal meeting set up by our hospital-team with the family physician and local home care providers and at least one visit at the child's home. 10 parents requested hospitalisation prior to their child's death. Two parents felt sorrow regarding rehospitalisation. Interestingly, for none of them we met their family physician or local home care providers and we didn't organize any visit at the child's home. Local home care providers who met with our hospital-based palliative care team had a more favourable parental view regarding their competence, quality of care, availability, as well as to show humanity. End of life symptoms with the highest impact on parents were their child's fatigue and pain. Parents cited helplessness, despair and loneliness as the most frequent feelings encountered while taking care of their child.
Conclusion: To our knowledge, this is the most important study conducted in France on parental feedback after hospice care of their child. The degree of commitment from the primary hospital-based team seems to be critical in paediatric hospice care.

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150. Pediatric Advanced Care Team: one of the models of delivery of pediatric palliative care in the USA.

Tamara Vesel

Dana Farber Cancer Institute and Childrens hospital, Pediatric palliative care/Pediatric oncology, Boston, United States

Pediatric Palliative Care focuses on optimizing the care of children whose lives are threatened.Dr Vesel will introduce you to the Pediatric Advanced Care Team (PACT), one of the models of delivery of pediatric palliative care in the USA. Formed in 1997, PACT is an interdisciplinary consulting team at Children's Hospital Boston and the Dana-Farber Cancer Institute both affiliated with Harvard Medical School in Boston, USA.Our model addresses helping children with life-threatening illnesses and families to identify goals of care, intensive symptom management,coordination of care between families, hospice, home nursing, pediatrician and hospital team, psychosocial and spiritual support, quality of life and end of life care with follow up bereavement services. We also provide prenatal palliative care. Members of the team are involved in education initiatives in local to international settings. Active clinical research is an integral part of the team's activity. We aim to help children feel as well as possible for as long as possible.

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151. Quality of life - a valuable concept?

Raymond Voltz

Uniklinik Köln, Palliative Medicine, Cologne, Germany

In this wake-up session, participants will have the chance to interactively discuss whether "QoL" is a valuable concept. Valuable for whom? What value? Value for the patient, family, for the researcher? Maybe there will be no definite answer.

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152. Nutrition - Meet the expert - morning session

Florian Strasser, Ylva Orrevall

Cantonal Hospital St.Gallen, Oncology & Palliative Medicine, St.Gallen, Switzerland

Decreased nutritional intake, loss of weight and decreased physical function impacts the majority of patients with far advanced incurable illness and also their families and caregivers. **Terminal care**: Cessation of oral intake is a natural part of the trajectory leading to death: many patients give up eating to prepare for a self-controlled, predictable, and dignified death, they attach minimal importance to food for their direct comfort in their last days. Caregivers experience often high levels of emotional distress, because of the strong association of eating and enjoying food with life, with care, and with nurturing. **Last few to many months**: In the last few to many months before the terminal phase, palliative care strives for offering patients good quality of life by total active (palliative) care, by goal-directed, repeated decision-making processes utilizing multidisciplinary and – professional teams focusing on alleviating suffering associated with multiple dimensions. A **practical approach** to care for patients challenged by nutritional issues includes **seven steps**: 1) screening for loss of weight and/or appetite and their consequences, 2) assessment of secondary reversible causes, 3) estimation of severity of primary anorexia/cachexia, 4) prioritization in the overall context of patients' illness burden, agreement on 5) specific goals (and no-goals) of pharmacological, nutritional, and psychosocial interventions, 6) best interventions and expected time needed to reach these goals, 7) well balanced burden of any intervention, including the adverse events of false expectations (Calman gap) and travelling needs. **Practice aids**: Practical assessment instruments (including secondary causes, psychosocial distress) and intervention packages can assist teams to face these everyday challenges, and "to respectfully dance between nihilism and overactivity".

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153. Constipation - European guidelines.

Nigel Sykes, Philip Larkin, Carlos Centeno, Antonio Noguera, Furio Zucco, John Ellershaw, Carla Ripamonti, Brigitte Eugene, Jaap Gootjes, Wouter Zuurmond

ST CHRISTOPHER HOSPICE, London, United Kingdom

This presentation will present European consensus recommendations on the assessment, treatment and evaluation of constipation in a palliative care context. The views expressed in this presentation are the summation of a two day international workshop of European palliative care experts with a view to providing a comprehensive framework for best practice, based on the contemporary evidence. Experts from six EU countries [UK, Ireland, Italy, Spain, France and The Netherlands] contributed to this work, the preparation of materials for practice and the development of an algorithm for clinical evaluation. This "meet the expert" session will provide an overview of those key recommendations and provide a forum for discussion around the key findings, clinical decision-making on the assessment and treatment of constipation and the appropriate use of laxatives and interventions to alleviate this troublesome symptom.

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154. Adult Education

Ruthmarijke Smeding [1, 2], John Ellershaw [2]

[1] *PallEd, Würzburg, Germany*
[2] *Marie Curie Palliative Care Institute Liverpool, Liverpool, United Kingdom*

Education in Palliative Care currently experiences rapid changes, both in the Western parts of Europe and in newer membership states.Introductions into already existing curricula for pre-graduate education require competencies of the (new) Palliative Care teacher, that differ from the educational needs to answer the steady progress of Palliative Care into communities, hospices, hospitals and other organisations.Adult education emanates from the learner's perspective rather than from "the course-content". Teachers will have to invite both the learner and the content to move together, in aiming for the required competencies at the bedside. Some teachers have learned the " trade" from their own teachers, others developed both courses and facilitative behaviours required, on their own. Empowerment of the teachers to empower their students seems underserved. Independent from where we are teaching and the outcomes we aim, learning together for advancing Palliative Care effectively seems a helpful next step.

Dr. Ruthmarijke Smeding will give a short introduction to the themes above from her perspective as an international trainer in Palliative Medicine/Care around the world. **Prof. John Ellershaw** will provide an overview of the exciting developments taking place at Liverpool University and within Palliative Medicine training in the UK.

The two introductions aim at opening a discussion with the room on their needs.

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155. Meet the Expert Session : user Involvement and Palliative Care

David Oliviere [1], Sheila Payne [2]

[1] *St Christopher's Hospice, Education and Training, London, United Kingdom*
[2] *Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom*

This session will capture the diversity of approaches to user involvement in its various models and practices. User involvement means strategies to enable patients, family carers and the public to engage in improving services and research. Short presentations will be made on a scoping study carried out by Sheila Payne and team at the University of Sheffield about user involvement in palliative care. This study reviewed the user involvement research, policy and practice literature, to identify methods of accessing user views and elicited the views of key informants and highlighted best practice.

David Oliviere will describe the user involvement activities at St Christopher's Hospice, involving the user forums, one-off consultation meetings, the Users' Education Advisory Group and how user views are translated into action and service improvement.

Facilitated discussion will identify participants' experiences of user involvement in their own settings and suggest how developments might be initiated. The session will demonstrate a user involvement meeting.