Oral abstracts

Thursday 7 June

CONNECTING DIVERSITY

10th Congress of the
European Association for Palliative Care

1. See page 66

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2. Funding — needs, responsibility and availability

Mary Callaway

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Fifty-eight million people die each year and it is estimated that up to 80% of these patients and families would benefit from palliative care. This enormous need around the world will require public and private partnerships and philanthropic support to catalyze country development and international networking. Support is coming from multilateral and bilateral donors such as the WHO, UNAIDS, Global Fund for HIV/AIDS, TB & Malaria, PEPFAR, World Bank, European Union, along with foundations such as the Diana, Princess of Wales Fund, Help the Hospices, the Ellenor Fund, the Open Society Institute, the Elton John Foundation, Foundations for Hospices in Sub-Saharan Africa. One of the challenges is that each of these organizations defines palliative care differently from "all activities outside of ARV therapy to social support provided by untrained volunteers to WHO's definition of medical, psychological, social, and spiritual care which is patient and family centered." To make the progress necessary, funders will be required to communicate with each other, coordinate their funding, provide long term financial support, and agree on one application and reporting form. We must assume the responsibility of working together as patients, health care providers, corporations, governments, and non-governmental organizations to leverage the funding we have and advocate for increased local, national, regional, and international funding to support palliative care services, education and training, policy development, and palliative care essential drug availability. The aging population, the growing incidence and prevalence of cancer, and the exploding HIV/AIDS epidemic requires a substantial increase in this funding to meet the needs of these patients and families.

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3. Access to controlled medications: impact for millions

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Over 80 % of the world population has no proper access to medicines controlled under the drug control treaties. The result is very scaring: consequences are unnecessary suffering from pain and preventable HIV-transmission. Women die in delivery by lack of access to ephedrine and ergometrine. WHO estimates that altogether over 600 million people will be affected during their lifetime.The drug conventions' aims are to ensure availability for medical use as well as the prevention of abuse but many countries enacted stricter measures than those required by the Conventions. Additional barriers are failure to develop and submit accurate estimates and statistics to the INCB, inappropriate medical practices and insufficient recognition of the therapeutic usefulness of controlled medicines by medical professionals and law enforcement officers. In developing countries procurement, available funds and infrastructure are additional barriers.The World Health Organization set up the Access to Controlled Medications Programme to deal with these barriers. Its activities will assist the countries when reviewing legislation, train officers responsible for statistics and estimates, and provide medical professionals with information and training on the rational use of these medicines. The optimal balance between access for medical use and prevention of abuse needs to be restored.

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4. A National Policy - Does It Make A Difference?

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In 2001, the Irish Government adopted a national policy based on the recommendations of the Report of the National Advisory Committee on Palliative Care.

The new policy clearly stated the need for a state-funded integrated palliative care service across all care settings, with the hospice in-patient unit as the hub of the service. It stressed the multidisciplinary nature of palliative care teams, and quantified some key resource requirements, for example:

- at least two palliative care consultants and one in-patient unit in each of the ten health regions, with a minimum of ten hospice beds per 100,000 of population
- a full, consultant-led specialist palliative care team in all acute general hospitals with over 150 beds
- one specialist palliative care nurse for every 25,000 of population.

Initial implementation of the stated policy was slow. In 2005, the Irish Hospice Foundation led a research project to quantify service gaps on a regional basis (*A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland*). Wide regional disparities were found in government spending on palliative care services in all care settings. Per capita spending on care staff and in-patient unit beds varied from ¤1.5 to ¤31.

The combination of a national policy and measurable evidence of deficits in service provision greatly enhances the capacity of voluntary and professional groups to advocate at institutional and political forums. Completion of the Baseline Study has given a new impetus to the implementation of policy.

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5. Palliative care and intellectual disability - exploring the knowledge of specialist palliative care providers in Kent

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Aim
As the age of people with intellectual disability (ID) increases there are increasing health and social care needs, particularly with a progressive illness, such as cancer or dementia. The involvement of palliative care services with this group of patients appears to be small and this study aims to investigate the knowledge of health care professionals working in specialist palliative care in the care of people with intellectual disability.

Methods
Focus groups are to be held in 7 hospices and specialist palliative care providers in Kent, Participants will include health and social care professionals. Topics for discussion will include levels of professional experience in the care of people with ID as well as areas of concern and barriers to care provision.

Results
Initial focus groups discussions with senior doctors in palliative medicine within Kent have suggested that the involvement of specialist palliative care services with people with intellectual disability is small, even though the population of this patient group is large. Specialists have expressed the view that their knowledge and experience in the care of people with ID is low, doctors had received very little training in the care of this patient group. It is expected that the focus groups will show similar results.

Conclusions
It is anticipated that specialist palliative care providers have little contact with patients with ID and have little training or knowledge of this patient group. Whilst there may be no obvious discrimination against these patients there is a need for greater awareness of ID amongst staff, at all levels, so that the needs of people with ID can be addressed adequately, and appropriately.

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6. "The Veronica Project": An ethnographic study into the experiences of people with Intellectual Disabilities (ID) who have cancer (preliminary findings)

Irene Tuffrey-Wijne

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Aims
To investigate how people with ID experience cancer, and to describe the barriers they experience in receiving cancer and palliative care services.

Methods:
Up to 15 people with ID who have cancer will be selected, using a purposive sampling method. The study uses ethnographic methodology. Data collection methods depend on the wishes and abilities of the participant, but typically include weekly or fortnightly sessions of participant observation for several months, studying the participants' notes, attending case conferences, and writing extensive field notes, including the researcher's own reflections. Data are analysed using grounded theory. Ethical issues are carefully considered.

Results:
This is the second year of a three-year project. Eleven people with ID and cancer have so far taken part in the study, and preliminary findings will be presented. Emerging themes include the importance of understanding the person's life story, the crucial place of the family, and issues around choice and empowerment.

Conclusion
If we are to offer sensitive and appropriate cancer and palliative care to people with ID, it is essential to listen to their experiences.

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7. Palliative care for people with intellectual disability: lessons we have learned and challenges for the future.

Karen Ryan

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The life expectancy of people with intellectual disability has increased, and conditions such as cancer, cardiovascular and respiratory disease are now leading causes of death. This has important implications in the provision of services to people with intellectual disability because the altered demographics challenge services that were originally developed for children and young adults, and that focused on enablement. As a result, organisations that provide services to people with intellectual disability are increasingly turning to palliative care services for support in this area. Little is known about how best to deliver palliative care services to this group, however. Although people with intellectual disability have the same palliative care needs as the general population, they also have additional needs that relate to the presence of impairment or the social consequences of impairment. The speaker will draw on data collected from focus groups and individual interviews with stakeholders in palliative care and intellectual disability services to describe the challenges that have been encountered by service providers to date. The merits of different models of service delivery will be debated, and recommendations for the future development of services will be made.

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8. Social resurrectionists: death in a disabilty context

STUART TODD

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Aims: This paper seeks to place the way intellectual disability services respond to the dying phase of the lives of people in their care and places this within a cultural and historical context. It argues that this past is one that has to be faced and resolved before more responsive services can be developed to meet the needs of this group at the end of life.
Method: The paper uses historical material and integrates this with data from a study of death of disability. The data are largely qualiative in nature and were derived from in-depth interviews of front-line cares in intellectual disability services.
Results: Services for people with intellectual disability services might be characterised as 'resurrectionist' in aims inasmuch as they are based upon a philosophy of giving life to a marginalised group. Death and dying find little space within such practices. Although death is expected to occur given that services have 'death policies', these are all focused upon sudden death rather than prolonged dying. Thus when service users are dying there is little to guide service providers other than an intellectual disability value base that is based upon an anti-medical model. There is then a reluctance to seek for wider support and front-line care staff must resolve the emotional and physical support needs of clients by themselves.

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9. An assessment tool for the bereavement needs of people with Intellectual disabilities

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It is well known that people with Intellectual disabilities have a higher propensity to develop complicated grief reactions following bereavement. This is in part due to the fact that there are often many hidden losses which accompany the death of a parent or close relative, when these go unrecognized the original grief is compounded and the person is more likely to have difficulties connected to their grief.

The Bereavement Assessment Tool has been developed in order that professionals supporting a bereaved person with intellectual disabilities can make a comprehensive assessment at the point of bereavement in order that concurrent losses are discovered and plans can be put into place as to how to attend to these.

A questionnaire has been developed based on experience collected over a number of years of having supported grieving people with intellectual disabilities. The questionnaire has been piloted by several teams of professionals working with people with intellectual disabilities and the findings will be used to further refine this as a tool to be used by such teams as part of a needs assessment.

The use of such a tool by professional teams heightens their awareness of the complex impact of bereavement on this client group and as well as influencing the path of grief for people with intellectual disabilities it also serves to raise awareness amongst the professionals supporting them.

10. A Global Perspective - World Health Organization Strategies and Resolutions

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Complementary and alternative medicine (CAM) refers to a broad set of healthcare practices that are not part of a country's own tradition and are not integrated into the dominant healthcare system. The use of CAM has increased in industrialized nations over the last decades. For example, in the US the expenditure is approximately $30 billion per annum, surpassing current out-of-pocket expenditures for conventional treatments by primary care physicians. CAM treatment include a variety of therapies (e.g. acupuncture, manual therapies, such as massage and chiropractic, qigong, tai chi, yoga, meditation, or spiritual practices), most of them based on ancient theories that differ markedly from the conventional medicine. Increased CAM utilisation has not been accompanied by a parallel increase in the quantity and quality of clinical evidence to support CAM claims. WHO recognises the importance of CAM and the contributions made to health care in many member states through recent World Health Assembly Resolutions and its first global strategy ever for the CAM area. In the strategy issues of policy, safety, efficacy, quality, access and rational use of CAM are addressed. The 56th World Health Assembly adopted resolutions on CAM, urges Member States, in accordance with established national legislation and mechanisms, to adapt, adopt and implement the WHO Strategy as a basis for national medicine programmes or work plans

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11. Complementary Therapies The evidence base

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Complementary therapy is defined as "a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health systems of a particular society or culture in a given historical period" (Ernst *et al*, 2000). It encompasses special diets, vitamins, mind/body approaches as well as physical/movement therapy. The popularity of Complementary therapy has grown considerably in Western societies over the last decade. A recent review reported that 31% of patients use Complementary therapies. Patients appear to use them to provide them with hope and a sense of control over their disease, symptoms and treatment.. However the evidence base for their effectiveness is sparse. The presentation will address which complementary therapies are being provided in palliative care, who is using them ,the evidence of effectiveness of the therapies provided in terms of patient benefit .and how the evidence base be strengthened.

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12. Effects and evaluation of haptotherapy for chemotherapeutical treated palliative cancer patients

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Introduction The purpose of this study was to evaluate a haptotherapeutic treatment and its effects on the well-being of cancer patients treated with chemotherapy in day care. Methods The study had a pretest-posttest semi-experimental design, with 31 patients in the experimental group and 26 in the control group. Patients in the control group were matched with patients in the experimental condition with respect to age, gender, type of cancer, type of chemotherapy, prognosis and the period between pretest and posttest. Standardized questionnaires were used measuring quality of life, mood, meaning of life, general functioning, symptoms, sleep quality, body awareness, and satisfaction with care. The intervention consisted of five haptotherapy sessions of 45 minutes each. Patients in the control condition received standard medical care. Results Most of the patients (61%) have a metastasized or palliative stage of cancer. Patients highly valued the haptotherapy treatment, and were satisfied with the personal attention and the relaxation they experienced. The haptotherapy treatment improved both the general quality of life and the cognitive and social functioning of patients. **Conclusion** Haptotherapy positively contributes to the of life of cancer patients during the period they receive chemotherapy. Haptotherapy as a type of complementary medicine is a potential valuable and effective intervention to raise the well-being of cancer patients undergoing invasive treatments.

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13. Users Perspectives on Homeopathy: Oscillating between Treatment and Companionship

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The study aims at exploring the views of people with chronic illness and practitioners on homeopathy, and their experiences with homeopathy, against the socio-political background in Austria.

Grounded theory (Strauss 1967) is used, encompassing interviews with users and homeopaths, and a group discussion with homeopaths.

Preliminary findings show an alternative conceptualisation of homeopaths' and users' roles: Users emphasise the homeopaths' ability to take seriously their complaints, their interpretations of illness and the impact of illness on daily life. The concept of trust appears in connection with the users' ability to deal with illness, the relationship with the homeopath, and the effect of homeopathic treatment. Trust is reproduced and also challenged during the course of treatment, and closely linked to the notions of self-sufficiency and empowerment, self-care and autonomy from conventional medicine (content-wise and system-wise).

Users' expectations and experiences point to key aspects of palliative care in terms of pain and symptom management, and dealing with the impact of illness on daily life, emphasising the importance of an ongoing trusting relationship from the users' perspective. The case of homeopathy might therefore serve as an example of uncovering users' needs and discussing them against the socio-political background of provision of palliative care.

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14. Oral problems - assessment and treatment Overview

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Oral problems are common in patients with advanced disease, particularly patients with advanced cancer (Table 1). These problems may be related to the underlying disease, the treatment for the underlying disease, a concomitant disease (or treatment), or a combination of the aforementioned causes. Oral problems are a major cause of morbidity in patients with advanced disease. These problems cause morbidity per se, and are also associated with a variety of physical (e.g. anorexia), psychological (e.g. depression), and social complications (e.g. isolation). Moreover, these problems can sometimes be associated with life threatening complications (e.g. septicaemia). Patients seldom report oral problems, even when such problems are causing significant morbidity. The reasons for this phenomenon are unclear, but one factor may be a perceived lack of interest amongst healthcare professionals. Hence, it is important that all patients are screened for oral problems, which involves taking a basic oral history and performing a basic oral examination. Many oral problems can be prevented by simple oral hygiene measures. Moreover, most oral problems can be treated with relatively simple interventions, although some oral problems will need more complex interventions (and involvement of the multidisciplinary dental team). Reference:Davies A, Finlay I. Oral Care in Advanced Disease. Oxford: Oxford University Press, 2005.

Table 1 - Prevalence of oral problems in studies involving palliative care patients with cancer.

PROBLEM	PREVALENCE
Oral symptoms	
Dry mouth	58-78%
Oral discomfort	33-55%
Taste disturbance	26-44%
Difficulty chewing	23-52%
Difficulty swallowing	23-37%
Difficulty speaking	31-59%
Halitosis	48%
Oral infections	
Oral candidosis	8-83%
Dental caries	20-35%
Periodontal disease	36%

15. Oral Hygiene

Margaret Sweeney

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Maintenance of oral hygiene is important for all groups of patients, especially those with advanced disease. It is well established also that there is a relationship between poor oral hygiene and advancing age for a variety of reasons. It can have physical, psychological and social consequences, can cause other oral problems such as dental caries and can also lead to certain systemic problems such as aspiration pneumonia. Clearly therefore, the maintenance of good oral hygiene is important both for general health and quality of life.

Oral problems are a major cause of morbidity in patients with advanced disease. Despite this, oral problems often assume low priority within palliative care settings and other medical specialties. The management of oral problems is often anecdotal rather than evidence-based and there is a dearth of reliable research on this topic.

It is important that oral care is seen as an essential part of whole body care of patients with advanced disease and that it becomes the concern of all healthcare staff.

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16. Intervention Possibilities in Cancer treatment Induced Mucositis and What about Guidelines.

Fred Spijkervet

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Oral mucositis remains a significant injury of the mucosa induced by drug or radiation therapy for cancer. Its severity has debilitating and painful side-effects and adversely affects the nutritional status of the patient. Mucositis is associated with an increase of systemic infections, days in hospital and overall costs, and these aspects have a negative impact on health related quality of life.Many studies have been published on intervention possibilities for prevention of mucositis, but most of these had small sample sizes, or used different scoring methods, which make comparison of outcomes difficult. Insufficient sample power, lack of sensitivity of the outcome measures, and study design flaws, make it hard to provide evidence-based guidelines on oral mucositis.This presentation will discuss meta-analyses of randomized clinical trials of intervention on prevention of oral mucositis and available guidelines.

-WorthingtonHV, Clarkson JE, Eden OB. Interventions for preventing oral mucositis for patients with cancer receiving treatment. *Cochrane Database Syst Rev 2006* (2):CD000978
- Stokman MA, Spijkervet FKL, Boezen HM. Preventive Intervention Possibilities in Radiotherapy and Chemotherapy-induced Oral Mucositis: Results of Meta-analyses. J Dent Res 2006;85:690-700
- Keefe D, Schubert M, Elting S. Updated clinical guidelines for the prevention and treatment of mucositis. Cancer 2007;109:820-31

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17. Bisphosphonates and osteonecrosis

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Intravenous bisphosphonate therapy is frequently used to palliate malignant bone diseases (bone metastasis) and hypercalcemia. Osteonecrosis (ON) of the mandible or maxilla is a recently described complication of this therapy, having a high impact on patients' quality of life. The incidence of ON is a few percent (ranging from 1% up to 7%), most common tumors include prostate, lung, and breast cancer, and multiple myeloma.
It seems that no major differences exist between the various available bisphosphonates, however, some reports suggest a higher incidence of ON with zoledronic acid. Underlying dental disease seems to be associated with ON, most patients report a prior traumatic incident to the teeth. In addition bacterial superinfections deteriorate the complication. No convincing data supports a relationship between the incidence of ON and demographic parameters, primary tumor, dosing interval, or cumulative drug dose, but it seems that patients who develop ON had longer infusion time and a higher number of infusions over long periods of time (> 2 years).
As practical management approach, before initiation of bisphosphonate treatment a careful dental-oral history should be undertaken and identified dental comordidity treated. Patients should maintain a good dental hygiene and undergo regular dental assessments. For patients who develop ON, a conservative, non-surgical approach is strongly recommended. A close interdisciplinary approach including the palliative care team, oncologist, dental specialist and oral surgeon should be cultivated.

18. Consultation and Involvement for Older Adults Living in Long Term Care Settings: An Action Research Study

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Aim
In the United Kingdom, end-of-life issues in care homes for older people are receiving increased attention. An action research study was undertaken in two care homes in order to explore how residents, relatives and staff can be involved in end-of-life care. In this paper, the nature of this consultation and involvement is presented.
Method
Data collection in the two care homes entailed: participant observation; a review of policies; and interviews with residents (n=8), relatives (n=12), staff (n=20) and primary care nurses (n=7). Data from staff education sessions and meetings of a staff working group were also collected. Data analysis entailed a content analysis of the interview transcripts and meeting notes. New ways to consult with residents were introduced in each care home.
Findings
Staff and relatives views about consultation with older adults reflected the extent to which the person was deemed to be capable of expressing views, occurring less for people with dementia. Revised assessment documentation and a group discussion based on reminiscence principles were introduced in the care homes to facilitate consultation. Both methods provided opportunities for individuals to express their views about end of life issues.
Conclusion
Assumptions cannot be made about older adults ability and willingness to participate in discussions about their future needs. Working with people with dementia in a group context is appropriate in this setting.

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19. Palliative Care in Nursing Homes - the need for organization development

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Background: Although the majority of the population says, that they want to spend their last days at home, in fact – in metropolitan areas in middle Europe – 80% die in institutions such as nursing homes and hospitals. "Death in dignity and character" therefore requires that the principles, philosophy and attitudes of palliative care – as they were defined by the WHO – are implemented in these institutions. Methods: A meta-analysis of several projects that aim at implementing palliative care in nursing homes will be conducted. The projects will be analyzed; special attention will be given to the designs and to the processes of the projects. Case studies that describe successful and failed examples of projects and their designs will be explored. Conclusions: The focus is on the question "How do we move from "palliphobia" to "palliation" (Eduardo Bruera) in palliative culture? Projects that aim at implementing palliative care require complex processes of organization development, that go far beyond trainings or education measures. Palliative care processes are changing the values and premises of the institutions which equals at changing the organizational culture (E. Schein, MIT). New and different communications, structures and decision making processes have to be established in the respective institutions in order to implement the philosophy of palliative care.

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20. Nursing homes and hospice - needs fulfilled?

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Introduction: Nursing homes (NH) and inpatient hospices (HO) represent different settings of care. HO are services for patients in advanced stages of an incurable disease. The demographic change will lead to an increasing need of NH residents for palliative care (PC). **Results**: We surveyed and assessed organisation and quality of physician-delivered care in inpatient hospices in the state of North Rhine Westphalia. 58 physicians (PH; 53%) and 33 heads of hospices (HH; 73%) thought the cooperation of general practitioners (GP) with a consultant in palliative medicine the best possible organisation of care. However, in no more than 36% of HO such cooperation was provided. 59% of PH had specialized in palliative medicine and 19% in pain therapy. Deficits were seen in communication and psychosocial skills of PH and expertise in use of analgesics. **Conclusion**: The survey results show good PH-delivered care in HO in most fields covered by this study. In order to facilitate high-quality PH care in HO, the usually GP-based care needs to complemented by specialists in palliative medicine. Palliative care teams can improve the quality of end of life care. In Germany, a new health law was established, facilitating specialised palliative care teams to complement the care of end-stage residents also in NH. NH must recognize that their responsibility for their residents includes awareness, education and networking in palliative care.

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21. A Palliative Approach in Nursing Institutions: Background and Perspective

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The aim of the paper is to describe the Nizhny Novgorod context of caring for older people in nursing institutions and discuss the possible ways for a palliative approach development in these settings. The population is aging globally. Between 1959 and 1990 in Russia, the number of persons aged 60 and over doubled. By 2015, out of all the people over 60, nearly one out of every three will be over 75. The Nizhny Novgorod region is one of the five areas, where demographic aging level is among highest in Russia. The rate of the elderly aged 60 or over has reached 19.9%. More than 70% who die are 65 or over. Older individuals coping with multiple progressive illnesses and socioeconomic difficulties experience complex medical, social and psychological problems.According to our research the elderly don't have specialist psychological care (81.4%); legal assistance (89.7%); assistance in products supply (17.1%), self-service (66.8%), and house keeping (41.7%). Majority of those who need (97.6%) don't have bed sitters. About a half are not satisfied with religious and spiritual support; 2/3 - with pain and other symptoms control; 88% would prefer to receive medical and supportive care at home. It was Nizhny Novgorod where the first geriatric service was found in the Russian Federation in 1989. The network of different medico-social institutions for the elderly has been created: nursing hospitals/departments, residential and mercy homes, homes for war and labour veterans, special homes for single elderly and social rehabilitation centers, etc. Today medical and social care for the elderly in the end of life is provided in community by GPs and district nurses and in nursing/residential institutions. Whilst care homes are a home for living, many of the residents also die there. The key element of palliative approach in nursing units is the end-of-life care. Within the country, the provision of palliative care in care homes has not become the focus of national or local initiatives yet. In care homes end-of-life care is impeded by lack of staff, inadequate training, poor symptom control and lack of psychological and emotional support for residents and cares. That is why special attention must be provided for implementing the end-of-life philosophy, culture, and education in long-term care settings. Hospice units or wards set up in the structure of care homes could fill the gap in end-of-life care. Special educational and management programmes are needed as well as inexhaustible enthusiasm of homes' staff and advocates, support from policy makers, and charitable funds.

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22. THE INTRAVENOUS TO ORAL MILLIGRAM POTENCY RATIO OF MORPHINE

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Aim: The parenteral (IV): oral (PO) conversion ratio for morphine (M) is controversial; some suggest 1:2 others 1:6. Serious under- or over-dosing (depending on the ratio used) may occur. We conducted a prospective study in consecutive patients to evaluate our clinical practice. **Methods**: Eligibility criteria: 1) continuous IV M for pain 2) good pain control for 24 hours before conversion to PO M 3) Stable co-analgesic doses for 48 hours prior to conversion and unchanged throughout the study. **Results:** 62 (32 males & 30 females) underwent successful conversion from IV M to PO M; median age 58 (Range (R): 34-84). Most common diagnosis was lung cancer (31%). All had metastatic disease. Median total IV M dose: 48 mg (R:12-330). Time to pain control using IV M was 3 days(R: 1-11). Conversion ratios (CR) used were 1:3 (40 %), 1:2.5 (37 %), 1:2 (8%), and 1:3.5(2 %). Pain control was maintained or improved in 94%. IV M dose before conversion was significantly higher (P<0.0001) in those who underwent 1:3 CR (72mg, R: 20-240) versus 1:2.5 CR (24 mg, R:12-48); this rendered an unbiased comparison of the efficacy of the two ratios impossible. **Conclusions:**1) Using the M (IV: P0) 1:3 conversion ratio yielded good pain control after route conversion during repeated dosing 2) A ratio of 1:3 was as safe as 1:2.5 despite the significant differences in IV M doses 3) The 1: 3 M IV: P0 relative milligram potency ratio appears correct and practical for most patients over a wide M dose range.

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23. INTERMITTENT CANCER PAIN: CLINICAL IMPORTANCE AND CLASSIFICATION

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Aim: In this study we report the characteristics of intermittent cancer pain proposing a new clinically based classification.**Methods:**Consecutive patients referred to a palliative medicine unit underwent a comprehensive pain evaluation including available laboratory and radiological studies, at the time of consultation.**Results:**100 consecutive patients reported 158 separate pains. The pain was continuous(CP) plus intermittent(IP) in 60%(N=95), IP alone 29%(N=46), or CP alone 11%(N=17). IP were further classified as breakthrough pain(BP) in 67% (N=95) and non-breakthrough pain (NBP) in 33%(N=46). BP and NBP were each sub-classified into 3 categories:(1) incident (2)non incident (3)mixed pains. A fourth category was added only to BP: end of dose failure. The etiology of IP was somatic (58%), visceral (24%), neuropathic(7%) or mixed(11%). Median duration of IP was four months with a median daily frequency of four episodes. Incident pains made up (N=66, 47%) nearly half of all IP. According to our classification incident pain was part of BP in 60%(N=39) or NBP in 40%(N=27). Incident NBP received less treatment than incident BP and the pain was less controlled.**Conclusions**:1) IP is a major problem in cancer patients 2) NBP is a common but underrecognized form of cancer pain 3) NBP is a less defined and controlled than BP 4) incident NBP accounts for half of all incident cancer pain 5) Variable IP definitions and classifications makes comparisons between studies difficult.

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24. Managing skin irritation of Buprenorphine TTS (BUP TTS)

Johan Van den Eynde

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Introduction: skin irritation is a side effect of the path system, witch occurs in 17% of the treated patients. The degree of irritation varies from light (itching, erythema) to severe (bullae).
Once the irritation has started rotation of application area fails to stop the sensitising process.
10% of the patients stops BUP TTS due to intolerable skin irritation. Aim: to reduce the percentage of therapy stop. Method: once the skin irritation appears, before the next path is applicated the skin area is sprayed with a corticoid powder device (secondary prophylaxis strategy). Results: 51 patients had BUP TTS for both malignant and non-malignant pain. 6 pts (12%) developed skin irritation after 8-55 (av. 26) weeks. All were treated with fluticasone spray and were able to continue BUP TTS until the end of the study. In 5pts (83%) skin irritation disappeared. In 1 pt (17%) it decreased and was tolerable (itching). In 0 pt (0 %) BUP TTS therapy had to be stopped. There were no problems of BUP TTS coming loose. Conclusion: despite rotation of application area, skin irritation often appears due to BUP TTS. It can be successfully treated by fluticasone spray before application. BUP TTS therapy had no longer to be stopped.

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25. Nasalfent, a novel intranasal formulation of fentanyl, is well-tolerated during treatment of breakthrough cancer pain

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Aim: To determine the acceptability and tolerability of fentanyl citrate nasal spray (FCNS [Nasalfent]) in the treatment of breakthrough cancer pain (BTCP)
Method: FCNS is a novel formulation of fentanyl, using PecSys a proprietary system designed to deliver lipophilic molecules to the nasal mucosa, via a conventional nasal spray. A Phase II, open-label, multi-centre inpatient study titrated 18 patients to identify an effective dose of FCNS (25-800 g fentanyl citrate) for episodes of BTCP, occurring in patients on opioids for background pain. 15 patients were then treated and assessed for up to 4 BTCP episodes. Acceptability and tolerability were assessed through a patient satisfaction

questionnaire.
Results: 13 patients completed the overall satisfaction questionnaire. All strengths of FCNS (0.25, 1.0 and 4.0mg/ml) were well tolerated in the dose range (25-800 g). A total of 14 possibly / probably drug-related adverse events were reported in 7 patients; all were transient and 79% were rated mild. No significant nasal findings or symptoms of irritation were seen at any dose. 77% of patients rated FCNS as good or better.
Conclusion: BTCP is a significant clinical problem, complicated by common oral problems that restrict oral drug application. Nasal delivery overcomes these problems. This study provides clinical evidence for FCNS as an acceptable and well-tolerated treatment for BTCP in cancer patients receiving opioids.

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26. Validation study of the Doloplus scale in six languages.

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Pain is a major healthcare problem especially in older persons and is still under-assessed and under-treated particularly in those with cognitive impairment. A number of clinical tools has been developed over the last fifteen years, but not all have been validated, nor translated nor validated in other languages than the original scale. Doloplus® has been one of the first scales to be published and statistically validated in 1999 by B Wary and the Doloplus® team. The validation characteristics are available on the Doloplus® site "doloplus.com . Translation in other languages was however missing and awaited by the geriatrics community. Considering the need for validated tools at an international level and the frequent request from many practitioners worldwide (more than 20 countries have contacted us since the creation of our web site in 2000), Doloplus® has been translated and validated in six languages, English, Dutch, German, Italian, Spanish and Portuguese and this study reports its validation. Twelve teams (two for each language) have been selected on the basis of their experience and competence in geriatrics and in pain evaluation of elderly patients with communication disorders. Each team tested the scale in her/his native language with 20 elderly persons. Test-retest reliability and inter-rater reliability have been analysed and showed excellent results in every language. The validation of this scale will allow its use on a broader scale in the evaluation of pain of elderly persons with communication disorders.

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27. Palliative Sedation in an Acute Care Hospital: Policy, Ethics and Case Studies

Kelli Gershon, Ahmed Elsayem

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Palliative sedation rates range between 2% and 50% for patients at the end of life. Generally, palliative sedation is used for refractory symptoms at the end of life and is supported both ethically and legally. Ethical justifications that support the use of palliative sedation include patient autonomy, beneficence, non-maleficence and the rule of double effect. While palliative sedation is widely accepted in the hospice setting, bringing palliative sedation into an acute care setting can be challenging. In our discussion we will review (a) how we established a palliative sedation policy for the Palliative Care Unit (PCU) at a major acute care cancer hospital, (b) barriers we faced during the development of the policy, (c) our actual policy, and (d) how palliative sedation is implemented in our PCU. We will present data from our experience using palliative sedation in our PCU, including reasons for sedation and outcomes.
This discussion will include looking at regulatory boards that create barriers to effective palliative sedation, and non-hospice/palliative healthcare providers providing sedation without training and policies. Two case studies related to palliative sedation will be discussed. The first case will involve a patient with refractory pain who was transferred to the ICU for "sedation." The second case will involve a patient who requested palliative sedation for psychological distress.

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28. View from the Observatory

David Clark

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

The International Observatory on End of Life Care was founded at Lancaster University in 2003 as the first research and development project to concentrate on the comparative analysis of hospice and palliative care around the world. Its aim is to add research effort to the task of promoting the development of hospice and palliative care – locally, nationally and globally. It engages in projects and activities that have academic merit but which are also concerned with policy and service development and which can inform changes in clinical practice. Observatory staff characterise their approach as that of a 'critical friend' – supportive of the overall effort to improve palliative care whilst adding the distance and objectivity that comes with an academic orientation. The Observatory operates within three 'programmes' of activity. 1. *global and historical development'* maps palliative care development through a rigorous method of producing in-depth 'country reports'; 2) *patient and carer experience* focuses on the giving and receiving of care in the context of life-threatening illness, including narratives of experience; end of life issues for older people; places of care; social inequalities and bereavement; 3) *service and policy evaluation* centres on the need to generate an 'evidence' base for the delivery of hospice and palliative care services, in different settings and for patients with varying diagnoses and problems. This presentation will highlight current priorities and future goals in the work of the Observatory.

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29. Palliative Care in Europe are moving forward

Carlos Centeno

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The EAPC Task Force on the Development of Palliative Care in Europe was created in 2003 and the results of its work are now being reported in full in conferences and several publications, such as the Atlas of Palliative Care, as well as in papers in peer reviewed journals.

Different models of service delivery have been developed and implemented throughout the countries. For example, in addition to the United Kingdom (UK), Germany, Austria and Poland and more recently, Italy, have a well-developed, extensive network of hospices. The model for mobile teams or hospital support teams has been adopted especially in France. Day Centres are a development characteristic of the UK with hundred of these services. The number of beds per million inhabitants ranges between 45-75 in the most advanced countries to only a few in others. The countries with the highest development of palliative care as measured in terms of ratio of services per 1 million inhabitants are: in Western Europe: the UK with 15; In Central and Eastern Europe: Poland with 9; and in the Commonwealth of Independent States: Armenia with 8.

Palliative medicine has specialty status in just two European countries: Ireland and the United Kingdom. In four countries it is considered a sub-specialty, for which a second certification is required: Poland, Romania, Slovakia and Germany. Some 10 other countries have started the process of certification for palliative medicine, in all cases opting for sub-specialty status that follows full recognition in an established specialty.

Our group paid special attention to identify barriers to the development of hospice and palliative care, specifically in 22 countries of Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS). From the varied data obtained, we identified four significant barriers to the development of hospice and palliative care in CEE and CIS: lack of funding; lack of opioid availability and choice; lack of public awareness and government recognition of palliative care as a field of specialisation; lack of palliative care education and training programmes. Despite huge variations in the levels of provision across many countries, data collected in the 'Eurobarometer' survey reveal many common barriers to development of hospice and palliative care in CEE and CIS.

We have planning new project for the next three years. In the next future we will be working together again to disseminate these results and for to do available to the professionals and researchers more information and materials to contribute to the higher development of Palliative Care resources in the big Europe.

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30. Council of Europe Recommendation: the Purpose and the Impact

Natasa Milicevic

BELhospice, Belgrade, Serbia

The need for increasing palliative care provision presents great challenge for all European countries. For that reason palliative care became a topic of particular interest for Council of Europe. Inspired by different documents and declaration on the protection the dignity of all human beings, and the rights which stem there from, and following the expert committee's report on the development of palliative care across member states, Council of Europe "Recommendation Rec 2003 (24) on the organization on palliative care" was issued. Translation of this useful tool was coordinated by EAPC-east Centre. It is now accessible in 20 European languages.

The purpose of the recommendation was to indicate the differences in palliative care development among the member states and to define a new standard for palliative care provision across member states. Since all countries of the Council of Europe have adopted this document it has put a unique moral obligation on all European Governments to follow the recommendation and take in serious consideration their own national policy framework for palliative care.

The impact of the recommendation in different countries depends on the existing level of palliative care provision, including existing national policy, services, palliative care workforce capacity and existing educational level in this field. In those countries in which palliative care is underdeveloped the impact of the recommendation can be measured by the readiness of decision-making people to change, in collaboration with health care professionals, NGOs, patients and their family members, the national policy framework for palliative care.

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31. The Social Worker in Palliative Medicine

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Aim: Identify the influence and effect of Palliative Medicine (PM) Social Worker (SW) role in PM teams across the spectrum of care. SW functions include: 1. Understanding family systems 2.Using a multi-dimensional psychosocial assessment to identify adverse functioning in patient and family caregiver 3. Co-facilitating a family conference to integrate medical and psychosocial information and post acute care. **Method:** We audited 150 psychosocial assessments and discharges of patients admitted to an acute inpatient PM unit and trends over ten years using an electronic database, as an outcome to SW intervention. **Results:** SW identified adverse functioning for both the patient and family caregiver as reduced performance status and problem solving, impaired communication and adjustment to illness. 52% of patients and 35% of family caregivers had inadequate support system. As a result 93% of the patients had a family conference. Post acute discharges were home with care 44%, follow outpatient 19%, placement 17%, or died on unit 20% remained consistent over ten years. Ten year trends revealed younger patients, increased case mix index, increased admissions, yet reduced length of stay. **Conclusion**: SW improves care by overcoming social and emotional barriers to care, and by reducing health care costs through decreased hospital days despite worsened case mix complexity. Addressing specialized needs of chronic life limiting illness is cost effective.

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32. Emotional preparedness at the time of wifes death predicts psychological morbidity for widowers 4-5 years after the loss - a population based follow-up.

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Background: When a cancer patient dies, the preceding fatal prognosis represents a forewarning which, if explicitly communicated to the spouse, may provide opportunities for gaining emotional preparedness for the loved one's death. *Method:* In a population-based study on 907 widowers, we investigated within age strata the impact of the widowers' degree of emotional preparedness at the time of their wife's death due to cancer on their risk of morbidity four to five years later. *Results:* A low degree of emotional preparedness at time of spouses' death increases the risk for (among other symptoms): depression (RR 1.9), anxiety (RR 2.4), emotional numbness (RR 2.2), low level of self-assessed quality of life (RR 1.7), no or little work through grief (RR 2.5), chronic pain (RR 4.6) and being on long-term sick leave or having had early retirement (2.1) in young men (38 to 61 years old). However, low degree of emotional preparedness did not increase the risk for morbidity in older widowers (62 to 80 years old), except for repeated painful memories (RR 1.9) and experience of heightened startle response (RR 3.6). *Discussion:* These findings call for further studies to identify care-related facilitators and inhibitors of high emotional preparedness as well as intervention studies to understand how these can be incorporated into clinical practice to avoid additional risk of long-term morbidity among men who lose a wife to cancer.

33. Promoting Resilience through Bereavement by Connecting Diversity Notably by Connecting Flesh and Soul, Loss and Bliss

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Inspired by the French neuropsychiatrist Boris Cyrulnik recent book (De Chair et d'Âme, Odile Jacob, 2006, 257p), we will present in this paper a new biology of attachment and resilience notably explaining why for each of us, life is a permanent conquest, never fixed in advance. Neither our genes neither our original environment preclude us from evolving. Everything remains possible. The goal of this presentation is to send a message of hope facing loss and bereavement, a message of human freedom facing genetic and environmental «determinants». Cyrulnik argues that one can discover in himself and around himself the means that permit to come back to life and go ahead still keeping in mind and in flesh his wound. Life paths follow narrow ridges surrounded by every form of vulnerabilities. Being invulnerable would mean being impossible to be wounded. Each time of life has its force and its vulnerability. Unwounded moments are the result of one capacity to master, indeed to overcome that in oneself is the matter of a constant reshaping of its biology, its affectivity and its social and cultural environment. Without suffering, would one be able to love? Without affective losses, would one need to feel safe? Life would be tasteless and one would possibly not have the appeal to savour it.

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34. Palliative Care: The Economic Perspective for Families and Health Care System

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Background: Demographic changes, new health technology developments, and an increase in life expectancy have resulted in an aging of the population. This situation has increased the demand for health and social services for people with diminishing abilities or a terminal disease. The main **purpose** of this study was to provide policy makers, policy analysts and other groups with information regarding the economic burden of personally borne costs attributable to the palliation phase of care and the context in which they occur. **Method**: Prospective survey of 250 family caregivers looking after terminally ill patients registered in a regional palliative care program in five regions across Canada. This study was comprised of four specific objectives: Identify and measure resource utilisation (goods/services) during the palliative phase of care; estimate resource costs; identify who delivers these goods and services (public health care system, families, private for profit and non profit, voluntary sector) and determine who (patient, informal caregiver, government, volunteer organisations, etc.) pays for what. **Results**: The study provides: descriptive data for the physical resources & costs; average personal costs; estimation of health care service utilisation and related costs. **Conclusion:** The study results allow us to draw a clear picture that highlights the extent to which, and the areas that, families need to be assisted in their efforts to care for their loved ones.

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35. When a child loses his brother or sister: interest of dynamic peer support groups.

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Background: Loss and mourning in children can lead to suffering and psychopathology. When a child loses his brother or sister, various supports are proposed, but are rarely evaluated.
Aims: Active protocol for observation and support. Collaboration with parents. Appropriate tools to evaluate this protocol's acceptability, feasibility and clinical interest.
Method: 3 groups of 4 to 8 children, from 6 to 16 years old experiencing mourning in their sibling since less than 1 year. Before inclusion: family interview and child's exam by a pediatrist and a psychiatrist; collection of Child Behaviour Checklist and standardized general data. After inclusion: 4 meetings for each group, based on expressing and sharing experiments and emotions, with mediations, conducted by 2 trained therapists, who also evaluate each child and group's dynamics; new evaluations by the pediatrist and the psychiatrist at 1, 6 and 12 months.
Results: For the 17 first included children and their parents, acceptability, feasibility and compliance are good. The first clinical evaluations show a positive evolution.
Discussion: What about these results, the refusal of certain families to take part to the study, requests of families and healthcare teams "out of protocol", the help to the excluded children?
Conclusion: preliminary encouraging results, but to be continued and confirmed; changes to be brought to the framework; future perspectives; psychopathological hypothesis.

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36. Does recognition of the dying phase have an impact on interventions during the last three days of life?

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Patients often undergo interventions not aimed at comfort during the dying phase. We investigated possible differences in the application of interventions between patients who died expectedly and patients who died unexpectedly. We distinguished interventions with a therapeutic, diagnostic, or comfort promoting focus. We included 489 of 591 patients who died in one of five hospital departments, one of seven nursing home departments, or one of three primary care settings in the Netherlands between November 2003 and February 2006. After the death of a patient, a nurse assessed the interventions that were applied to the patient during the last three days of life. Information about interventions that were possibly discontinued during the dying phase was gained from the patient's medical record. Of the 489 patients, 380 (78%) had died expectedly. Patients who died expectedly were significantly more often free of diagnostic interventions (63%) as compared to patients who died unexpectedly (43%), (p = 0.00). Comfort promoting interventions were applied to significantly more patients who died expectedly (55%) as compared to patients who died unexpectedly (39%), (p = 0.013). Therapeutic interventions were evenly applied to both groups of patients. We conclude that in the different care settings recognition of the dying phase resulted in a decrease in the number of diagnostic interventions and an increase of the number of interventions aimed at comfort.

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37. Defining Unbearable Suffering

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Introduction The purpose of this study was: how do professionals and non professionals defined unbearable suffering both for themselves and for terminally ill patients.In the Dutch jurisprudents for Medical Decisions End of Life unbearable suffering is mentioned but not defined **Methods** According to the Delphi methodology, two panels of 16 persons,(8 medical practitioners and 8 nurses, and 16 non professionals), were included. Their reasoned opinions are expressed in four written rounds of questioning. 12 and 10 panel members finished all 4 rounds of questioning **Results and Discussion** In the **1st round** of questioning both the panel members were asked to describe unbearable suffering, both for themselves and their fellow human being terminally ill. Both the panel members mentioned different answers. In the **2nd rnd** the panel members were asked to value all the answers. In the **3rd rnd** the panel members were asked about the answers scoring an average rate higher than 5.5 from round 2 The results of the 2 panels were very different. There was no consensus at all. In the **4th rnd** the panel members were asked to give their opinion on the conclusion of the other panel. Both panels found their own panel opinion the best **Conclusion**1.there is no consensus about the definition of unbearable suffering 2.unbearable suffering is not an unequivocal concept.3. concerning the description of unbearable suffering the majority provides different parameters for one selves and for terminal ill patients

38. Measuring pain and symptoms in resource-poor settings: a comparison of verbal, visual and hand scoring methods in Sub-Saharan Africa

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AIM Self-report measurement methods are often unfeasible in settings with limited patient literacy. This study aimed to compare 4 methods. **METHOD** Patients in 5 African palliative care settings completed cross-sectional assessment for pain then symptoms using a) APCA African POS scored verbally and b) scored using "hand" method, where a closed fist =0 no problem, 5 open fingers=worst problem; c) Faces Scale; d) visual scale using a Gerry can image where an empty can represented no problem and a full can =worst. The Gerry score was transformed so all measures used a 0-5 scale. Matrices of correlational coefficients reported strength of methods' relationship. Graphs plotted scores by methods. **RESULTS** 315 participants, 71.1% HIV, 35.6% cancer, 49.2% rural. All associations significant at 0.1% level, & correlation coefficients high, but there were consistent differences between methods. Taking POS verbal score as validated gold standard, pain correlated highly with hand POS score (r=0.90), and faces scale (0.84), less highly with the Gerry Can visual scale (r=0.74). POS verbal symptom score correlated very highly to POS hand scale (r=0.9) and faces scale (r=0.83), but relationship further weakened for Gerry can (r=0.73). Graph plots demonstrate POS, faces and Gerry can scores diverge at scale extremes and fit closely through mid intervals. **CONCLUSION** POS scores are reliably measured by hand scores for those unable to score verbally (an important validation of current practice). Alternative methods offer high, but weaker, correlation.

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39. Delirium Observation Screening scale: its use in cancer patients after opioid change

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Aim
Delirium is a common complication in the palliative phase of cancer patients and is often related to opioid use. Patients with a risk of developing a delirium at the Palliative Care Unit of our cancer center are monitored for 72 hrs using the Delirium Observation Screening (DOS) scale. In case of a DOS-score ≥ 3, a diagnosis is established by a physician. We earlier assessed a change in opioids (shift or increase in dose) as a risk factor for the development of delirium and thus as an indication for monitoring. However, the DOS has never been evaluated for its use in cancer patients after a change in opioids.
Method
Records of the patients admitted between February 2004 and March 2006 were studied for risk moments after a change in opioids.
The number of patients with an established diagnosis of delirium within 4 days after the start of the DOS were assessed for DOS scores < 3 and ≥ 3, respectively.
Results
The DOS was used for 353 risk moments after a change in opioids. The DOS-score remained < 3 in 309 cases. In this group, a delirium was found in 8 patients. In 39 cases, a DOS-score ≥ 3 was found. In 17 of them the diagnosis delirium was established. Five DOS records after opioids change were missing.
Conclusion
These results suggest a high sensibility and a rather low sensitivity of the DOS in cancer patients after opioid change with the standard cut off point at ≥ 3. Further research is needed to establish the optimal cut-off point for the use of the DOS in these patients.

40. Predictive value of the prognostic inflammatory and nutritional index (PINI) in terminally ill cancer patients

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Aim : We aimed to identify biological markers correlating with a survival of 15 days or less.
Patients and Methods : From January 2004 to May 2006, terminally ill cancer patients entering in a palliative care unit were prospectively analysed for inflammatory and nutritional proteins (ferritin, fibrinogen and PINI = [alpha-1 acid glycoprotein x C-reactive protein(CRP)] / [albumin x prealbumin]) and serum lipids (total and HDL cholesterol). Amongst 285 consecutive patients, 246 were evaluable. Uni- and multi-variate analyses according a logistical regression were used to estimate the relative risk (RR) of death within two weeks based on baseline patients characteristics at admission.
Results : 133 men and 113 women were analysed (median age : 64.4, range : 18-93.7). In univariate analysis, RR of death within two weeks were 2.67 if CRP>150mg/l (95%CI, 1.36 to 5.23 ; p=0.004), 4.08 if ferritin>2500µg/l (95%CI, 1.84 to 9.08 ; p<0.001), 2.85 if albumin>20 and ≤25g/l (95%CI, 1.31 to 6.20 ; p=0.008), 4.43 if prealbumin ≤0.05g/l (95%CI, 1.98 to 9.96 ; p<0.001), 3.88 if PINI>20 and ≤100 (95%CI, 1.77 to 8.48 ; p<0.001) and 3.37 if PINI >300 (95%CI, 1.56 to 7.21 ; p = 0.002). In multivariate analysis, PINI (p=0.033) is a strong predictive factor.
Conclusion : The measurement of PINI may help physicians to evaluate the short-term life expectancy.

41. Use of the APCA African Palliative Outcome Scale (POS) improves nursing assessment of palliative care patients

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Aim of Project The need for palliative care in Africa has never been greater. The burden of provision falls to nurses, yet the majority have no palliative care training. APCA recognised the need to measure the 'quality' of the care provided through the use of an outcome scale. **Method** The APCA African POS, consisting of 10 patient and family-level indicators, is the first African palliative outcome scale. It was piloted in 8 African countries, and both content and consensus validity were assessed along with data on utility. These were measured using anonymous feedback from nurses in the 11 participating centres. Open text responses were analysed. **Results** The analysis demonstrated that nurses had used the measure as a structured tool to aid the assessment process. The main clinical gains from using the tool were that it 'gave nurses permission' to ask difficult questions, the patients "opened up" to them, ensured regular systematic assessment of the domains relevant to palliative care, and helped improve treatment and management of specific problems. **Conclusion** The use of the APCA African POS can help improve the provision of palliative care. It is a tool to measure the quality of services provided and can be used as an educational and assessment tool thus empowering the nurses to 'dig deeper' and ask questions that they otherwise find difficult to ask.

42. See page 67

43. See page 69

44. EPCRC: Improved treatment of pain, depression and fatigue through translation research

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The European Palliative Care Research Collaborative (EPCRC . http://www.epcrc.org) consists of eight participating centres from six European countries: UK, Italy, Switzerland, Germany, Austria, and Norway, coordinated by the Pain and Palliation Research Group at the Medical Faculty, NTNU, Trondheim. The collaborative proposal was successfully evaluated in 2006 and received a 2.8 mill Euro EU funding for a 3 year period. Parts of the application are based upon previous work undertaken within the context of the EAPC Research Network. The project has the following aims: 1. To identify genes and genetic variation relevant for inter-individual variation in opioid responses and genetic variation that may identify patients at particular risk for developing cachexia.

2. To improve classification and assessment of pain, depression and cachexia by computer assisted approaches. 3. To combine the new knowledge of symptoms, genomics and assessment in an internet-based system for implementation of European evidence-based guidelines, which will include standardized assessment and individualized treatment plans for pain, depression and cachexia, and 4. To develop a long lasting European Collaborative in palliative care cancer research. The collaborative is dependent on broad input and feedback from the palliative care community and will use the EAPC conferences to this end. We believe that this collaborative has the potential for long lasting impact on palliative care in Europe.

Three workshops will present the preliminary results. These results will need discussion and feedback from the Palliative Care Community, space and opportunity will be given to all participants during the workshops. Three workshops will be organised – covering the three lag symptoms, depression, cachexia and pain.

45. Hydration attitudes and practice: The nursing perspective.

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Throughout the care of terminally ill patients and their families, nurses are confronted with the subject of dehydration and the question of artificial hydration at the end of life.

When a patient gradually ceases to drink, the family often worries about their loved one experiencing dehydration. When a dying person becomes unable to express his or her needs , the decision shifts from the patients to their caregivers, who are concerned to find the right intervention to ensure comfort at the end of life.

However, different attitudes (some cultural) exist on how this goal can best be achieved. There are sound medical arguments for both terminal dehydration or artificial rehydration within terminal care. Today, the decision often depends on the setting of care, and the personal preferences of the members of a healthcare team. It is a priority for the nurse to frequently evaluate the comfort of the patient, and any signs of discomfort should lead to a reassessment of the chosen intervention. Open communication with family members is essential to reassure them that everything possible is being done for the comfort of their loved ones to the very end.

46. Hydration attitudes and practice Ethical decision-making

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Background: Ethical decision-making has a major role in palliative medicine, as topics like hydration in terminal care are being discussed controversially. There is no clear evidence that increased fluid therapy alters comfort, mental status or survival time of dying patients. Respect for patients' wishes is an indispensible precondition for ethically justifiable decision-making. **Methods:** HOPE (Hospice and Palliative Care Evaluation) is the core documentation system for palliative care services in Germany. An ethical decision-making checklist was used in two annual evaluation periods (2004 und 2005). **Results:** In 1211 of 2214 (in 2004) and 779 of 1903 (in 2005) patients documentation was completed at the time of admission. Advanced directives were available for 17% / 21% of the patients. Waiving treatment options were documented most frequently for resuscitation (57% / 59%) and most scarcely for fluid substitution (16% / 15%).**Conclusions:** Hydration can be withheld or withdrawn if this is consistent with the dying patient's wish. When a conflict arises, the decision to administer or withhold hydration needs to include ethical deliberations as well as knowledge of risks and benefits. Whenever possible, the decision-making process should include health care providers, the patient and his family, for a deep understanding of ethical and clinical reasons for the chosen treatment is a condition sine qua non for avoidance of feelings of guilt and burnout.

47. When Is It Time To Stop - Cultural Perspectives

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The vast majority of terminally ill patients will become unable to maintain oral hydration for periods ranging from hours to weeks before death. The main reasons for reduced oral intake include delirium, nausea, dysphagia, and profound anorexia. Alternative hydration can be administered by the intravenous, subcutaneous, rectal, and gastric route. Healthcare professionals, patients, and families differ in their attitudes and beliefs toward artificial hydration. The decision making process regarding artificial hydration is guided by the presence of clinical indications [clinical evidence of hydration, delirium, severe fatigue, etc.), clinical indications for specific routes [presence of an indwelling intravenous catheter, bleeding risk, rectal pain, etc.], logistic considerations [ability to delivery parenteral fluids at home, presence of caregivers, financial considerations, etc.], and patient and family values [the meaning of hydration and dehydration within the context of care and end of life]. Some major cultural differences exist in the perception of futility of hydration among ethnic groups and also among healthcare professionals in different regions of the world or in different clinical settings within the same region of the world [i.e. acute care versus hospice-based physician and nurses, etc.]. This presentation will discuss the main clinical issues and cultural considerations regarding the initiation and discontinuation of artificial hydration. Areas of future research will be proposed.

48. Stopping hydration a step towards euthanasia

Bregje Onwuteaka-Philipsen[1], Agnes Van der Heide[2]

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Decisions to forgo potentially life-prolonging treatment are taken relatively frequently at the end of life. A European study on end-of-life decisions showed incidences ranging from 6% (in Italy) to 41% (in Switzerland) of all deaths; for most countries (Belgium, Denmark, The Netherlands and Sweden) the incidence was between 20% and 30%. In all 6 countries forgoing artificial administration of nutrition or hydration was the type of treatment that was forgone second most frequently. When studying the relation between forgoing artificial administration of nutrition or hydration and euthanasia, it is relevant to consider the different elements from the definition of euthanasia: administering a drug, doing so with the explicit intention to hasten death, doing so on the explicit request of the patient, and the effect of the act being the hastening of death. Aim is to examine these elements in patients for whom artificial administration of nutrition or hydration was forgone. Furthermore, characteristics of these cases will be described. This is done using data from a death certificate study for which we mailed questionnaires to physicians attending 6860 deaths that were identified from death certificates in 2005 in the Netherlands. The response rate was 78%.

49. Building Resilience into Family Palliative Care: unlocking resilience in the family and its implications for clinical practice

David Oliviere

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A new concept of resilience (the capacity to be positive and build a new life in the face of great difficulties) is permeating palliative care and embraces the importance of practitioners being able to work with processes of vulnerability and risk together with harnessing and promoting patient and families' strengths and resources.

The aims of the project were to: explore the concept of resilience in palliative care; to identify key findings in the increasing international literature on resilience; to consider evidence from practice on how clinicians promote resilience; and make recommendations for practice with families/caregivers.

A series of nine study days on resilience were conducted, with themes ranging across palliative care. Thirty-six presentations were made by leaders in practice and academia from psychology, psychiatry, sociology. The growing knowledge base was analysed, based on a thematic analysis of the study material generated for the study days and the key literature.

The results of this study throw light on a range of concepts employed in palliative care that promote resilience and have useful implications for the multi-faceted processes involved in how families cope, resilient family typologies and how clinicians assess and intervene, with the tools that promote coping and achievement.

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50. Palliative care in a multi cultural society

Nathan Cherny

Shaare Zedek Medical Center, Cancer Pain and Palilative Medicine, Jerusalem, Israel

Across all cultures, advanced cancer and terminal illness present a common set of challenges: Fear, uncertainty, loss, physical deterioration, intellectual deterioration, dependency, physical suffering, emotional suffering of anxiety and depression, spiritual distress related to hope, meaning, and purpose.

As amazing as the commonality of the challenges, is the diversity of patient and family responses to these challenges. Culture is a collective environment that refracts perception and influences these responses. It is derived from heritage, collective memory and identification and shared values and beliefs. The world and its peoples represent the scope of cultural diversity. But, within each culture itself, there is, again, vast heterogeneity: a spectrum of beliefs and patterns of response that are influenced by idiosyncratic local factors, education and family factors. Cultural sensitivity and competence have become a motto of palliative care.

In addressing cultural sensitivity, the general approach has been a reductive approach of describing differences. The "Jewish approach to death and dying" the "Mediterranean approach to issues of truth telling" The "Japanese approach to the doctor patient relationship" . Since similarities and overlap are so common, clinicians should be wary of reductive anthropology such that each patient and each family must be taken on its own merits, but with an awareness for potential issues that are common to their cultural milieu.

Clinicians should avoid clichés and stereotyping and need to be aware of range of culturally appropriate responses to any given clinical challenge. This approach requires the dexterity to cope with a wide range of potential coping strategies of patients and their families and the tolerance and sensitivity to deal and cope with the patients and family behaviours and responses that are foreign to our own.

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51. RELATION BETWEEN JOB STRESS AND SATISFACTION AMONG PALLIATIVE CARE PROFESSIONALS

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Aim of study
The aim of this study is to identify the job stress implied in palliative care for children and his relation with job satisfaction of professionals.

Method
We realized a corelational study on professionals group of 30 women, who are working in palliative care units for children. For job satisfaction evaluation we used an "SP Questionnaire" with 4 factors: remuneration and promotion, leadership and relationships.

Results
Death and dying represent a major source of job stress among professionals because the patients are children and the professionals has formed a close relationship with them. Other stress sources are: several deaths of children occurring in a short time, resource limitations, difficulties in relationships with other professionals, a lack of understanding of roles, difficulties in building a culture of palliative care despite. Concerning the job satisfaction, the professionals have a significantly lower level of job satisfaction (62%) or a medium level (38%) which are correlated with a higher level of job stress.

Conclusions
The professionals must benefit from more effective training in communication skills, including helping patients through controlling symptoms and having good relationships with patients, relatives and other professionals.

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52. Burden and support needs of family caregivers of patients with malignant brain tumors

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Aim Many patients with malignant brain tumours suffer from cognitive impairments and psychiatric symptoms, often requiring 24h support. The aim of the study was to investigate the burden and the support needs of their family caregivers. Methods Family caregivers of patients with highly malignant brain tumors (astrocytoma III or glioblastoma) were asked to participate in a cross-sectional survey. Beside demographic data the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW), the Hospital Anxiety and Depression Scale (HADS) and the Burden Scale for Family Caregivers (BSFC) were used. A narrative interview was performed to learn more about the individual needs of the participants.Results27 caregivers took part in the study. Only 48% felt sufficiently informed about the course of the illness. 41% had to reduce their work time or stop work to ensure care. 35% showed an increased risk for psychosomatic illnesses (BSFC); 50% had indications of a depression, 74% increased anxiety values (HADS). In the narrative interviews the caregivers indicated the following areas as being the most affected by the illness: everyday life, private life, financial situation, constant preoccupation with illness and death.Conclusion Family caregivers of brain tumor patients are extremely burdened and do not feel sufficiently informed. The support available often does not correspond to their needs. A specific support concept is required for these families.

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53. "Are you depressed?" The need for diagnostic tools in palliative care Representing the EPCRC research group

Jon Håvard Loge

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The prevalence of depression varies from 6-58 % in palliative care patients. This variation is mainly explained by differences in assessment methods and lack of consistency in the classification of depressive symptoms. Few studies have used structured interviews, most have relied on assessment by self-report instruments, many studies are small-scaled with high non-participation rates and correction for confounding variables has rarely been performed. Further, the present diagnostic criteria such as the DSM-system are not fully valid in the palliative care setting or among somatically diseased in general because the so-called somatic symptoms are unspecific and can be related to the underlying somatic disease or a depression. Overlap between depression and other psychiatric conditions such as adjustment disorders and anxiety disorders have rarely been explored and there might also be other overlapping conditions such as the demoralization syndrome or the sickness syndrome. Diagnosing depression is further complicated by the question of whether depression should be viewed as a categorical disorder or a spectrum condition.

In general one may therefore state that both treatment and research on depression in palliative care patients are primarily hindered by uncertainties about the diagnostic criteria and the lack of adequate diagnostic tools. The lack of any national or international consensus on how to classify and measure depression further supports the need for development and validation of tools for screening and diagnosing depression that are suitable for use in palliative care. Ideally, such tools should identify those patients in need of specific anti-depressive treatment.

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54. Guidelines for depression in palliative care: current challenges and research agenda Representing the EPCRC research group

Irene Higginson

King's College London, London, United Kingdom

Depression is a common problem in advanced cancer and other serious progressive illnesses. While there are difficulties in the definition, diagnosis, detection and assessment of depression in advanced illness, equally there are difficulties in making recommendations about effective treatments. Fisch's review[1] in 2006 noted that despite several decades of research and many clinical trials, there was a lack of evidence to make strong recommendations about the effectiveness of particular antidepressants and/or psychological interventions at improving depression for patients with cancer and other serious chronic illnesses. In palliative care there is also a need to be aware of potential drug interactions and to explore the effectiveness of drug and non-drug therapies.

Although some systematic reviews and guidelines have been produced (see for example [2-4]) there is a need to develop more robust guidelines that can apply across Europe. Using a standard methodology the EPCRC project will (1): determine the important questions about which guidelines are required, and then (2): conduct or build on existing systematic literature reviews and work with an expert panel to develop and test guidelines that might be applied across a range of palliative care settings.

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55. Symptom prevalence amongst people affected by advanced and progressive neurological conditions - a systematic review

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Background: In recent years, specialist palliative care services have increasingly recognised the needs of non-cancer patients. **Aim:** To determine whether patients with various different late stage neurological conditions have similar or different symptom profiles. **Method**: Articles reporting symptom prevalence in five neurological conditions - motor neurone disease/amyotrophic lateral sclerosis (MND), multiple sclerosis(MS), Parkinson's disease (PD), multiple systems atrophy and progressive supranuclear palsy were systematically searched for in four databases: Medline, Embase, Cinahl, Psycinfo. This was supplemented by hand searches and citation tracking. **Results:** 40 papers were identified. Eight symptoms were common across all five conditions. Problems with mobility and communication (in ≥ 80%); bladder dysfunction, swallowing problems and depression varied between conditions (in 50-80%) and weakness, spasms, bowel problems (in ≥ 50%). Three conditions (MND, MS, PD) reported high levels of pain and fatigue (≥ 50%). Other symptoms including anxiety, memory problems, sleep disturbance, sexual dysfunction, shivering, dribbling and weight loss, for some conditions. **Conclusions:** At least eight highly prevalent symptoms, which need appropriate symptom control, are common to all five conditions. Service provision across conditions, rather than disease specific, may be appropriate.

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57. Successful fundraising for palliative care

David Burland, Neelam Makhijani

Help the Hospices, National Centre, London, United Kingdom

A session hosted by Help Hospices on key fundraising issues for palliative care services.

Aimed at palliative care service delivery leads and national associations of palliative care.

The session will review
- what works and what doesn't work
- specific fundraising methods e.g. such as Major Donor/direct donor/fundraising events
- the principles of fundraising
- ethical issues
- specific palliative care concerns
- why some hospice and palliative care proposals fail

There will be an opportunity to question a leading fundraising consultant,on what gaps often exist in proposals.

Aim - To generate creative thinking and new perspectives regarding fundraising proposals, both large and small

Learning Objectives By the end of the workshop, participants will be able to address the common problems that proposals have and funders ask; using a proven logical format for presenting an informal proposal and produce an appropriate balance between emotional and rational arguments in a proposal

There will be follow up meet the expert sessions on the Friday and Saturday mornings for more individual coaching. The session will also lead to a fundraising manual .

58. EEG FREQUENCIES: EVIDENCE OF CENTRAL ORIGIN OF CANCER RELATED FATIGUE

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Aim:The purpose of this study was to evaluate the influence of prolonged muscle exercise on central nervous system (CNS) signals in CRF in order to elucidate its pathophysiology.
Methods: Sixteen patients with solid cancers and 16 age, gender-matched healthy controls completed a Brief Fatigue Inventory (BFI). Participants performed a sustained elbow-flexion contraction at 30% maximal strength until fatigued. Electrical stimulation-evoked muscle response and continuous 128-channel scalp-EEG data were recorded before, during and after task. Spectrum EEG analysis was performed at the initial, middle and end of task. Statistical analysis was done using student's *t*-test and ANOVA repeated measures between and within-groups.
Results: Compared to controls, (**i**) CRF were more subjectively fatigued by BFI, but had less muscle fatigue ($P = 0.0001$), (**ii**) spectrum analysis found substantial differences in gamma frequency between control and CRF groups, (**iii**) relative changes in gamma power between two hemispheres during sustained contraction was significantly greater ($P<0.05$) in CRF, (**iv**) brain signal activity was higher in CRF during task when relative power of frequencies spectrum were compared, (**v**) post-task ipsilateral brain signal activity did not return to pre-fatigue levels during the 2 minutes rest period, as measured in the ipsilateral hemisphere.
Conclusions: CRF is associated with altered CNS signals during a standard motor task.

59. Symptom prevalence in patients with incurable cancer: a systematic review

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Background: The suffering of patients with incurable cancer is determined to a large degree by the symptoms of their disease. Knowledge of symptom prevalence is important for clinical practice.
Aim of this study: To obtain a reliable estimation of symptom prevalence in patients with incurable cancer.
Method: systematic review of studies of studies giving prevalence data (assessed by questionnaire, standardized interview or the medical record) on symptoms of palliative care cancer patients.
Results: 44 studies (including 25074 patients) on overall symptom prevalence (Group 1) and 6 studies (including 2219 patients) on symptom prevalence during the last 1-2 weeks of life (Group 2). We identified 37 symptoms assessed in at least 5 studies. Almost all symptoms occurred in >10% of the patients. Five symptoms (fatigue, pain, lack of energy, weakness and appetite loss) occurred in more than 50% of the patients of Group 1. Weight loss occurred significantly more often in Group 2 compared to Group 1, and pain, nausea and urinary symptoms significantly less often. Generally, symptom prevalence was highest if assessed by a questionnaire.
Conclusion: The results of this study should be used to guide doctors and nurses in symptom management. Proper attention to symptom burden and suffering should be the basis for individually tailored treatment aimed at improving or maintaining quality of life of cancer patients in their last period of life.

60. Dyspnea in palliative care a multidimensional experience

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Aim: The aim was to describe dyspnea experience in patients with lung cancer in palliative care.
Methods: Approached when active anti-tumour treatment was finished, 105 patients with lung cancer completed questionnaires concerning aspects of dyspnea i.e. intensity, frequency, discomfort, qualities, including three dimensions of dyspnea; activity-related dyspnea; other symptoms and coping capacity. Performance status was also obtained.
Results: Above 50% of the patients perceived dyspnea. Only 3% perceived dyspnea intensity above 70 on VAS scale, but 23% perceived dyspnea discomfort above 70 on VAS. Correlations between intensity and frequency were 0.68; between frequency and dyspnea qualities 0.30; between intensity, qualities and activity-related dyspnea ranging from 0.48 to 0.56. Different aspects of dyspnea correlated with other symptoms, performance status and negatively with coping capacity. Dyspnea qualities and activity-related dyspnea were related to psychological distress; and intensity and activity-related dyspnea to performance status. Lower coping capacity and higher levels of anxiety explained 22% (R2) of variation in total dyspnea quality.
Conclusions: Dyspnea is a multidimensional experience, with relations between different aspects of dyspnea and physical and emotional measures, which indicate that there are both sensory and affective components in the dyspnea experience which needs to be acknowledged by healthcare professionals in palliative care.

61. What do patients with inoperable lung cancer report as MOST DISTRESSING during the first year post diagnosis in the Stockholm region of Sweden? An inductive structured assessment approach

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In this study, we complement data from structured questionnaires with a more explorative perspective. Inductive, structured data from 400 people consecutively diagnosed with primary inoperable lung cancer (LC) through 2 university hospitals, was collected through 'freelisting'. Patients responded to an open question "What do you find most distressing at present?", at baseline (prior to treatment; median 23 days post-diagnosis) (T1), & 2 weeks (T2), 1 (T3), 3 (T4), 6 months (T5) & 1 year (T6) after T1. Inductive content analysis resulted in 15 categories structured in 3 dimensions: somatic distress; distress related to living with LC, and iatrogenic distress, i.e. that triggered by contact with the health care system. Data will be presented using Onwuegbuzie et al's (2002) typology of effect sizes in mixed methods research. Somatic distress comprised 57-72% of issues reported, with dyspnea, pain & fatigue dominant, although even symptoms often not assessed were also reported. Distress related to living with cancer decreased from 34% at T1 to 23% at T6. Iatrogenic distress was less common, but contained both possibly avoidable and unavoidable distress. Strengths and weaknesses of this inductive approach versus structured questionnaires as means of collecting data on distress will be addressed. Some limitations of the present day focus on symptoms rather than distress will also be discussed.

62. Development of a Care Pathway for the management of constipation on an In-Patient unit

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Background
Constipation is a frequent and disabling symptom in terminally ill patients. Studies have shown that around 50% of patients admitted to UK hospices complained of being constipated.
To enable optimum management of constipation, a thorough initial assessment and daily documentation of bowel action and subsequent management needs to occur.
Aim
The aim of this study was to produce an evidence based care pathway that encompassed initial and daily assessment, and ongoing management of constipation.
Method and results
An action research methodology was utilised, in order for multi-professional staff to take an active role in the project, thus leading to a better chance of sustainable change.
The methods used included:

- Analysis of documentation pre and post-study
- Focus group interviews with the multi-professional team
- Literature review on documentation and management of constipation

A working group consisting of Doctor, Physiotherapist, Occupational therapist and In-Patient palliative care nurses used the initial findings of the pre-study audit to develop documentation. After further consultation with the in-patient unit, the pathway was launched with an accompanying teaching programme.
Notes were audited and showed that staff were completing the pathway.
A survey of in-patient staff showed that 80% felt the documentation had improved the management of constipation
Conclusion
This demonstrates how a change in practice can be brought about by action research

63. Constipation on Opioids: Inter-individual variation calls for individually tailored treatment plans.

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Method:
This project was part of an observational study assessing patients on oral morphine for cancer pain. Data collected included current laxatives and a subjective assessment of constipation in the preceding week. Doses for individual laxatives were analysed in 5 clusters: none (0), sub-therapeutic dose (1), low therapeutic dose (2), moderate therapeutic dose (3), high therapeutic dose (4) and above usually prescribed dose (5).
Results:
Data on 244 patients on oral morphine was analysed.

175 (71%) of study patients said they had been constipated during the previous week.

45 (26%) of all constipated patients were not on any laxatives at all. Only 91(52%) of the constipated patients were on a combination of a stimulant and a softener laxative.

21 (23%) of patients who were constipated were so despite being on optimal doses of both softener and stimulant laxative. 34 (16%) of all patients felt they were not constipated and were not taking any laxatives.
Conclusion:
There is wide inter-individual variation in the level of constipation in patients taking morphine for cancer pain. Although constipation in these patients is multi-factorial, genetic variation in response to opioids may play an important role.

Constipation associated with opioids for cancer pain is generally inadequately managed. Laxatives should be titrated according to individual patient need and tolerance.

64. Attitudes of Flemish Palliative Care Nurses and Physicians towards Euthanasia and Physician Assisted Suicide

Bert Broeckaert, Joris Gielen, Trudie Van Iersel, Stef Van den Branden

Katholieke Universiteit Leuven, Interdisciplinary Centre for the Study of Religion and World Views, leuven, Belgium

Aim of the Study: Several studies have already investigated attitudes of medical professionals towards end-of-life issues. Less research has been conducted concerning the attitudes of palliative care professionals. In 2006 the Interdisciplinary Centre for the Study of Religion and World Views (K.U.Leuven) and the Flemish Federation for Palliative Care undertook a quantitative study of attitudes of pallitive care physicians and nurses towards physician assisted suicide, and voluntary and non-voluntary euthanasia. **Method:** An anonymous questionnaire was sent to all physicians (147) and nurses (589) employed in palliative care teams and institutions in Flanders (Belgium). The questionnaire contained a demographic part, and an attitudinal part, consisting of a long series of ethical statements using a five-point Likert-scale. **Results:** 70.5% of the nurses (*n*=415) and 67.3% of the physicians (*n*=99) responded. Most physicians considered non-voluntary euthanasia never ethically justified. The statistical analysis of the results will be completed in February 2007. In our analysis we will investigate the relation between attitudes toward voluntary euthanasia, attitudes toward non-voluntary euthanasia and attitudes toward PAS on the one hand and several demographic background variables on the other hand. Provisory analysis has shown that a meaningful factor-cluster-analysis of attitudes toward the end-of-life issues is possible. Results will be compared to available international data.

65. "It turned out that we were in charge"

Gillian Chowns

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Aims: This paper identifies - and challenges - some key ethical principles in conducting research with children, in a palliative care context. It argues for a revisioning of our understanding of childhood and for a more robust

critique of some taken-for-granted ethical 'rules'.
Method: The research project investigated children's experience of living with serious parental illness. It used a participative methodology, whereby the children themselves acted as co-researchers, identifying their own themes, and interviewing each other. The use of video, both to make a film for public consumption, and to research the process of collaborative inquiry, brought into sharp focus issues such anonymity, confidentiality, consent and censorship.
Ethical issues: This project demonstrated that anonymity is not necessarily essential in conducting ethically rigorous research with children, that allegedly vulnerable individuals can conduct research on sensitive topics, that consent is a multi-layered and constantly negotiated construct, and that truth is always a perspectival and contested concept.
Conclusion: Palliative care has tended to uncritically adopt the traditional health and social care models of childhood that are developmental and protectionist; this study argues for a more ethically respectful model which frames the child as a capable, competent citizen rather than a passive, vulnerable individual.

66. Diversity in aims of palliative chemotherapy: a care ethical perspective

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Not starting or foregoing futile treatments is an essential part of palliative care. Chemotherapy in palliative oncology is given for life prolongation and/or improvement of symptoms. However, in our empirical research we found that sometimes people want chemotherapy regardless the fact that above mentioned aims cannot be met so that the treatment can be considered futile. Patients may want the treatment to 'do at least something'.

In this presentation we will answer the question whether doing something can ethically justify using chemotherapy at the end of life. In principle based ethics one would say there is a conflict of the principle of respect for autonomy, of the patient who wants an active but ineffective treatment, and the principle of to do no harm, that the physicians needs to hold up to. To use chemotherapy just to do something cannot be justified in principle based ethics, whereas care ethics might sometimes accept this treatment aim. From the perspective of care ethics the treatment can be interpreted as a form of care within the patient-physician relation. Doing something has a meaning in the process of acceptance; everything possible is tried by the patient and his physician before death. Supposing that the patient receives good palliative care, chemotherapy for reasons of doing something might be accepted. Toxicity and high costs would be the contraindications, therefore low dose or even placebo chemotherapy might be considered for this specific aim.

67. The wish to hasten death among ALS patients in a palliative care program

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Aim. Amyotrophic lateral sclerosis (ALS) is a major challenge to palliative care, particularly as the characterics of the disease may provoke patients' wishes to hasten death. The study investigates the prevalence and determinants of the wish to hasten death in ALS patients and the opinions of their caregivers.
Methods. The semi-quantitative questionnaire study included patients and their primary caregivers enrolled in an outpatient ALS palliative care program in Munich, Germany.
Results. The study comprised a sample of 30 patient-caregiver-pairs. 31% of patients expressed the desire to hasten death. Suicidal ideation was admitted by 50%, 24% had planned and 6% actually tried suicide. 44% of patients could imagine asking their doctor for physician-assisted suicide or euthanasia. The desire to hasten death correlated significantly with loneliness and both the depression and anxiety subscales of the Hospital Anxiety and Depression Scale, but not with religiosity as measured by the Idler Index of Religiosity. Only 11% of caregivers said their relatives communicated with them about hastening death. 25% and 20% of caregivers could imagine assisting in suicide or performing euthanasia, respectively.
Conclusions. The wish to hasten death is common among German ALS patients in a palliative care setting. Its correlations with loneliness, anxiety and depression pose challenges to palliative care. Physicians and caregivers should address this issue more openly.

68. Advance directives in palliative care units: a prospective study

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Aim of the study: Advance Directives (AD) have been developed to ensure patients' autonomy as they become incapable of making their own decisions. Study objectives are to better characterize patients with advanced cancer who complete AD and to measure their impact on satisfaction with end-of-life care.
Method: Prospective clinical study in 3 palliative care units (total of 44 beds). 60 patients with advanced cancer, an estimated life expectancy <6 months, fluent in French and with MMSE >20 who had not yet completed AD will be recruited. Patients receive specific information and decide whether to complete AD or not. Patients and surrogates level of satisfaction with end-of-life care is assessed via "the satisfaction statement after death interview support PHASE II". Physical and psychological comfort of patients is measured with ESAS and HADS. Usefulness of AD as patients become incompetent is evaluated.
Preliminary results: 125 eligible patients have been hospitalized during the first 6 months. 93 (46 males, mean age 70.9) could not be included because of MMSE 20 (n=42), poor general conditions (22), refusal (10), no surrogate (16), not fluent in French (2), pre-existing AD (2). 32 patients have been included: 21 males, mean age 70 10.1, mean MMSE 27.3, mean HADS depression 6.4, anxiety 7.7. 15 patients died, 11 are still in and 6 returned home. 6 patients completed AD, those with higher MMSE 28.83 vs 26.78, lower HADS Depression 6.83 vs 8.06 and HADS Anxiety 5.17 vs 6.82. 6 patients were not completely satisfied with end-of-life care. All but one surrogate were completely satisfied with care.
Conclusion: Even if hospitalised patients with advanced cancer receive complete information about AD, only a minority decide to complete them. Preliminary results dont suggest any notable impact on satisfaction with end-of-life care.

69. Connectedness: ethics and advanced home care technology in the last phase of life

Dick Willems

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Background: Among the initial worries in bioethics was the way people spent their last days in intensive care units, connected to technology. This paper, based on empirical ethical research finished in 2005, is about the ethics involved in the migration of advanced technology to the homes of patients. Its question is how advanced home care technology incorporates a (new vision on a) good last phase of life.
Method: Ethnography combined with interviews with patients who were using mechanical ventilation at home, their families and professional caregivers. At the EAPC-conference, I will report on the data that concern the last phase of life and the dying process.
Results: Three normative ideas seemed to be particularly linked to high-tech palliative care at home: firstly, that the last phase may be good when *boundaries are kept*, secondly when there *synchronicity between physical and social death*, and thirdly when death remains, to some extent, *natural*. A concern that was often mentioned that mechanical ventilation in the home can, at least in principle, be continued indefinitely, and therefore almost inevitably leads to the problem of when and how to stop it.
Conclusion: Technological innovations such as advanced home care technology are at the same time philosophical and ethical innovations, performing new definitions of a good last phase of life.

70. An assessment of the confidence that staff working in palliative care and intellectual disability services have in their ability to provide palliative care to people with intellectual disability.

Karen Ryan[1], Suzanne Guerin[2], Philip Dodd[3], John McEvoy[4]

[1] *St Francis Hospice, Palliative Medicine, Dublin, Ireland*
[2] *University College Dublin, Department of Psychology, Dublin, Ireland*
[3] *St Michael's House, Department of Psychiatry, Dublin, Ireland*
[4] *Dundalk Institute of technology, School of Nursing, Midwifery and Health Studies, Dundalk, Ireland*

Aim: Staff working in palliative care and intellectual disability services were surveyed to assess experience and confidence in the provision of palliative care to people with intellectual disability. **Method:** Two questionnaires were prepared. Descriptive statistics were calculated. Staff rated their confidence in managing different aspects of palliative care. Mean scores were calculated, and confidence levels in various settings were compared using Wilcoxon and Friedman tests. Ratings of different groups were compared using Mann Whitney and Kruskal Wallis tests. **Results:** 389 questionnaires were distributed (response rate 67%). 59.3% of palliative care staff and 67.3% of intellectual disability staff had cared for someone with intellectual disability who had died. Intellectual disability staff rated the importance of palliative care highly. Palliative care staff were very confident of their ability to care for the general population (mean score of 86.85, SD 11.49). However, confidence dropped to moderate levels when caring for a person with intellectual disability (mean score 63.47, SD 24.12). They were no more confident than intellectual disability staff in this area. Confidence was affected by previous experience. Confidence of intellectual disability staff was affected by whether they were a health or social care worker, and by previous experience. **Conclusion:** Staff lack experience and confidence in the delivery of palliative care to people with intellectual disability.

71. Transition towards Palliative Care. An exploration of its meaning for advanced cancer patients in Europe

Philip Larkin

University College Galway, Nursing & Midwifery Studies, Galway, Ireland

This presentation reports on a qualitative study into the transition experiences of advanced cancer patients at the palliative/terminal interface.
Method: Using a qualitative phenomenological framework, 100 patients in 6 EU countries were interviewed about their first perception of transition to hospice/palliative care unit, the supportive and inhibitory factors experienced and what, if anything, had changed for them since the transition. Findings were analysed using the ATLAS.TI programme for hermeneutic data.
Results: Patients were unable to identify how transition towards the hospice/palliative care unit occured, nor the personnel involved. Transition was a period of hurried decision-making at a time of increased symptom burden and a fear that refusal may mitigate against future care options. Respondents needed more time to make decisions. However, once admitted, patients reported that the safety and security offered in the caring clinical environment was key to their adaptation to the new surroundings. Relationships with other patients became important, in some cases superceeding relationship with family. Being present at the death of others was seen as important.
Conclusions: In terms of service delivery, palliative care is itself in transition, from terminal care to one more closely allied to acute, supportive care. Services need to ensure that the clinical benefits of integration does not subsume the positive aspects that patients derive from the values of the "hospice" approach.

72. Advanced care planning for Indigenous Australians: the process of engaging, the lessons learnt and the way forward

Mark Boughey

Territory Palliative Care, Royal Darwin Hospital, Darwin, Australia

Advance care planning and its documentation is playing an increasingly important role in a patient's self-determination towards their future health care decisions. The advanced care planning process is focussed on a competent individual expressing their views and giving their consent to the process.
Within Australian indigenous cultures, decision making and the process of consent is not the individual's responsibility but that of a family and community appointed decision maker, which may vary depending on the nature and seriousness of the decisions being made.
As a consequence, it has proven difficult to engage indigenous patients successfully in the usual advanced care planning processes. Territory Palliative Care, in the Northern Territory of Australia, has developed a method and approach to the patient-decision maker engagement that has assisted in beginning the process of advanced care planning and raised community awareness, such that when a decision is acted upon the community can cope with the consequences of the event, maintain traditional cultural practices and minimise the risks of blame and physical and emotional "pay-back" towards the family and decision maker.
I will present our methodology, give case studies of the process and demonstrate the lessons learnt while working within the indigenous framework that has

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

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

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

Amitai Oberman [1, 2], Mali Szlaifer [2]

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

Lorna Rosenwax [1], Bev McNamara [2], Kirsten Auret [3]

[1] *Curtin University, Division of Health Sciences, Perth, Australia*
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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

Sabine Pleschberger [1]

[1] *University of Klagenfurt, IFF-Palliative Care and Organizational Ethics, Vienna, Austria*
[2] *Justus-Liebig-University of Giessen, Institute of Sociology, Giessen, Germany*

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

Per Sjögren [1], Franco De Conno [2]

[1] *National Hospital, Multidisciplinary Pain Centre, Copenhagen, Denmark*
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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.
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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

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

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

Oral abstracts

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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

Mildred Solomon [1, 2], David Browning [2], Deborah Dokken [2]

[1] *Harvard Medical School, Division of Medical Ethics, Boston, United States*
[2] *Education Development Ctr, Center for Applied Ethics, Newton, United States*

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.

Leanne Monterosso[1], Linda Kristjanson[2], Marianne Phillips[3], Kate White[4], Sue Rowell [3], Martin Watson[5]

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[3]*Princess Margaret Hospital, Haematology & Oncology, Perth, Australia*
[4]*University of Sydney, Nursing Research, Sydney, Australia*
[5]*Princess Margaret Hospital, Allied Health, Perth, Australia*
[6]*Children's Hospice Association, Children's Hospice, Perth, Australia*

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

Leanne Monterosso[1], Linda Kristjanson[2], Marianne Phillips[3], Rosemary McPherson[3], Martin Watson[4]

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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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[2]*University of Lancaster, Institute for Health Research, Lancaster, United Kingdom*
[3]*University of Sheffield, School of Nursing, Sheffield, United Kingdom*

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.

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[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

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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]

[1] *The Danish Association for Palliative Medicine, Copenhagen, Denmark*
[2] *The Finnish Association for Palliative Medicine, helsinki, Finland*
[3] *The Norwegian Association for Palliative Medicine, Trondhjem, Norway*
[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*
[2] *American Board of Hospice and Palliative Medicine, Silver Spring, MD, United States*
[3] *American Board of Hospice and Palliative Medicine, Palliative Medicine Review Commmittee, Silver Spring, MD, United States*

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]

[1] *Grünenthal GmbH, Medical Marketing, Aachen, Germany*
[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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117. See page 73

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118. See page 74

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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.

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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[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".

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.

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.

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

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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

135. Family-Oriented Communication in Palliative Care

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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.

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

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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.

137. Body images and communication in psychotherapy and pastoral care

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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.

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 .

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

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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.

141. What Are Patients Research Priorities for Palliative Care?

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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.

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.

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

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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.

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

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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.

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.

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.

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.

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.

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.

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.

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.

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".

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.

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.

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.

Oral abstracts

Saturday 9 June

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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]

[1] *Harvard Medical School, Division of Medical Ethics, Boston, United States*
[2] *Education Development Ctr, Center for Applied Ethics, Newton, United States*
[3] *Johns Hopkins Univeristy, School of Nursing, Baltimore, United States*
[4] *Albert Einstein Medical College, Pediatrics, New York City, United States*

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

University of Huddersfield, HUman & Health Sciences, Huddersfield, United Kingdom

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]

[1] *Centre Léon Bérard, paediatric oncology, LYON, France*

[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.

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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.

156. Meet the Expert - Volunteers

Anne Merriman[1], Barbara Monroe[2]

[1] *Hospice Africa Uganda, Home care, Kampala, Uganda*
[2]*St Christopher's Hospice, Cancer department, London, United Kingdom*

This session will offer the chance to discuss changing patterns of volunteering opportunities, organisation and training in end of life care. It will be informed by evidence from the UK Commission on the Future of Volunteering about changes in volunteering such as its use as a route to employment and increases in employer supported activity. Challenges include understanding the barriers to volunteering and action to remove them, the provision of training, infrastructure support and equal opportunities to volunteer and the potential impact of a risk averse culture.

The different concepts and expectations of volunteering in developing countries are explored. The role of volunteerism in resource strapped situations will be discussed. In countries like Uganda where only 57% access health care, volunteers play a key role in identifying those in need in their own villages and bringing palliative care to them in their homes.

The West faces the challenges of ageing populations and increasing health care expectations within limited availability of human and financial resources. The developing world has the challenge of people dying at younger ages when Life's tasks are unfulfilled. However death is part of life in many countries and the impact of bereavement not so disastrous when the culture has devised its own methods of coping. The role of volunteers in assisting families to move forward after death will be explored.

Used effectively volunteering can build social capital and cohesion and break down the taboos that still exist around death and dying. Diverse examples will be provided.

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157. See page 75

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158. See page 77

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159. Managing the Patient with Pain and Delirium

Eduardo Bruera

UT MD Anderson cancer center, Palliative Care and Rehabilitation Medicine, Houston, Texas, United States

Pain and delirium are syndromes that occur in more than 80% of patients with advanced cancer. It is therefore very frequent that patients with cancer pain will develop delirium during the trajectory of their illness. In patients with chronic pain delirium can develop as a consequence of opioid induced neurotoxicity, side effect of analgesic adjuvants or other psychoactive drugs, development of dehydration, renal failure, metabolic abnormalities, or infection, or as a consequence of direct invasion of the brain by advanced cancer. Early stages of delirium will be frequently accompanied by disinhibition resulting in increased expression of pain and other symptoms including emotional distress. This increased expression of symptoms can result in a vicious circle of escalation of opioids and other psychoactive drugs with resulting aggravation of delirium. One of the major challenges in the management of these patients is to regularly screen for the presence of delirium, conduct rapid assessment of probably and possible causes, and establish early interventions to reverse this syndrome. With appropriate assessment and management approximately 50% of the episodes of delirium can be completely reversed. This presentation will discuss the different mechanisms and clinical findings in patients with delirium, the methods for the screening and assessment of this syndrome, and the management of delirium in the patient and the family. Areas for future research will be discussed.

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160. Delirium in the patient and its impact on the family and staff.

Pam Firth

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

Much has been written about the difficulties of treating and managing the effects of delirium in advanced cancer and it is described as a common problem in the terminal stage of the disease. The effect of the range of symptoms of severe confusion in a loved one is particularly disturbing and frightening for the family. Family members require sensitive and skilled responses from the multi professional team. **Discussion** The author will consider the reactions and difficulties delirium in patients cause for the family and the staff treating them. The needs of family members to feel close and recognised as an important person in the life of the terminally ill patient can be frustrated if the patient fails to recognise them and the family and patient have no opportunity to have satisfactory communication. There is anecdotal evidence from family and carers that they need to be prepared when patients are sedated as an attempt to manage the symptoms. Furthermore the patient and family may have failed to make arrangements if the patient becomes incompetent to make decisions which add to the distress. Staff too may feel that they have let the family down. The pressure for all concerned can be stressful. Good support, clinical supervision, discussion amongst team members and sensitive communication with the family can all help.

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161. Delirium - a challenge to contact and communication. Nursing challenges

Marianne Hjermstad[1, 2]

[1] *Ullevål University Hospital, Dpt. of Oncology, Oslo,Norway, Norway*
[2] *Norwegian University of Science and Technology Trondheim, Faculty of Medicine, Trondheim, Norway*

Background. Cognitive failure (CF) is an imprecise description of a loss in cognitive function (i.e attention, concentration, memory, orientation, perception). Thus, CF has profound impact on quality of life (QOL) in various domains; understanding of information, informed consent, decision making, treatment compliance, and relationship with relatives and care givers. Delirium is the most prevalent condition with CF in palliative care (PC). It is due to a general medical condition and presents as an agitated, a hypoactive or a mixed form.

Relevance. Prevalence rates for delirium in PC range from 28%-52%. Up to 85% develop delirium at some stage before the end of life. Delirium is potentially reversible. It is a psychiatric syndrome that's mainly seen by non-psychiatric clinicians and nurses, which in part explains why it is misdiagnosed or overlooked in 32−67% of cases, hence goes untreated. The high non−detection rates point to the urgent need to raise the awareness of delirium in PC units, nursing homes and home care.

Results. A review (2004) revealed an increasing interest in delirium/CF in PC; 64% of 22 studies were published from 2000 to 2003. The interchangeable use of CF to describe specific diagnoses makes firm conclusions difficult, evidenced by the prevalence rates varying from 10%-85%.

Discussion. A standard mental examination should reveal impairment in central cognitive functions. Identification of early signs of CF may reveal predisposing factors for delirium. Many of the assessment tools are regarded as cumbersome, and are not used, resulting in less than optimal treatment.

Conclusion. To detect early stages of delirium in PC, nurses and clinicians should routinely screen for CF with a few central questions related to orientation and memory. These are sufficient to identify patients who would need more detailed assessment

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162. Definition and principles of palliative sedation therapy

Alexander De Graeff[1], Mervyn Dean[2]

[1] *University Medical Center Utrecht, Medical Oncology, utrecht, Netherlands*
[2]*Western Memorial Regional Hospital, Palliative Care Department, Corner Brook, Canada*

Background: Palliative sedation therapy (PST) may be used as a treatment of last resort in the last weeks of life for patients with unbearable suffering due to severe uncontrolled symptoms (mostly delirium, dyspnoea and/or pain). Its use varies between centers and countries and may be increasing.

Definitions: PST may be defined as the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness. Intolerable suffering is defined by a patient as a symptom or state that (s)he does not wish to endure. Refractory symptoms are symptoms for which all possible treatment has failed within a reasonable time frame and/or is accompanied by unacceptable side effects.

Principles: The aim of PST is to adequately relieve refractory symptoms by means of appropriate sedative drugs, carefully titrated to the cessation of symptoms (proportionality). The physician should regularly review the patient's condition and continue to search for non-sedating alternatives. Only under exceptional circumstances is deep and continuous sedation required. In that case, the disease should be irreversible and advanced, with death expected within hours to days. PST should only be initiated if the team has enough expertise and experience. Advice from a palliative care specialist is strongly recommended. A systematic and inclusive decision-making process should be used, actively involving the patient or the designated surrogate decision maker and/or family. The whole process should be carefully documented.

Conclusion: When other treatments fail to relieve suffering in the imminently dying patient, PST is a valid palliative care option.

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163. Palliative sedation: Pharmacology - evidence and practice

Staffan Lundström

Stockholms Sjukhem Foundation and Karolinska Institute, Palliative Medicine, Stockholm, Sweden

Different drugs are used to deliberately reduce consciousness in order to relieve intolerable refractory symptoms in palliative care patients where conventional treatments have failed. Palliative sedation therapy for symptom control in care of the dying should be proportionate to the situation of the individual patient and carefully monitored. Sedatives can be administered either intermittently or continuously and the level of acquired sedation can range from somnolence to unconsciousness. In absence of delirium, benzodiazepines should be considered first-line choice. Midazolam is the most frequently used sedative agent. The short half-life allows rapid dose titration; it can be administered subcutaneously or intravenously, has few undesirable side-effects and possess also anxiolytic, antiepileptic and muscle relaxant properties. Haloperidol or levomepromazine, either used alone or in combination with midazolam can be used in patients with delirium. Antipsychotic drugs have longer half-life, and levomepromazine should only be considered if the intention is continuous sedation. In severe cases, phenobarbital and propofol are used. Propofol has a rapid onset and a short duration of action allowing a tight control of the level of sedation. Opioids are often part of the combined medical treatment in palliative care patients but should not be used for the purpose of sedation.

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164. Ethical Considerations

Lars Materstvedt

Norwegian University of Science and Technology, Norway, Trondheim, Norway

Many take palliative sedation to be a last resort treatment strategy. That is, it may only be used when all other, conventional strategies to relieve intractable symptoms have either failed or have been deemed inappropriate. Thus, patients eligible for palliative sedation find themselves in an emergency situation. Since extreme suffering calls for extreme measures, it could be claimed that providing palliative sedation in such patients is both a clinical and an ethical duty. However, palliative sedation comes at a cost. The induction of a permanent coma entails the eradication, or "killing", of the person as such. While still biologically alive, socially the individual is "a living dead", unable to relate to the world around him including his next-of-kin. It may be asked in what sense then, if at all, palliative sedation is a contribution to quality of life − arguably *the* value of, as well as the primary goal of, palliative care − when the patient no longer has "a" life. Sometimes, patients will ask that artificial hydration and nutrition not be given (be withheld) after palliative sedation has been initiated since it would only prolong the dying process and hence be futile. Death will then come rather soon. Do we therefore, in such withholding, have a case of so-called slow euthanasia? Lastly, in palliative sedation, the suffering is not reduced but disappears altogether since the patient is no longer able to feel a thing. In that respect, this treatment strategy appears to have an unclear border with euthanasia which also completely removes suffering. This paper will analyse these issues using various tools and concepts within medical ethics.

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165. From basic education to specialist training - EAPC Taskforces on Nurse Education

Philip Larkin, Martine De Vlieger, Francoise Porchet, Corry Van Tol, Avril Jackson, Marilene Filbet

National UNiversity of Ireland, Division of Nursing Science, Galway, Ireland

The EAPC guidelines on palliative nursing education were published by the EAPC in 2004. This presentation will provide an overview of the key recommendations of the project in relation to the acquisition of knowledge, skills and attitudes for best nursing practice.

The presentation will largely focus on a strategic development arising from the nurse guidelines, namely a new EAPC taskforce looking at clinical practice opportunities across Europe. The basis for the STAGE project will be described in terms of increased opportunity for sharing knowledge and skills across Europe and setting nursing practice within a broader multidisciplinary paradigm. Proposals for the dissemination of the STAGE project will be described and timelines and evaluation strategies presented.

166. Palliative care education and accreditation

David Clark

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

There is an increasing move to recognise palliative medicine as an area of certificated are of specialisation. Drawing on a survey conducted by the EAPC Taskforce on Palliative Care Development, an overview of palliative medicine specialisation and accreditation practices will be presented. Palliative medicine has specialty status in just two European countries: Ireland and the United Kingdom. In four countries it is considered a sub-specialty, for which a second certification is required: Poland, Romania, Slovakia and Germany. Some 10 other countries have started the process of certification for palliative medicine, in all cases opting for sub-specialty status that follows full recognition in an established specialty. Across countries there is disparity in the certification criteria followed and considerable variability in the demands that are made in order to achieve certification. Further studies are needed that focus in depth on palliative medicine certification and accreditation across Europe. Establishing uniform approaches to certification for palliative medicine in different European countries will contribute to wider take up of specialty status and the improved recognition of palliative care as a discipline.

167. Suggestions in the communication with cancer patients

Éva Bányai

Eötvös Loránd University, Center for Affective Psychology, Budapest, Hungary

The shock caused by the emotionally traumatic information about the life threatening diagnosis of cancer generally induces an altered state of consciousness in patients. The stress, pain, anxiety, and especially the fear of death cause a change in the persons' usual frame of reference. Since patients become very vulnerable and develop a feeling of being at the mercy of others, their dependence often causes a relinquishment of control function. All this leads to increased susceptibility to suggestions. In this situation, suggestions (often unintended) made by authority figures - medical doctors, nurses, psychologists - may have enormous positive or negative effects. The paper demonstrates that, unfortunately, verbal and nonverbal communication related to cancer act as negative suggestions - both in the hospital and in the wider social milieu of the patients -, sending "messages" of helplessness, hopelessness, and total isolation. Thus, the patients sense they are left alone and shut out from life. A special training in suggestive techniques is recommended to help professionals in recognizing spontaneous trance states, in phrasing their communications in a fashion that is more likely to do good than unintended harm, and in formulating effective positive suggestions. This may help patients also, in regaining the feeling of control, in sensing social support toward the end of their lives, and in facing death with human dignity.

168. Integrated Psycho-Oncology focussing the needs in palliative care: experiences and empirical data

Elisabeth Andritsch, Silke Zloklikovits, Verena Ladinek, Hellmut Samonigg

Universitätsklinik für Innere Medizin, Klinische Abteilung für Onkologie, Graz, Austria

The Palliative Care Unit of the University Hospital Graz, Austria is associated to the Department of Clinical Oncology with a Psycho-Oncology Working group integrated in both. One of the tasks for the psycho oncologist is running the regular multi-professional meeting in the Palliative Care Unit focussing the different perceived needs of patients and their significant others by different professions. Another responsibility is to carry out and support studies e. g the survey about the symptom assessment of patients and of physicians, nurses and family caregivers.

The Palliative Care Unit of the University Hospital Graz, Austria is associated to the Department of Clinical Oncology with a Psycho-Oncology Working group integrated in both. One of the tasks for the psycho oncologist is running the regular multi-professional meeting in the Palliative Care Unit focussing the different perceived needs of patients and their significant others by different professions. Another responsibility is to carry out and support studies e. g the survey about the symptom assessment of patients and of physicians, nurses and family caregivers;

In palliative care, symptom assessment as a critical component of effective symptom management requires knowledge about discrepancies of patient and proxy symptom ratings as well as factors influencing the accuracy of assessment by other raters. Our research activity focuses on following purposes: to identify differences in symptom severity ratings between patients and their nurses, physicians and family members and to determine which selected variables are associated with discrepancies in assessments of different raters. Each of them completed a modified standardized Symptom List for Quality Assurance in Palliative Care (MIDOS) drafted by the Working Group on the Core Documentation for Palliative Care Units in Germany, the psychological subscale of the Memorial Symptom Assessment Scale (MSAS-PSYCH) from Portenoy and the Distress Thermometer (Holland). In addition to this the family members filled in the MSAS-PSYCH as well as all proxy raters assessed their distress for his/her own person. The survey was made at two measuring times (within the first three days after admission to the ward and 1 week later).

A total of 50 patients with advanced cancer admitted to the palliative care unit of the University Hospital Graz, Austria participated in the study. Further results and conclusions of this study and expereinces of the Model of an integrated Psycho-Oncology Working Group will be presented in the lecture.

169. Communication skills - a core competence in Palliative care

Luzia Travado

CENTRO HOSPITALAR LISBOA CENTRAL-HOSPITAL S. JOSE, CLINICAL PSYCHOLOGY UNIT, Lisboa, Portugal

Communication Skills (CS) is a fundamental competence for creating a trusting, supportive, empathic relationship with patients and families essential for comprehensive care in oncology. The first therapeutic technique available to any health professional if trained. Good communication skills facilitate addressing patients' concerns and needs, provide basic emotional support, detection of emotional problems and a patient-centered care model. It has positive outcomes on various patient health measures, including adjustment to illness and satisfaction with care. Professionals also benefit from greater confidence and less burnout. Improving and training these competences is crucial and have been recommended to be part of routine education for health professionals in cancer settings. Nevertheless there is an enormous lack of formal training. To overcome this gap the Southern European Psycho-Oncology Study (SEPOS) has developed a training model designed to improve health staff communication skills and their ability to recognize psychosocial morbidity. Data from this study conducted in Italy, Portugal and Spain will be presented. If CS is crucial in any phase across the cancer continuum it becomes a mandatory competence in Palliative Care (PC). This is true not only for the central purpose of addressing patients bio-psycho-social-existential-spiritual needs and their families, which become more complex and demanding at this phase, but also for maintaining effective multidisciplinary team work within the group and as consultants with patients' reference health teams. An example is given of a project carried out in a central hospital in Lisbon designed to organize and develop PC and health professionals' competences in this area.

170. A LOVE AFFAIR AS PALLIATIVUM?

Hans-Christof Müller-Busch [1], Matthias Richard Kraska [2]

[1] *Gemeinschaftskrankenhaus Havelhöhe, Zentrum Schmerz- und Palliativmedizin, Berlin, Germany*
[2] *Witten/Herdecke University, Medical, Witten, Germany*

Aim of investigation: The term palliative (from latin palliare, to cloak) to describe a special form of care was first in 1973 by B. Mount. However the word palliative had been used before with different connotations in the non-medical literature in Germany, France and England. In 1776 J.W. Goethe wrote a letter, in which he describes *"a love affair as palliativum in certain circumstances"*. Aim of our study was to find out, when, by whom and with which intention the word palliative was introduced into the medical literature and where the origins can be found.

Methods: A systematic linguistic literature research in encyclopedias of the 17th, 18th and 19th centuries was initiated to find out, where and with which meanings the word pallia* was mentioned. Bibliographic studies where undertaken in the contemporary medical literature to look for the word pallia* in a medical context.

Results: The word pallia* was widely used in the 18th century in german literature as well as in other languages but more in a descriptive context. The german physician, and founder of homoeopathy CFS Hahnemann used the word in his medical works. There is still uncertainty if he was the first person to introduce the term into medicine.

Conclusion: The presentation of these preliminary results should encourage further research into the history of terms and meanings in palliative and hospice care.

171. An Alternative Perspective on Palliative Care: How Homeopaths approach Chronic Illness

Petra Plunger, Claudia Wenzel

University of Klagenfurt and Vienna, Department of Palliative Care and Ethics, Vienna, Austria

The study aims at exploring the views of people with chronic illness and practitioners on homeopathy, and their experiences with homeopathy, against the socio-political background in Austria.

Grounded theory (Strauss 1967) is used, encompassing interviews with users and homeopaths, and a group discussion with homeopaths.

Preliminary findings point to a complex set of interwoven attitudes and practices: homeopaths conceptualize their work as supporting cure, and patients' processes of illness work, pointing out the psychosocial and spiritual effects of homeopathy. Patients' active involvement in care is emphasised to a varying degree. The importance of doctor-patient relationship and its healing potential is specifically mentioned. As for practice patterns, informal networks with well-known colleagues from diverse medical and non medical specialities are established. The regulatory framework in Austria, placing Homeopathy outside the scheme of remuneration by sick-funds, is critically assessed in terms of its benefits and pitfalls.

The micro-level analysis of homeopathy presents insights into alternative modes of practice dealing with chronic illness, highlighting patient-centeredness, the relationship between care and cure, and issues around empowerment of patients. Implications of this mode of practice on further development of Palliative Care and more broadly on health system development will be discussed.

172. Complementary therapies in cancer: exploring the contributions of therapy & therapist to patient care

Charlotte Wilson [1], Dai Roberts [1], Ann Caress [2], Andrew Long [4], Chris Todd [2], Peter Mackereth [3], Jackie Stringer [3], Sam Parkin [5], Ann Carter [1], Alison Christine McNulty Delgado [2]

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Whilst Complementary Therapies (CTs) are increasingly used by patients with cancer, it is unclear, whether it is the *therapy* or the interaction with the therapist which is perceived as beneficial. Patients' perspectives on interactions with therapists were explored. Data were collected at three sites via postal questionnaire surveys (n=266) including the Medical Interview Satisfaction Scale (MISS-21) and Empathy Scale, face-to-face in depth interviews (n=46) & documentary analysis. There were several contra-indications, but few specific indications for CT. One site reported matching patients to therapist rather than to therapy. Patients' levels of perceived benefit were higher for general/emotional well-being and for psychosocial issues than for physical issues. Mean MISS-21 scores were much higher for scales relating to provider-patient relationships than for treatment-related scales.Empathy scale scores were very high; scores were the highest in the two sites offering the most therapies and lowest in the site offering the fewest. Survey data were reinforced by the interview data, which highlighted the value of 'talk, time and touch' for patients.

Patients most commonly describe the benefits of complementary *therapy* in terms of general & emotional well-being rather than the management of symptoms.The benefits of complementary therapies, was mediated by the *therapeutic relationship* which was found to be extremely strong in terms of empathy

173. A large multicenter prospective randomised trial on the treatment of death rattle in palliative care.

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[4] *University of Antwerp, Palliative care unit, antwerp, Belgium*
[5] *Stedelijk Ziekenhuis, Palliative care unit, aalst, Belgium*
[6] *A.Z. Jan Palfijn, Palliative care unit, gent, Belgium*

Death rattle is a frequent symptom (25-50%) in the terminal stage of life, but there is neither standardized treatment nor prospective investigation performed on the efficacy of anticholinergic drugs. Palliative medicine should be more evidence-based, implying the need for large prospective randomised trials.

We designed a large multicenter prospective randomised trial in 6 Belgian institutions with administration of one of three frequently used anticholinergic drugs (scopolamine, hyoscine butylbromide and atropine). Inclusion criteria are presence of death rattle, without clinical evidence of secondary causes of rattle like respiratory infection, cardiac failure or aspiration pneumonia (so-called pseudo-death rattle). Informed consent was required from the patient or the legal guardian. With an expected response rate of about 60%, a sample size of 273 patients is required to assess the primary end point with at least 80% power.

Primary endpoint is a 20% difference in efficacy in the treatment of death rattle by one of the drugs; secondary endpoints are differences in side effects.

Results: 280 Patients have been recruited between 11-2001 and11-2006.

The data analysis is ongoing and results will be presented at the EAPC meeting.

This study proofs that large multicenter prospective randomised trials with informed consent are feasible in palliative care and should be encouraged. This is the only way to reach a more evidence-based palliative medicine.

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174. Measuring Attitudes to Change and Relation Competence in a Palliative Medicine Unit

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Background: Understanding a work group's culture can facilitate the change process. In this study the relations on organization level were subject to investigation.
Methods: Health care personnel (N=25) at the Palliative Medicine Unit (PMU) answered a questionnaire. The respondent groups consisted of physicians, nurses, physiotherapists and others. Systematizing Person-Group Relations method was used for gathering data and their analysis. The respondents were asked about different statements according to the tree different conditions*: today, future* and *desired*. The respondent's statements in the condition *today* and *future* were nearly equal while their statements in the *desired* condition had largest difference.
Results: This study found that the passivity of the respondents can be a severe barrier to changes in a PMU. The difference between the *today* and *desires* condition shows that the respondents are not satisfied with the current situation.
Conclusion: The passive attitude found in this study can also be characterized as a passive resistance that has lead to a resignation in their belief in their own influence on the future. This resignation may also have been influenced by the work situation of the respondents with close relation to patients with short expected time to live. Implications are discussed.

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175. Double-blind randomized comparison between double-dose of immediate morphine versus single-dose morphine at bedtime to cancer patients

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Aim
The EAPC guidelines for treatment of cancer pain recommend a double dose (DD) IR morphine at bedtime instead of 4-hourly single doses nightly (SD). A previous open controlled study reported more side-effects after DD than after SD (Todd et al. *Palliat.Med.* 2002). To increase the bulk of evidence a similar, but double-blind study was conducted.
Methods
This was a randomized, double-blind crossover study comparison of DD and SD of IR-morphine during night The primary outcome this was average pain intensity during night (11-point NRS scale), secondary outcomes were morning pain, number of rescue medications and adverse effects (nausea, xerostomia, tiredness, sleep quality and number of awaking episodes) and patient preference.
Results
Nineteen patients completed the study. A lower average pain during night for DD versus was close to statistical significance (mean 0.8 and 1.4, respectively, p=0,058). The mean (95% CI) for the difference between the two groups was 0.50 (-0.02; 1.0). A similar trend was observed for strongest night pain (p=0.069) and sleep quality (p=0.077). Only two patients required rescue morphine. Four patients had no treatment preference; nine and six favoured DD and SD, respectively.
Conclusion
The observations of Todd et al were not confirmed. Although apparently DD performed slightly better than SD, the two procedures are clinically equivalent, allowing for individual choice of SD or DD among patients

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176. Hospital death rates in six European countries: a population-based cross national study of clinical, sociodemographic and health care system factors

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PURPOSE
This population-based study examined the proportion of hospital deaths in six European countries (Belgium, The Netherlands, Sweden, Scotland, England, Wales), and associated factors.
METHODS
Data of all deaths in 2003 of the studied countries (2002 in Sweden) were gathered via official death certificate data, linkage with other population data files, and linkage with regional healthcare statistics, and were integrated into one common database (N=891,780) for analyses.
RESULTS
Of all deaths, 33.9% in The Netherlands to 62.8% in Wales occurred in hospital. Associations of hospital death with other factors, in particular age and type of terminal illness, differed per country. Older age was less in Sweden, Scotland, England, and Wales, than in Flanders and in The Netherlands associated with dying outside hospital. Cancer was especially in The Netherlands, and England, but not in Sweden associated with dying outside hospital. Especially availability of care home beds partly explained country differences in hospital death rate, but relatively large differences maintained.
CONCLUSION
Country differences in proportion of patients dying in hospital are only in part accounted for by differences in health care provision, and were in particular large for certain patient populations, suggesting country-specific end-of-life practices in these populations. Our findings can contribute to a rational policy aimed at reducing hospital death rates for specific patient populations.

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177. Description of a new integrated palliative care model

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Background: Palliative care needs to develop and evaluate new models for implementation of care. The integrated palliative care model, which includes formal cooperation between a special Palliative Medicine Unit (PMU), St. Olavs University Hospital and a Palliative Care Unit (PCU), Havstein nursing home, was established in Trondheim, Norway in 1998.
Objective: To describe the integrated palliative care model, the characteristics of its development and to compare patients between the sites.
Methods and material: Patients who were admitted to and died in the PCU (n=85) and in the PMU (n=188) 1 January 2002 to 31 December 2003 were consecutively included.
Results: Patients who died in the PCU were significant older (76 vs. 67 years, p<0.001). The majority of the entire cohort had gastrointestinal cancer, 45% PCU, and 35% PMU. There were significant differences between units, assessed during the last week of patients life, in use of indwelling bladder catheter (31% PCU, 60% PMU), oxygen treatment (24% PCU, 50% PMU), intravenous treatment (46%PCU, 76% PMU) (p<0.001) and central venous catheter (2% PCU, 12%PMU) (p=0.07). PCU had a median survival of 30 days (95% CI 15.95-44.05) versus to 11 days (95% CI 9.01-12.99) in the PMU (p<0.001)
Conclusion: The study is the first description of an integrated palliative care model in Trondheim, Norway. There were significant differences, with regard to medical interventions, which may be explained by patient selection and/or medical preferences guided by site.

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178. Inequity in the provision of and access to palliative care services for cancer patients in Italy. Results from the Italian survey of the dying of cancer (ISDOC).

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Aims: estimating the distribution of places of care for Italian cancer patients in their last three months of life, the proportion who received palliative care (PC) at home and in hospital, and the determinants of referral.
Methods: this is a mortality follow-back survey of 2,000 cancer deaths identified with a 2-stage probability sample, representative of the whole country. Information on patients experience was gathered, after the patient's death, from the non-professional caregiver with a semi-structured interview. Multivariate logistic analyses were conducted to identify the determinants of PC referral.
Results: valid interviews were obtained for 67% of the caregivers (n=1271). Most Italian cancer patients were cared at home (91%) or in hospital (63%), but with wide differences within the country. A PC support was provided for 14% patients at home (2% in the South and 18% in the North) and for 20% hospitalized patients (16% in the South and 25% in the North). Significant determinants of referral were: a long interval between diagnosis and death (P=0.01) and the caregivers high educational level (P=0.01) for cancer patients at home; the low patients age (P<0.01) and the caregivers high educational level (P=0.01) for cancer patients in hospital.
Conclusions: in Italy the provision of PC services are unequally distributed across the country and their access is strongly associated with socio demographic characteristics of the patients and their caregivers.

179. A comparison of the quality of care provided to cancer patients in the last three months of life in hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire.

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Background: Accounts of care at the end of life are varied, with limited information on the quality of care at this time in hospitals compared to that provided by hospices. **Method:** The VOICES questionnaire is a validated post bereavement questionnaire designed to assess the peoples' experiences of care towards the end of life. This questionnaire was sent to a random sample of people who had registered a death (the informant) in South London in 2002. 189 completed questionnaires were returned, a response rate of 48%. 43 cases were identified in which the deceased had died from cancer and had experienced both inpatient hospice and hospital care; chi square tests for association were carried out to compare 'last hospital stay' with 'last hospice stay'. **Results:** Overall quality of care was better in hospices on 10/17 aspects of care. The care provided by doctors and nurses in hospices exceeded that experienced in hospitals. Pain control and symptom management were significantly better in hospices. **Conclusion: On** a number of measures the quality of care provided to inpatients in hospices exceeded that of care provided in hospitals. Further research is needed to identify key components of "quality" in end of life care. Experts in palliative care should continue to educate and promote exemplary pain and symptom control to specialists working in other health care settings.

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180. SPECIALIST PALLIATIVE CARE SERVICES (PCS) AT HOME IN SPAIN: STRUCTURE, OUTPUTS, AND OUTCOMES.

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Aim

To describe the structure, activities, and clinical outcomes of specialist palliative home care support teams (HCST) in Spain.

Methods

Analysis of the data of HCST from 3 different sources: the National Spanish Directory of PCS (D) , a Spanish nation-wide longitudinal multicentre study describing the PCS activities (A), and a study on the effectiveness of PCS in Spain (B). In the D of 2004 there are 138 HCST registered, and their structure and basic outputs are described. In the A study, 89 HCST participated which is a representative sample of the Spanish HCST & in the B study participated 60 HCST.

Resultats

Overall evaluated patients were 331. The mean follow-up was 7.2 wks. with a median survival of 7 wks. A mean of 2.58 health care interventions /patient/week was carried out. The most frequent activity was the home care visit, phone calls and visits to the GP's centres. Hospital admissions were required by 35.9% patients with a mean length of stay of 10.6 days. The emergency services were used by 37% of patients, representing the 3.2% of activities. Death at home happens in the 68.1% of patients. Effective symptom control was obtained at 7 and 14 days of follow-up.

Conclusions

HCST promote a radical change in the use of health care resources at the end of life, being one of the most remarkable the shifting from crisis to scheduled care. Efficiency and effectiveness of HCST in Spain is confirmed.

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181. Cultural Pain and its impact on patient and family care: Connecting diversity in culture, policy and practice

David Oliviere

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Europe is increasingly diverse in the communities and patient population it serves. This presentation aims to identify a number of challenges that exist in understanding the nature of "cultural pain" (Oliviere, 2004) and facets of culture and ethnicity at the interface with palliative care services, policies and practice.
Areas that will be specifically presented will include how advanced illness, death and bereavement impacts on human cultural experience and vice versa; how the absence of safe cultural practice or cultural insensitivity can leave patient need unmet; and identify areas of commonality and difference in delivering culturally appropriate palliative care. Managing diversity in its connection with other core aspects will be a constant theme.
Method: This paper will draw on the authors review of key literature on culture, the findings of a series of conferences at the Education Centre, St Christophers Hospice, based on diversity and access, and his own training of health professionals in best practice. It includes the changing perceptions and ethical complexities in determining the nature of cultural pain.
Result and Conclusion: The paper will make suggestions for practice in what health professionals can do to meet cultural needs more accurately, cultural competence and guidance in safe cultural practice. Case scenarios will reinforce best practice points.

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182. AIDS challenges for palliative care in Uganda

Anne Merriman

Hospice Africa Uganda, Home care, Kampala, Uganda

Uganda has moved from being the country with the highest incidence of HIV in Africa in the late eighties and early nineties, to now being among the medium to lower, with 6% of the population being affected.

However this is still a significant disease burden. The challenges of AIDS have changed over the years. This paper will discuss the present challenges:

- The good and some of the bad effects of donor involvement.
- The problems of reaching the poorest with ART and other treatments: meeting this challenge in the community.
- Why palliative care in the era of ART?
- This is a familiar cry from our colleagues etc. However many of the patients on ART require palliative care which is not available in centres delivering ART.
- Palliative care is needed in the era of ART in Uganda for the following reasons:
- Patients with AIDS related pain and symptoms eg neuropathy
- Patients with side effects of ART: control of side effects improves compliance
- Patients with AIDS related cancers
- Patients who present too late for ART with overwhelming infections
- Patients with opportunistic infections for which there is no treatment eg CMV
- Interactions with ART
- Psychosocial and spiritual distress
- Poverty and other factors limiting access to ART

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183. HIV infection and AIDS challenges for palliative care in Romania

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HIV / AIDS infection is a major public health problem in Romania, with serious social and economic implications, and affecting, at the end of 2006, a total number of more than 10000 persons (6613 HIV+ and 5293 AIDS patients). A series of particular trends proved to be important in the last decade: maintenance of a high number of pediatric cases, an increase of the number of new adult cases, an overall increase of the number of HIV positive persons

Since 1999, a National Strategy anti-HIV/ AIDS has been put in place. A National Surveillance and Monitoring Program has been developed, through 9 Regional Centers. Priority targets of this program are 1/ risk categories; 2/ nosocomial infection control; 3/ education; 4/ social support provided for infected subjects; 5/ quality of health care provided and 6/ testing HIV policies and surveillance. The means to attain the purpose of this program are: antiretroviral treatment, educational measures for general population and high risk groups, screening in areas with a high incidence of infection and routine HIV testing, psychological assistance. According the National Strategy anti-HIV / AIDS (2006), several directions should be pursued to obtain a better efficiency, some of these directions pertain to the domain of palliative care: specialized home-based palliative services for the HIV / AIDS patients., evaluate the needs of palliative assistance, development of general practitioners' skills. All these trends and developments, including public awareness, efficient allocation of resources, could constitute in the near future viable nuclei for running a more satisfactory palliative care assistance of HIV / AIDS patients in Romania.

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184. AIDS and Palliative Care in France: new challenges

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Epidemiology

Until June 2005, they reported 60 212 AIDS cases (24% IV drug users, 45% Men having Sex with Men and 27% heterosexual contact) and 34 351 AIDS deaths.
Out of an estimated 85 000 patients in 2005, 58 000 were on antiviral therapy (ART).The mortality dropped in 1996 of 60% between the first and the second semesters of the year. due to the introduction of ART .
Now, Hepatitis C Virus(HCV) co-infection is a major issue for Aids and Palliative Care(PC): around 10% of deaths were related to HCV in 2001:Liver transplants are realized for this patients with problems of pharmacological interactions.
The number of cancers is also increasing due to the immunodysfunction and the prolongation of life in HIV patients (lymphoma; cervical carcinoma; Hodgkin disease)

Training

Three European Conferences on AIDS and PC were organized in France in the 90s at the peak of the epidemic (91;92 and 96) while PC were implanted in AIDS Units.
Moreover, AIDS is one topic of many Universitary Diploma on PC in France.

Organization of Care

Houses were opened in response to the epidemic in our country but also in Switzerland or UK: "La Maison" is one of them still opened in the South of France with an rehabilitation unit ."La maison d'Hestia" was opened in 1996 in Lyons welcoming terminal patients at the beginning and now more patients with social problems. Some PC Units were involved at the same time in the care of AIDS patients in major cities.

Research on management of specific symptoms

One pivotal study on Pain and AIDS was performed by François Larue in France in 1997.

The AIDS epidemic has changed since the introduction of ART and the challenge now is to deal with a chronic illness and older patients.

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185. The Song Rooms

Lucinda Jarrett Jarrett

Rosetta Life, Health and Wellbeing, London, United Kingdom

Rosetta Life has pioneered an interactive music composition site that uses state of the art technology to enable children using paediatric palliative care across the world to participate in music making and upload music directly to a site where others can respond and remix tracks. Children will make musical penpals, celebrate their vitality and create a new peergroup online of children in a similar situation.

We created an international network of hospices from South Africa, Zimbabwe, Canada, USA, Australia and England that will enable children to meet others across the world. Working with technology that ranges from mobile phones, laptops with wireless access and mobile recording devices enables us to challenge political prejudice about access to technology across the globe so that children from rural Zimbabwe can participate as peers alongside children from Canada and the UK.

Children in need of palliative care are often isolated from their peers through the stigma of illness and difference. This project enables children to discover their own creative voice and celebrate this online, within their place of health care and within their immediate communities.

An essential feature of the project is public education through a programme of concerts sponsored by local primary school partnerships and BBC. We hope to present the interactive site and videos produced by the BBC that record the concert and the friendships made online.

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186. Wound Care Part 2 - Wound Pain and Other Symptoms Associated with Wound Care

Frank Ferris, Rosene Pirrello

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

Chronic wounds are frequently associated with pain and other symptoms that are distressing for patients, families, caregivers and members of the healthcare team. If they are not managed properly, the chronic and acute pain associated with dressing changes, foul odors, uncontrolled bleeding, and the accompanying anxiety, depression and delirium can cause suffering and lead to abandonment of the patient.

During this interactive workshop, the presenters will guide participants through the underlying pathophysiology that leads to wound pain ; both continuous background pain and the acute intermittent pain associated with dressing changes. We will use clinical cases to discuss effective approaches to wound pain assessment and management, including both systemic and topical analgesics and anaesthetics.

We will also discuss approaches to assess and manage wound odor, bleeding, and other significant symptoms associated with chronic wounds.

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187. Fatigue in palliative care - a position paper from an EAPC workgroup

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Fatigue is one of the most frequent symptoms in palliative care patients. However, diagnosis and treatment of this symptom are often neglected. The Research Network of the EAPC has initiated an expert working group to produce recommendations for diagnosis and treatment of fatigue. However, the expert group decided not to use an evidence-based approach for guideline construction, but to produce a position paper highlighting the problems and incongruities related to fatigue in palliative care.

The word fatigue is not known in other languages than English or French. The concept of fatigue is not entirely clear yet, as some authors consider it a physical symptom, whereas others have used it as a behavioural construct. There is broad consensus that fatigue has to be treated, but it also may be a common endpoint of the disease trajectory, not requiring treatment but even shielding the patient from suffering and distress. There is general consensus that fatigue involves a physical (weakness) and a mental dimension (tiredness), but some studies have identified other dimensions. Research on fatigue has been predominantly in oncology patients, and the results may not be transferable to palliative care.

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188. Distress or just a symptom?

Carol Tishelman

Karolinska Instituet, Stockholms Sjukhem, Department of Neurobiology, Care Sciences and Society, Division of Nursing, Stockholm, Sweden

In this presentation, I will critically discuss issues about the manner in which we define, assess and research symptom experiences in palliative care. While palliative care has made major strides in assessment and treatment of many symptoms, I argue that we still do not adequately address the whole spectrum of relevant symptom experiences. Most often, we evaluate symptoms with regard to whether or not they occur, and how intense or severe they may be, rather than focus on the level of distress patients perceive from the symptom in question. An underlying assumption in much of the literature appears to be that symptom intensity is equivalent to symptom distress.I will question this assumption, basing this argument primarily on data derived from a research project exploring symptom experiences in 400 men and women with inoperable lung cancer during the first year after diagnosis, which was also the last year of life for most participants.

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189. An integrated care pathway - overview

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The European Pathway Association (www.E-P-A.org) definition of care pathways includes: An explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations. The facilitation of the communication, coordination of roles, and sequencing the activities of the multidisciplinary care team, patients and their relatives; the documentation, monitoring, and evaluation of variances and outcomes; and the identification of the appropriate resources. The aim of a care pathway is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources. Clinical paths are clinical management tools to define the best process in their organisation, with the best procedures and the best timing, to treat patients with specific diagnoses or conditions according to Evidence Based Medicine (EBM). To build the clinical pathways the following steps, based on PDSA cycle can be used:

1. Select the area of practice.
2. Build the multidisciplinary work-team.
3. Define the diagnosis.
4. Define the patients.
5. Review practice and literature.
6. Develop the clinical path.
7. Pilot and implement the clinical pathway.
8. On going evaluation.
9. Implementation.

Despite widespread enthusiasm for clinical pathways, rigorous evidence to support their benefits in health care is still limited. The next step in research will be the development of more highly integrated pathways, that span the continuum of care for patients. Conclusion. The adoption of clinical pathways can add permanent value to healthcare organisations and help diffuse EBM and the practice of evaluating.

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190. Promoting excellence in care of the dying: The Liverpool Care of the Dying Pathway (LCP)

John Ellershaw

Marie Curie Palliative Care Insitute Liverpool, Departmennt of Palliative Medicine, Liverpool, United States

Excellence in Care of the Dying has been championed by the Hospice movement in the UK. This model of excellence is recognised by society and also by healthcare professionals. However, so often this model has not been translated into acute hospital settings. Caring well for patients at the end of their lives is important for the patient, their relatives and also the health care professionals involved in that care. The Liverpool Care of the Dying Pathway (LCP) has been developed to transfer best practice from Hospice into Acute Hospital settings. The LCP is used as a framework of care and documentation in the last hours and days of life and is initiated when the patient enters the dying phase. It contains three sections: initial assessment, ongoing care and care after death. The LCP framework is part of the Department of Health 'End of Life' initiative and is currently being disseminated throughout England. Collaborations with a number of European countries have been established to translate and implement the LCP.

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191. EXPERIENCES WITH THE LIVERPOOL CARE PATHWAY FOR THE DYING IN THE NETHERLANDS

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Introduction: In 2001 the Liverpool Care Pathway for the Dying (LCP) was translated into Dutch following EORTC guidelines. To assess the effects of the LCP in different care settings a study was performed in which the Comprehensive Cancer Center Rotterdam (CCCR) supported the implementation of the LCP. *Method:* Two home care organizations, two nursing homes, and two hospitals participated in the study comparing care before ('baseline') and after the introduction of the LCP ('intervention'). Documentation of symptoms and care was evaluated. For each patient, a nurse and a relative filled in a questionnaire about symptom burden, interventions, and communication during the last *three* days of life. *Results:* During 'baseline' 220 (78% of the deceased) and during 'intervention' 255 patients (87% of the deceased) were included. All nurses and 55% of the relatives filled in a questionnaire. Patient characteristics and places of death were the same in both periods. The LCP had been used for 197 patients (78%) in the intervention period. The median duration of use was 63 h in home care, 35 h in the nursing home and 16 h in the hospital. In the intervention period the documentation was more complete and communication was slightly better. No differences were seen in the application of interventions. The total symptom burden decreased after implementation of the LCP in the perception of both nurses and relatives. *Conclusion:* The LCP could be used for most patients who entered the dying phase. The quality of documentation improved, the symptom burden decreased and there were indications for improvement of communication. The LCP will be further introduced in the Netherlands by the CCCR and follow-up research will be done by the Rotterdam Center of Expertise in Palliative Care.

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192. Liverpool care pathway for the dying phase: implementation process in Slovenia

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2 *Palliative Care Development Institute, Oncology and Palliative Care, Ljubljana, Slovenia*

Background: Main difficulties of the implementation of palliative care (PC) into Slovene health care system are lack of common vision, little education on PC, ineffective teamwork, lack of organizational solutions for continuity of care across all settings, and others. Liverpool care pathway (LCP) might be a tool to improve this situation. National steering committee decided to start the pilot project in three clinical settings.
Methods: After contacts with LCP authors, translation, development of educational curriculum, identification of local steering committees, and co-ordinators the implementation of LCP in three hospitals started. Process of this implementation is carefully followed up in order to quickly identify the obstacles and find effective solutions.
Results: Some significant findings are described: the national consensus, which is of paramount importance, was easily achieved; on the local level the implementation was much harder discussed; the authorship over the clinical pathway and meticulous attempts to adapt the LCP to each institution were the most obvious features in our findings. Development of common vision, education and involvement of all the staff is sometimes hard to establish. Some solutions to these problems were found and will be presented.
Conclusions: Through this type of implementation process we learned several weaknesses of co-operation and decision-making in our health care system and found some applicable solutions.

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193. PALLIATIVE CARE IN GEORGIA

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First palliative care clinic for advanced cancer patients in Georgia was opened in January 2005 and served 216 patients. During 2006, 261 patients have been hospitalized. 64 % women, 36 % men. Patients' average age 57,3. Average duration of hospitalization 17,5 days. The reason of incurability in 90% was metastasis, in 10% the locally spread tumors. Most frequent cancer localizations - colorectal (28 %), breast (25,3 %), lung (9,6 %), cervical (4,6 %), ovarian (8,4%), gastrointestinal (5,4%). Cost of care (55 GEL) was covered by the State Program on Oncology (70%), the patients pay 30 %. Patients' health condition was assessed with ECOG scale. Performance status was: I gradation −2,7%, II−24,5%, III−29,1%, IV−43,7%. Most frequent symptoms were: asthenia (91.2%), pain (84.3%), anorexia (76.4%), the dysfunction of the gastro-intestinal tract (70.4%). Strong pain was observed in 37.5%, moderate − 31.5%, mild − 15.3%. Visual analogy scale was used for pain assessment. Patients were provided: detoxification − 100%, vitamin therapy − 93.1%, pain management therapy −84.3% (by opioid in 42.9%), energy and appetite stimulation - 28.2%, small surgical manipulations (laparocentesis, pleurocentesis and others) − 6.5%, radiotherapy − 2.3%, chemotherapy − 44.4%, the correction by bisphosphonates − 5.1%, hormonal therapy − 4.2%. In 117 cases 42 patients (29.8%) have been provided care for second time. Number of lethal cases − 13,9 %. Therefore, the analysis of the palliative care clinic activities during first year of its functioning can be considered as successful medical organization of specific profile.

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194. My own Palliative Care Service

Furio Zucco

Azienda Ospedaliera, Anestesia e Rianimazione Cure Palliative e Terapia del Dolore, Garbagnate Milanese, Italy

The Palliative Care Unit (UCP) of the "G. Salvini Hospital Trustee" in Milan (Italy), completely managed with public funds, since 2003 provides: **1. Home palliative care**, in home hospitalisation model; **2006: 463** patients assisted; mean period of assistance: 28 days). **2. 10 beds in-patients hospice** (additional 5 beds in 2007); **2006: 216** patients assisted, mean duration of hospitalization: 15 days). **3) day hospice**; 2006: 452 services; **4) out-patients ward;** 2006: 9722 services. **5) in-hospital consultancy**; 2006: 3125 services. The UCP is part of the Anaesthesia and Intensive Care Department, with an autonomous budget, management and personnel. The 2005 budget was **3.043.673,00** ¤ supplied by the Regional Health Service: the service is totally free for patients and their families. The UCP full-time staff: 1 Director (doctor), 11 doctors, 1 head-nurse, 23 nurses, 10 health and social service operators, 1 physiotherapist, 2 administrative employees. Moreover the Hospital supplies as part-time specialized personnel: a) psychological support, b) social assistant, c) religious support (volunteer). Volunteers, belonging to 2 non-profit organizations, members of the Palliative Care Italian Federation (), work both in the hospice and at home. 80% of the personnel is member of the Italian Society for Palliative Care (). The UCP takes part in the national and regional project of the Hospital Without Pain (OSD). The Director coordinates the local Committee for OSD.

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195. The regional palliative care program of Extremadura

Javier Rocafort

Regional Palliative Care Program of Extremadura, Mérida, Spain

More than a single service, the Regional Palliative Care Program (RPCP) of Extremadura (Spain) is a network of services and strategies oriented to guarantee palliative care provision to everyone in need. In 2002, a RPCP was built by the government. It is entirely funded by the public insurance system, and patients have not to pay for any service. The annual cost of the program is around 3 million ¤ (equivalent to 3 ¤ per inhabitant per year).
Structure and funding: Primary care provide basic palliative care, and 8 specialized palliative care teams (PCTs), one per health district, take part in complex situations in hospital or in the community. They are mobile and staffed by doctors, nurses and psychologists. Each team offers comprehensive coverage within their corresponding health district. Moreover, all 41 professionals from the PCTs are involved in 4 working groups (evidence, quality, education and tools). In addition, there is a central office where the regional manager of the program, the regional observatory, the research office (two full time researchers) and the voluntary coordinator are located.
Process and activities: During 2006, in Extremadura (1,086,373 inhabitants), 1,687 terminally ill patients were seen by PCTs. 89% of them had a cancer diagnosis. The average survival time in palliative care program was 37.3 days. In the total year, PCTs did 6372 hospital visits; 2100 outpatient clinics; 4039 home visits; 27340 advice or coordination activities; 450 teaching sesions; and 632 meetings. Four of these teams have some beds available in acute hospitals. Last year, 304 patients were treated there, with a median stay of 8.9 days. Moreover, from 2005, there are 30 beds available in medium-term care centres and 50 beds available in long-term care centres.
Opioid consumption: In the year 2005, 494,654 Defined Daily Doses of opioids were prescribed by the Public Health System in Extremadura (equivalent to 49,63 kg of oral morphine per million inhabitants).
Quality control: Quality indicators were chosen by the quality group and the regional coordinator from the criteria of Spanish Palliative Care Association (SECPAL). Last year, the group identified and measured 28 of these indicators in every PCT.
Conclusion: The RPCP care of Extremadura offers a model that is integrated into the Public Health Care system and is able to offer comprehensive coverage, availability, equity and networking.

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196. My own palliative care service

Simkó Csaba

Semmelweis Hospital, Elizabeth Hospice, Miskolc, Hungary

The Elizabeth Hospice provides a complex palliative and terminal care for cancer patients in Miskolc. A 20-bed in-patient unit, a home care team, an outpatient, a hospital consulting and a bereavement service belongs to it with a wide spectrum of palliative education activity. The 450 patients cared by the complex system a year take a considerable part of the cancer patients of the city (about 70%). Collaboration with GP-s is exemplary and based on a deliberate management strategy. As one of the first hospice organizations in Hungary the Elizabeth Hospice has a special mission. It works as an educational and methodological centre for palliative care in the north-east part of the country.

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197. Competencies in Palliative Care

Jose Pereira

Université de Soins Palliatifs Foundation Leenaards, Service de Soins Palliatifs, Lausanne, Switzerland

Competencies are the set of cognitive, affective and psychomotor functions that support the "*habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, knowledge, technical skills, clinical reasoning, emotions, values and reflection in daily practice*". Numerous other dimensions influence competencies, including self-awareness, compassion, and scientific and humanistic judgement. Competency integrates several attributes necessary to successfully and adequately complete the tasks required in a specific clinical role and these include combinations of knowledge, attitudes, and skills.

Internationally, there is an increased move towards competency-based health care education. The WHO, a strong advocate of such an approach, has also emphasized that any definition of medical competence should be linked to: a) local social, cultural, political, and economic circumstances; b) health needs; c) availability of resources; and d) structure of the health care system. Competency-based programs are shaped by the content and context of work rather than by the subject areas of traditional training programs. Some competencies are common to all disciplines, there are others that are discipline-specific.

The benefits of developing clearly articulated competencies have been well described by Yuen and colleagues and include: a) provide an objective framework for evaluation and performance appraisal; b) help professionals evaluate their own competencies and identify areas that need further development; c) guide recruitment and selection of new personnel and team members; d) prepare new team members to the team; and e) to clarify the quality of the work.

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198. Assessment in Palliative Care education: Reviewing the instruments and their properties

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The need for skilled healthcare professionals to provide high quality end of life care has led to an increasing amount of palliative care education interventions over the past few years. This phenomenon calls for appropriate evaluation and assessment practices to ensure the quality of these learning experiences. Numerous methods have been described in the literature to assess competencies in medicine using instruments that are valid, reliable, and feasible. The strengths and limitations of several assessment tools are well known and thus, could be used to assess palliative care education. Among them, Objective Structured Clinical Examinations (OSCEs) and written tests using multiple choice response format seem appropriate in assessing palliative care competencies.The OSCE is a means of assessing clinical competency, based on objective testing through direct observation. This method uses "stations" in which examinees are assessed on their performance of clinical tasks. OSCEs have high face validity; can focus on specific content areas or skills; and provide direct observation of performance. In spite of these strengths, OSCEs have a number of limitations. Written tests using Multiple Choice Questions (MCQs) can be used to measure knowledge and attitudes. MCQ tests are good for assessing knowledge and application of knowledge but they lack ability to assess communication skills and ethical behaviours. The presenters will discuss the strengths, limitations, psychometric properties and other practical aspects of the use of these instruments in assessing palliative care education.

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199. "Multiprofessional teaching and learning: taking the lead in a novel approach"

Steffen Eychmueller

Palliative Care Service, St.Gallen, Switzerland

The WHO highlighted in the late 80's the fact that multiprofessional team work is a major need and challenge for health care. Thus, WHO edited some essential ideas under the title "Learning together to work together for health".Some major steps proposed by this paper have been integrated in more recent educational strategies, namely in the "5- star- doctor"-framework defined by Ch. Boelen, and more explicit, in the 12th Medical Education Guide formulated by the Association for Medical Education in Europe (AMEE) with the leading author R. Harden. Most medical curricula in the world (and also curricula for nurses, psychologists etc.) define team working skills as mandatory.But how is the reality ? This talk wants to highlight some concrete examples for **education** in multiprofessional teamwork. It intends also to strengthen the role of Palliative Care as one of the most obvious examples and disciplines for up-to-date health care. Some examples for educational strategies in multiprofessional teaching will be given.

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200. TWIST IN THE EVALUATION OF THE TERMINAL PATIENT

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Objetive: show if the admission time in a Palliative Care Unit, affects the QoL of the patient, througt an easily applicable parameter as the TWIST (Time Wihtout Symptoms of Disease and Toxicity). **Methodology:** from 63 patient, were selected 37 who fulfil the conditions of having died in this unit after a stay of more than 3 weeks, with an average stay of 5.7 weeks. The study was done using, on the one hand, the indepent variable is weekly admission period; diferentiated in three stages: first week, last week and the period betweenthose weeks averaged out to seven days, and on the other hand, the depended variable is number of days in which the patients had felt discomfort/comfort (TWIST), on those stages (rank 0-7). For doing the statistical analysis, the non parametrical Friedman test. **Results:** percentile was found that us much us 40% of patients, had discomfort during the two first admits days lowering until 13% during hospitalisation period, and raising until 50% before to they died. The Friedman test of the three admission periods, gave us a significant difference between them, with a X^2 value of 12.6 ($p<0.001$). Tabular value of 14.23 to check what admission period gave the signification. Only were found significant differences in the period between the first and the last stage period ($p < 0.001$). **Conclusions:** disconfort feeling in a U.C.P. is high in the first week, lowering during the hospitalitation and with an increasing defore they died.

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201. The Use of Drugs at the End of Life

Ruth Flockton[1], Helen Ferguson[1], Melanie Brooks[2], Andrew Dickman[1], Karen Groves[3]

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Aim
The project aimed to establish the usual prescribing intentions of healthcare professionals who work in Specialist Palliative Care (SPC) caring for patients in the last days of life.
Method
A questionnaire was distributed to senior medical and nursing staff in SPC across the Mersey and Cheshire Palliative Care Network. They were asked to state the drugs they would use to manage symptoms arising in the last days of life. They were asked to assume the patient was opioid naive and that each symptom arose in isolation.
Results 88 healthcare professionals returned questionnaires. 83% of the healthcare professionals would suggest morphine or diamorphine as the first line opioid in the last days of life subject to local availability. 89% suggest midazolam first line for the management of agitation and 61% suggest levomepromazine second line. 64% of healthcare professionals suggest hyoscine hydrobromide for the management of respiratory tract secretions. Cyclizine is the anti-emetic suggested by 37% and levomepromazine by 35%. Morphine is the most commonly suggested drug for the management of breathlessness.
Conclusion
The project has led to the development of guidelines for the management of symptoms in the last days of life. The guidelines aim to empower the general healthcare professional and provide an integrated approach across the Palliative Care Network.

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202. PHYSICIANS PREFERENCE OF THROMBOPROPHYLAXIS IN PALLIATIVE CARE PATIENTS

Katharina Kierner, Verena Gartner, Maria Schwarz, Herbert Watzke

Medical University of Vienna, Palliative care unit, Vienna, Austria

Background:Thromboprophylaxis (TP) is an unresolved issue in palliative care. **Methods**:We asked a panel of internationally recognized medical experts (n = 20) in palliative care, oncology, blood coagulation and intensive care about their practice of TP in palliative care patients. They were asked to select a prophylactic regimen out of five predefined options which were attributed to a specific case scenario.
Results:Prophylaxis was continued by almost all

physicians (99%) in a patient with metastatic bronchial carcinoma and a Karnovsky Index (KI) of 40, waiting to be transferred to a palliative care unit. The majority of physicians (75%), but all palliative care physicians opted for a discontinuation of TP when the KI deteriorated to 20 (refractory pneumonia). TP was discontinued by all physicians (100%) when the patient was described as dying (KI: 10, unconscious, no i.v. fluids). Following results were obtained when the above patient was described as having a history of recent pulmonary embolism: Full dose heparin by 80% of physicians in the patient with KI of 40; no prophylaxis by 75% of physicians in the patient with KI of 20; no prophylaxis by all physicians (100%) in the dying patient (KI: 10). **Conclusions**: The willingness of physicians to deliver thromboprophylaxis to palliative care patients is low and is rather unequivocal among experts in oncology, blood coagulation, intensive care and palliative care.

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203. HELPING PEOPLE WITH ADVANCED CANCER AND THEIR CARE GIVERS MANAGE CONFLICT OVER FOOD

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Aim This paper is the first to discuss ways of helping people with advanced cancer and their care givers manage eating related conflict[1].
?**Method** The research was a mixed methods investigation of weight loss and eating difficulties in people with advanced cancer. The study participants included 32 patient-caregiver pairs receiving palliative home care in the South of England in either 2003 or 2005. Methods of data collection included semi-structured interviews that were analysed using both content and thematic approaches. An emergent theme was 'conflict'. **Findings** Conflict over food had arisen between 26 of the patient-caregiver pairs. Some patients had found ways of self-managing the conflict, revealing potential for a supportive intervention. The evidence of self-management was synthesized with the emerging literature on collective coping[2], generating a new perspective from which to approach the conflict problem. **Conclusions** Further work is needed to understand the process through which some patient-carer dyads effectively manage conflict over food. This understanding would provide an evidence base for building a complex intervention for the problem.

1. Meares C.J. (1997) Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncology Nursing Forum* **24**, 1751-7. Revenson T.A. et al. (2005) *Couples coping with stress: Emerging perspectives on dyadic coping*. American Psychological Association. Washington.

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204. Categorising palliative care development: a global perspective

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Background: An estimated 60% of the 55 million people who die each year would benefit from palliative care. Yet globally, palliative care development appears patchy, comparative data are generally unavailable and there is a weak evidence base on which to build policy. **Aims:** 1) To categorise hospice-palliative care development, country by country, throughout the world and 2) to depict this development through world and regional maps .
Method: A multi-method review involved the synthesis of evidence from published and grey literature, regional experts and an EAPC task force. Development was categorised using a 4-part typology 1) no identified hospice-palliative care activity 2) capacity building activity but no service 3) localised palliative care provision and 4) countries where palliative care activities are approaching integration with the wider health system.
Results: One or more palliative care services were found in 115/ 234 countries. Total countries in each category were 1) no identified activity 78 (33%); 2) capacity building 41 (18%); 3) localised provision 80 (34%) 4) approaching integration 35 (15%). The ratio of services to population among Group 4 countries ranged from 1: 40,000 (in the UK) to 1: 4.28 million (in Kenya); among Group 3 countries, it ranged from 1: 14,000 (in Gibraltar) to 1: 157 million (in Pakistan).
Conclusions: The typology differentiated levels of palliative care development in both hemispheres and in rich and poor settings. Although half of the countries in the world have a palliative care service, far more are needed before such services are generally accessible worldwide.

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205. Opioid prescribing changing Romanian legislation

Daniela Mosoiu, Alison Landon

Hospice, BRASOV, Romania

Access to drugs is essential in any national palliative care programme. The restrictive laws governing the medical use of opioids and psychotropic substances in Romania dated from 1969. Only one preparation per patient was permitted, obtaining this was an extremely complicated procedure for the patient and his/her family, including approval from the county oncology hospital for any initiation or change in treatment, medications were only dispensed from pharmacies in the county towns ; to mention a few of the hurdles. These laws were finally replaced by the Romanian parliament in November 2005 after four years collaboration between national government, local health care professionals and international experts. WHO guidelines were used to frame legislation that allows for modern clinical management but also gives adequate statutory control of any substances with a potential for misuse. It is a simple, flexible, regime that permits any appropriately trained doctor to prescribe, sanctions multiple therapies and is generally much easier for patients and their families. A national education programme to implement the new law has been organised and training began in November 2006. It is hoped that a minimum of 3000 doctors and 500 pharmacists will attend the courses.

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206. Creativity in Promoting Palliative Care Awareness

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Palliative care (PC) services in Israel are still not part of the regular health care basket. The limited awareness of public figures and policy makers may hinder the additional development and establishment of PC services. Various methods to promote PC awareness have been used in our country. These included presentations about PC in the professional and public visual and written media. Many of these methods are time consuming and unfortunately have only limited success and impact. Two years ago, we were invited to a large health care policy making conference to introduce PC concepts. We were granted only six minutes to do so. Frustrated and determined to make an impact, we decided to use a different approach. Instead of lecturing, we presented a 4.5 minute long home-made video clip containing the major PC concepts. The video clips goal was to produce an emotional impact. As a result, we received multiple requests for formal and didactic presentations to various health care professionals and organizations. Realizing its influence, these lectures always ended with the video clip Subsequently, we offered to project the video clip during intermissions at several medical conferences. We were pleased to receive additional requests for formal presentations. We hope to share our video clip with other national organizations who are struggling to promote PC development in their countries.

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207. Providers' Assessments of Barriers to Optimal Cancer Pain Management in 5 Latin America Countries: Argentina, Brazil, Cuba, Mexico, and Peru

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Aim: To identify the barriers to optimal cancer pain management in Latin American institutions as reported by providers and to compare these findings across nations, practice-settings, and specialties.
Methods: A cross-sectional, convenience sample survey of 777 Latin American advanced-cancer care providers was conducted by MD Anderson's WHO Collaborating Center in Supportive Cancer Care. Surveys were collected through mass mailings, distribution at conferences, collaboration with Latin American institutions/organizations, and the Pan American Health Organization, and online posting.
Results: Overall, the top 4 barriers were: inadequate staff knowledge of pain management (71%); patients' inability to pay for services/analgesics (54%); inadequate pain assessment (52%); and excessive state/legal regulations of prescribing opiates (47%). Stratified analyses revealed important differences. While 87% of Cubans identified "lack of access to a wide-range of analgesics" as a top barrier, only 49% of Mexicans and 38% of Peruvians did. Respondents from private institutions were more likely to identify "patients' inability to pay for services/analgesics" than others. Anesthesiologists were less likely to identify "inadequate assessment of pain" as an important barrier than other specialties.
Conclusion: Findings from this study will provide critical information needed for developing targeted programs and policies to improve palliative cancer care in Latin America.

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208. Renal patients have symptoms too - a cross-sectional survey of symptoms in stage 5 Chronic Kidney Disease managed without dialysis

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Background: Numbers of patients with advanced chronic kidney disease (CKD) managed conservatively (without dialysis) are increasing, but their symptom prevalence and severity is unknown.
Aim: To describe symptom prevalence, severity, and total burden in patients with advance (stage 5) CKD managed conservatively.
Method: A cross-sectional symptom survey across 3 UK renal units, using the patient-completed Memorial Symptom Assessment Scale-Short Form (MSAS-SF)
Results: 66 patients were recruited (response rate 62%), mean age of 82 yrs (± SD 6.6) and mean estimated glomerular filtration rate of 11.2 (± 2.8) ml/minute. Symptoms reported by > 1 in 3 patients were: lack of energy 75% (95% CI = 66-83%), pruritus 74% (65-82%), dyspnoea 60% (50-69%), pain 52% (42-62%), anorexia 48% (38-58%), restless legs 48% (38-58%), sleep disturbance 42% (32-52%), and constipation 35% (26-45%). Mean ±SD number of symptoms was 11.6 ± 5.2 (median 11.0),with 2.8 ± 1.7 added renal symptoms. Both symptom prevalence and total burden in these patients are high - similar to advanced cancer populations previously studied using MSAS-SF. Differences in patterns of symptom prevalence and symptom severity between renal and cancer populations will be discussed.
Conclusion: Stage 5 CKD patients have major symptom control needs, similar to those with advanced cancer, but with different patterns of individual symptoms and severity.

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209. Multiple Sclerosis and Palliative Care: Unmet needs of severely affected patients in Germany

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Aim of project The aim of this project was to assess unmet needs in severely affected Multiple Sclerosis (MS) patients in Germany.
Method In 15 purposefully sampled patients feeling severely affected by MS episodic in-depth interviews were conducted. Episodic interviews enable both focussing on certain topics and giving room for narratives by flexibly using a guideline. Clinical data were obtained from physicians. In global analysis the range of needs in patients was assessed.
Result Sample included six men and nine women living in rural or urban areas. Age ranged from 24-73. Marital status differed from unmarried, married, divorced to widowed. Nine of the patients had children. Patients considered themselves as severely affected independent of their physical status given by EDSS (EDSS range 3-9). Most *important needs* for the patients are support from family, physiotherapy and aiding devices. However, as *unmet needs* coordination of services, transparency, information about possible services and psychosocial support were identified. As Palliative Care (PC) initially is associated with Terminal Care, patients do not consider it a suitable health service. However, when explained what PC can offer for MS patients they are often interested in this form of care.

ConclusionAs categories of unmet needs correspond to PC expertise, a complementary PC service for severely affected MS patients and their caregivers should be developed which may improve their quality of life.

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210. Addressing the diversity of symptoms in every day life in end-stage COPD patients

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Aim Chronic Obstructive Pulmonary Disease (COPD) is a chronic condition characterised by a progressive loss of lung function and leads to a slow, steady decline with intermittent serious episodes. The aim of our study was to explore the end stage of COPD and to describe problems that patients encounter in their every day life.
Methods We are conducting a prospective mixed-methods study of 90 end-stage COPD patients, including repeated interviews with a subsample of 20 patients.
Results Physical health changes dramatically from day to day, and even within a single day. Patients experience frequent attacks of breathlessness that are mostly unexpected. Although these patients have lived with their disease for many years, most cannot control or predict these sudden attacks. The unpredictability of the disease has an influence on various elements of every day life. Planning things becomes extremely difficult. Even within one day, patients have difficulties in planning their activities. Most patients are reluctant to show their breathlessness in public and some develop a fear of going outside.
Conclusion Patients with end-stage COPD are suffering from a disease which causes a slow deterioration of their general health. On top of this, patients are confronted with a diversity of symptoms that changes daily, like unpredictable attacks of breathlessness. These changes are important for caregivers in determining the appropriate care for these patients.

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211. Patients with advanced heart failure attending a specialist heart failure unit - do specialist palliative care services have a role?

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Background: Many studies have identified unmet specialist palliative care needs of patients with advanced heart failure. Few have focused on patients receiving specialist multidisciplinary care at a heart failure unit(HFU).
Aim: To determine whether patients with advanced heart failure attending a specialist HFU have unmet specialist palliative care needs.
Methods: A prospective cross-sectional study, using quantitative and qualitative methods, of 50 patients consecutively sampled at a specialist HFU.
Results: Mean age(SD): 74.2 yrs(8.6), 76% male. Mean systolic ejection fraction: 27.7%(8.1). Mean ESAS symptom distress score:33.1(13.2). HADS: mean anxiety score:5.4(3.5), mean depression score 6.2(3.4). Mean SEIQoL score:79.2(14.9). Mean Minnesota Living Living with Heart Failure Questionnaire score: 39.9(18.4). Most patients had good understanding of their diagnosis but many had unanswered questions regarding prognosis.
Conclusions: This cohort of heart failure patients had symptom burden equivalent to cancer patients accessing specialist palliative care services. Many had information needs. Communication barriers were identified. Emotional wellbeing was good and SEIQoL scores were higher than cancer patients accessing specialist palliative care services. Some but not all palliative care needs were met. Specialist palliative care and cardiology services should work in partnership to fully address the needs of heart failure patients.

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212. A Family Perspective on the Emotional Burden of End-of-Life Decision Making in an Intensive Care Unit

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Summa Health System, Internal Medicine, Akron, United States

Aim: This study aims to understand families' perspectives on decision making about a loved one's care in an intensive care unit (ICU) and the emotional burden of those decisions. **Methods:** Semi-structured interviews were completed with 27 family members who participated in a decision making family meeting with the Palliative Care Consult Service (PCCS). Interviews were taped, transcribed and content analyzed using methods from grounded theory. **Results:** Families described specific communication issues and compassionate gestures important to decision making and relief of emotional burden. Communication issues include: timing of the family meeting; listening to family members' understanding of the illness, prognosis, and patient's perspective; and acknowledgement of the patient's personhood. Compassionate gestures include attentiveness to the patient and family's comfort. **Conclusion:** The family meeting is experienced as one event in a series preceding the death. The family members' emotional response to the decisions made is further influenced by their experience of the dying process. The PCCS appears to help families make decisions by communicating their sensitivity to the family's perspective and concerns. Emotional burden is reduced when there is consistency between the decision making and the care provided during the dying process.

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213. Are psycho-social factors underestimated in managing nausea?

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Nausea has multiple potential causes at end stages of life. This study aimed to identify clinician's and patient's perspectives of factors contributing to nausea in advanced cancer.

110 patients (from 4668 screened) experiencing nausea were recruited from palliative care services. Patients completed an interviewer-administered questionnaire comprising rating scales to assess nausea severity and impact (0-10), and checklists to rate the extent to which 17 clinical, emotional and environmental factors contributed to nausea. Clinicians rated how 21 factors were contributing to a patient's nausea.

The final multiple regression model to identify predictors of nausea severity was significant ($p<0.0005$) with emotional factors, anxiety and having primary GI cancer accounting for 17.6% of the variance. Emotional factors made the largest unique contribution (sr^2=.34), while the contribution of primary GI cancer (sr2=.17, p=0.07) neared significance. Emotional factors, anxiety and age accounted for 36.7% of the variance in nausea impact ($p<0.0005$). Emotional factors made a significant independent contribution (sr2=.53) while the contribution of age (sr2=-0.152, p=0.07) neared significance. Anxiety did not make a unique contribution to nausea impact.

Emotional factors are important in patient's reports of nausea, suggesting that management strategies which incorporate these dimensions may have an important role in controlling the problem.

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214. BURNOUT SYNDROME, COPING STRATEGIES AND RISK BEHAVIORS IN DOCTORS FROM ROMANIAN PALLIATIVE SERVICES

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This study examined the comparative incidence of burnout syndrome, risk behaviors and use of coping strategies of doctors working with incurable patients in several representative Romanian palliative services. 34 doctors, dealing with incurable adults, 32 dealing with incurable children and 36 controls were tested using COPE questionnaire, Maslach Burnout Inventory and an own questionnaire assessing risk behaviors, such as smoking, alcohol consumption and work overload. Doctors working with incurable cases had a much more substantial use of emotion-centered strategies, such as positive reinterpretation, mental and behavioral disengagement, focus on emotions, denial and religious coping ($p < 0,05$). Denial, mental disengagement and religious coping were especially prevalent in doctors dealing with children with incurable diseases, compared to other two groups ($p < 0,05$). Heavy smoking (over 15 cigarettes / day) was significantly higher in doctors dealing with incurable adults. The burnout score was higher in both groups of doctors dealing with incurable patients, compared to the control group.?The results of this study show a high inefficiency of Romanian doctors from palliative services in dealing with daily professional stress. This suggest that supplementary actions (including psychotherapeutic assistance and active screening for burnout) are needed, in order to assure a better quality of life and work performance of these doctors.

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215. Physician strategies in communication about prognosis. An observational study

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Background and aims: Full disclosure of diagnostic information has become the standard in medical practice. Because of greater uncertainty about prognosis and huge ethical dilemmas related to information about bad news the same standard does not apply for prognostic disclosure. The present study examines how physicians in practice solve the dilemmas related to information about prognosis. **Material and methods:** 25 physicians performed 185 outpatient consultations with patients suffering from haematological or rheumatologic diseases of different severity. Qualitative analysis was performed by three researchers who independently identified and classified sequences of the consultations assessed to deal with prognosis. A final joint classification was gradually reached in consensus meetings. **Results:** physicians seldom explicitly examine patients' preferences for prognostic disclosure and they seldom give elaborate prognostic information. In stead they use tentative or implicit strategies such as *invitations, implicatures* and *unspecific information*, which may result in further information if requested by the patient. In order to balance between the demands to promote hope and give (true) information they use strategies like *good news- bad news spirals, authentications, safe-guardings, use of positive words* and *focusing on the positive*. **Conclusion:** Physicians apply a range of sophisticated communication strategies in prognostic disclosure. The appropriateness of each strategy as well as new alternative ways should be researched for different patient populations.

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