Thursday 7 June

CONNECTING DIVERSITY

10th Congress of the European Association for Palliative Care
2. Funding — needs, responsibility and availability

Mary Callaway

Open Society Institute, Palliative Education and Research Center, New York City, United States

Fifty-eight million people die each year and it is estimated that up to 80% of these patients and their 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 of public health organizations that parallel 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 Hospice, the Ellison 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 A&E 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 framework. We must assume the responsibility of working together as patients, health care providers, communities, researchers, 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 drug availability. As population, the growing incidence and prevalence of cancer expand the existing HIV/AIDS epidemic into a substantial increase in this funding to meet the needs of these patients and families.

3. Access to controlled medications: impact for patients

William Scholten

World Health Organization, Medicines Policy and Standards, Geneva, Switzerland

Over 80% of the world population has no proper access to medicines controlled under the drug control regime. The result is very scaring: consequences are unnecessary suffering from pain and preventable HIV transmission. Women die in delivery by lack of access to oxytocics 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 failing to communicate and submit accurate and up-to-date statistics to the INCSR, inappropriate medical practices and the lack of recognition of the therapeutic usefulness of controlled medicines by medical professionals and law enforcement officers. In developing countries, procurement, available funds and infrastructure along with financial 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 optimum balance between access for medical use and prevention of abuse needs to be restored.

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

Eugene Murray

Irish Hospice Foundation, VOLUNTARY ORGANIZATION, Dublin, Ireland

In 2005, the Irish Government adopted a national policy based on the recommendations of the Report of the National Advisory Committee on Palliative Care. This Committee stated that the need was for a fully 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:

• at least two palliative care consultants and one in-patient consultant of the ten health regions, with a minimum of ten hospice beds per 100,000 of population

• at least two consultant-led palliative care teams in all general acute hospitals with over 150 beds

• a specialist palliative care nurse for every 25,000 of population

Initial implementation of the stated policy was slow. In 2006, 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 settings. For capital spending on care staff in patient unit beds varied from 91.5 to 317.5.

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.

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

David Oliver 1, Rachel Forrest-Jones 1, Lisa Duplock 2

1 Kent University, Kent Institute of Medicine and Health Sciences, Canterbury, United Kingdom
2 Kent University, Thiel Centre, Canterbury, United Kingdom

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. Integration 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 provision of care.

Results

Initial focus group discussions with senior doctors in palliative medicine within the Kent have suggested 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.

6. “The Veronica Project” - An ethnographic study into the experiences of people with Intellectual Disability (ID) who have cancer (preliminary findings)

Irene Tuffrey-Wijne

St George’s, University of London, Division of Mental Health, London, United Kingdom

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’ needs, attending cancer 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 identity of the individual, 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.

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

Karen Ryan

St Francis Hospice, Department of Palliative Medicine, Dublin, Ireland

The life expectancy of people with intellectual disability has increased, and conditions such as cardiovascular and respiratory disease are now leading causes of death. This has impacted on the need for the provision of services to people with intellectual disability because the altered demographics challenge services that were originally designed for children and young adults, and that focused on enablement. As a result, there are now greater individual experiences of 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 examples of individual experiences of palliative care services for people with intellectual disability and reflect on the palliative care needs of these people. The paper will consider 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 future development of services will be made.

8. Social resurrectionists: death in a disability context

Stuart Todd

Canoff University, University Hospital, Canoff, United Kingdom

Aims

This paper seeks to place the way intellectual disability services respond to the dying phase of the lives of people with intellectual disability in an historical and cultural context. It argues that this past one has both been faced and resolved better than more recent 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 recent study of social support provided by untrained volunteers to people with intellectual disability. The data are largely qualitative in nature and were derived from in-depth interviews of front-line carers in intellectual disability services.

Results: Services for people with intellectual disability services might be characterized 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. There may be no obvious discrimination against these patients: particularly with a progressive illness, such as cancer or dementia. Integration of 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.

Conclusion

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.

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

Noelle Blackburn

Respund, Directorate, London, United Kingdom

It is well known that people with Intellectual disabilities have a higher propensity to developcomplications 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 experience caring for people with intellectual disabilities and the findings will be used to further refine this as a tool to be used by others in the part of a need assessment.
Complementary and alternative medicine (CAM) refers to a broad array of therapies and practices that are not part of a country’s own tradition and are not integrated into the conventional healthcare systems. The use of CAM has increased in industrialized nations over the last decades. For example, in the Netherlands, the expenditure of approximately $30 billion per annum, surpassing current out-of-pocket expenditures for conventional treatments by primary care physicians. CAM treatment includes 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 system of medicine. Increased CAM utilisation has not been accompanied by a parallel increase in the quality and quantity of clinical evidence to support CAM claims. Who recognizes the importance of CAM and its use, and makes health care to many European member states through recent worldwide health-related surveys, and it is not clear whether CAM is an integral part of the WHO strategy for global strategy and the CAM area. In the strategy of issues of policy, safety, efficacy, quality, access and rational use of CAM are addressed. The WHO is assembling relevant national legislation and mechanisms to adapt, adopt and implement the WHO Strategy as a basis for national medicine programs or work plans.

11. Complementary Therapies The evidence base

Susie Wilkinson
Royal Free Hospital, Mental Health Sciences, London, United Kingdom

Complementary therapy is defined as “a broad domain of healing resources that encompasses all healthcare systems, modalities, and practices and their accompanying theories and beliefs, other than those incorporated in the dominant health system of a particular society or culture in a given historical period” (Ernst et al, 2000). It encompasses special diets, vitamins and minerals, herbal medicine, homeopathy, and a variety of physical/movement therapy. The popularity of Complementary and alternative medicine (CAM) 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 care, and in addition to their sense of well-being and satisfaction. 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 for the therapy, and the evidence base for the therapy, and how the evidence base is strengthened.

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

Adriana Visser1, Machteld Van den Berg2
1 Helen Dowling Institute, Research, Rotterdam, Netherlands
2 University Medical Center Utrecht, Research, atrecht, Netherlands

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 21 patients in their 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, sex, type of chemotherapy, type of chemotherapy in 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%) had a metastatic or palliative stage of cancer. Patients highly valued the haptotherapy treatment, and were satisfied with the personal attention and the relaxation they experienced. They perceived the treatment improved their quality of life and the cognitive and social functioning of patients. Haptotherapy contributes to the well-being 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 suffering with a variety of symptoms.

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

Petta Planger
University Klagenfurt, 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 show an alternative conceptualisation of homeopaths’ users’ roles: Users emphasise the homeopaths’ ability to seriously contemplate their illnesses, their interpretations of illness and the impact on everyday 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 (context-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, emphasizing 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.

14. Oral problems - assessment and treatment overview

Andrew Davies
Royal Marsden Hospital, Palliative Medicine, London, United Kingdom

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 these. Oral problems are a major cause of morbidity in patients with advanced disease. Oral problems cause morbidity and are also associated with a variety of physical and emotional problems (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. sepsis). 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 that patients are reluctant to report oral issues to their healthcare professionals. Hence, it is important that all patients are screened for oral problems, which involves taking a comprehensive oral examination. Many oral problems can be prevented by simple measures, such as improved oral hygiene measures. 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.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral symptoms</td>
<td>56-78%</td>
</tr>
<tr>
<td>Oral discomfort</td>
<td>13-55%</td>
</tr>
<tr>
<td>Taste disturbance</td>
<td>26-44%</td>
</tr>
<tr>
<td>Difficulty chewing</td>
<td>23-52%</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
<td>23-37%</td>
</tr>
<tr>
<td>Difficulty speaking</td>
<td>31-59%</td>
</tr>
<tr>
<td>Halitosis</td>
<td>48%</td>
</tr>
<tr>
<td>Oral infections</td>
<td>R-82%</td>
</tr>
<tr>
<td>Dental caries</td>
<td>20-35%</td>
</tr>
<tr>
<td>Periodontal disease</td>
<td>36%</td>
</tr>
</tbody>
</table>

15. Oral Hygiene

Margaret Sweeney
Glasgow University, Dental School, Glasgow, United Kingdom

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 care can often assume low priority within palliative care settings and other medical specialities. The management of oral problems is often anecdotally related more 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 health staff.

16. Intervention Possibilities in Cancer Treatment Induced Mucositis and What About Guidelines.

Fred Spikervet
University Medical Center Groningen, Oral & Maxillofacial Surgery, Groningen, Netherlands

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 and quality of life. Mucositis is associated with an increase of systemic infections, deterioration in hospital and overall costs, and these aspects have a negative impact on health related quality of life. Many studies have been published on prevention 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, type of drugs, design flaws, make it hard to provide evidence-based guidelines on oral mucositis. This presentation will discuss meta-analyses of randomized clinical trials, and will discuss the need for randomized clinical trials for prevention of oral mucositis and available guidelines.

17. Bisphosphonates and osteonecrosis

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

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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor. 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 injury to the teeth. In addition bacterial superinfection is only a minor factor.
19. Palliative Care in Nursing Homes - the need for organization development

Katharina Heimer

University of Klagenfurt, J.B. Palliative Care and Organizational Development Vera, Austria

Background. Although the majority of the population over 85, but why want to spend their last days at home, in fact - in metropolitan areas in middle Europe – 80% die in nursing homes.

Results: Schnitte in the group discussion based on reminiscence principles were introduced in the care homes.

Conclusion. Assumptions cannot be made about older adults ability and willingness to participate in discussions about their future needs.

20. Nursing homes and hospice - needs fulfilled?

Friedemann Nauck, Stefan Johns, Eberhardt Klaschik

1 University Hospital Goettingen, Department of Palliative Medicine, Goettingen, Germany
2 University Hospital Goettingen, Department of Palliative Medicine, Goettingen, Germany
3 University of Bonn, Department of Palliative Medicine, Bonn, Germany

Introduction. Nursing homes (NH) and inpatient hospices provide different settings of care. NH are services for patients in advanced stages of an incurable disease, whereas hospices are for patients in end-stage and dying care processes.

Methods: The survey results show good PH-care delivered in HO in most fields covered by this Palliative care teams have the opportunity to improve the quality 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 education and research in palliative care.

Conclusion. 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 2005, 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 with demographic aging level among highest in Russia. The rate of the elderly aged 60 and over has reached 20%. It is more than 70% who die or are 65 or older. Older individuals coping with multiple progressive illnesses are confronted with difficulties experience complex medical, social and psychological problems.

22. THE INTRAVENOUS TO ORAL MILLIGRAM POTENCY RATIO OF MORPHINE

WEIL LASHEEN, FADE MAHMoud, DECLAN WALSH, NABEL SarihIL

Cleveland Clinic, Palliative Medicine, Cleveland, United States

Methods: FCNS is a novel formulation of fentanyl, using an osmotic pump for sustained-release controlled drug delivery. BUP TTS therapy had no longer to be stopped. Method: once the skin irritation appears, before the stop. Conclusion: despite rotation of application area, skin irritation often appears due to BUP TTS. It can be successfully treated by fluticasone spray application. BUP TTS therapy had no longer to stop.

23. INTERMITTENT CANCER PAIN: CLINICAL IMPACT AND QUALITY OF LIFE

WEIL LASHEEN, DECLAN WALSH, MILLAR DAVIS, NABEL SarihIL

Cleveland Clinic, Palliative Medicine, Cleveland, United States

Aim: In this study we report the characteristics of intermittent cancer pain proposed a new clinically based classification Method: 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: 190 consecutive patients reported 158 separate pains. The pain was continuous(CP) plus breakthrough pain(BP) in 65% (N=95) and non-breakthrough pain (NBP) in 33%(N=64). CP and NBP were each subclassified into 3 categories (1) incident (newly diagnosed pain) (2) chronic pain and (3) category was added only to BP. end of dose failure. The etiology of pain was IP (45.8%), visceral (24%), neuropathic(7%) mixed(13%). Median duration of IP was 4 months with higher frequency of incident pains in patients with cancer types (N65, 47%) nearly half of all IP. According to our classification incident pain was part of BP (IP) In 38%(N=9), IP and NBP in 5 cases (12%) received less treatment than incident BP and the pain was less controlled Conclusions: IP is a major problem in cancer patients 2) NBP is a common but undertreated problem of cancer care. 3) Non-controlled pain is defined and controlled by BP) 4) incident NBP accounts for half of all cancer pain 3) Variable IP and NBP classifications makes comparisons between studies difficult.

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

Johan Van den Eynde

Network Palliative Care, Palliative Care, Sint-Niklaas, Belgium

Introduction: Skin irritation is a side effect of the path system, which occurs in 17% of the treated patients. The degree of irritation varies from light (itching, erythema) to severe (bullae).

25. Nasafent, a novel intranasal formulation of fentanyl citrate sustained released treatment of breakthrough cancer pain

Geoffrey Davis, Anthony Fisher, Andrew Knight, Robin Love

1 St. Joseph’s Hospital, Thunder Bay, Canada
2 Regional Cancer Care, Regional Cancer Care, Thunder Bay, Canada

Aim: To determine the acceptability and tolerability of fentanyl citrate nasal spray (FCNS) (Nasafent) in the treatment of breakthrough cancer pain (BTCP). Method: A novel intranasal formulation of fentanyl citrate (FCNS) has been developed by Chiesi. Pechy a proprietary system designed to deliver iontophoresis (5.3% and 3.3% of 5.3% and 3.3% of 1:1 3:1) thought the cooperation of general practitioners (GP) and palliative care units. The study identified patients with possible organ of care. However, in no more than 36% of HO such cooperation was provided. 59% of PH had specialized knowledge in palliative medicine and 39% 1.3% 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-care delivered in HO in most fields covered by this study. In order to facilitate high-quality PH care in HO, the usually CP based on the significant difficulties to be complemented by specialists in palliative medicine. Palliative care teams can improve the quality 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 education and research in palliative care.
26. Validation study of the Dolorpos scale in six languages.

Bernard War, Gisèle Pickering, Said Serbouti
CHR Mézières-Thionville, Service Regional de Soins Palliatifs, Thionville, France

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 language. This has led to the first scales to be published and statistically validated in 1999 by War et al.

The validation characteristics are available on the Dolorpos site “donor’s observance” in other languages was however missing and awaited by the geriatrics community. Considering the need for validated tools at an international level, a frequent request of the National Observer Committee of the Council of Europe “Recommendation Rec 2003 (2) on the protection of the rights of persons with disability, in its concluding observations for the State of France in 2000”, Dolorpos 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.

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

Kelli Gershon, Ahmed Elsayem
UT MD Anderson cancer center, Palliative Care and Rehabilitation Medicine, Houston, United States

Palliative sedation rates range between 2% and 50% for patients at the end of life. Generally, palliative sedation is used to control symptoms at the end of life and is supported both ethically and legally. Ethical justifications that support palliative sedation include patients’ self-determination, autonomy, beneficence, non-maleficence and the rule of double effect. Palliative sedation is widely accepted in the hospice setting, bringing palliative sedation into an acute care setting can present challenges. In our institution we will review (a) how we established a palliative sedation policy for the Palliative Care Unit (PCU) at a major acute care 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, which will include information in 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 retraction who was transferred to the ICU for “sedation.” The second case will involve a patient who requested palliative sedation for psychological distress.

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 globe. 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. The 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’s work focuses within three “programmes” of research: ‘end of life and global and historical development’ maps palliative care development through a rigorous method of exploring deep ‘counter reports’; ‘patient and care 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; 6 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.

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 included in full in conferences and several publications, such as the Atlas of Palliative Care, as well as in papers of our professional journals.

Different models of service delivery have been developed and implemented throughout the countries. For example, in the United Kingdom (UK), Germany, Austria and Poland and more recently, Italy, there are several well-developed networks of hospices. The model for mobile teams or hospital support teams has been adopted in both the UK and France. Day Centres are a characteristic of the UK with hundreds of these services. The number of beds per million inhabitants ranges between 45-73 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. Four countries is considered a sub-speciality, for which a second certification is required; Poland, Romania, Slovakia and Germany. Some 10 other countries have started the process for certification of palliative medicine, in all cases opting for sub-speciality 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 factors for the development of hospice and palliative care in CEE and CIS: lack of funding, lack of cooperation between healthcare and social services, lack of public awareness and government recognition of palliative care as a full service, lack of palliative care education and training programmes. Despite huge variations in the levels of provision across European countries, data collected in the “Eurobarometer” survey reveal many common barriers to development of hospice and palliative care in CEE and CIS.

We are 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.

30. Council of Europe recommendation: the purpose and the impact

Natasa Milicevic
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The need for increasing palliative care provision presents great challenge for all European countries. For that reason the Council of Europe took a topic of particular interest for Council of Europe. Inspired by different documents and declarations on the protection the dignity of all human beings and the rights which stem from there, and following the expert committee’s report on the development of hospice and palliative care across member states, Council of Europe “Recommendation Rec 2003 (2) on the organisation of hospice and 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 hospice and palliative care among the member states and to define a new standard for palliative care provision across member states. All countries of the Council of Europe have adopted this document. There was just one unique moral obligation for the European Governments to follow the recommendation and to consider it as a part of their national policy framework for palliative care.

The impact of the recommendation in different members states can be described on the existing level of palliative care provision, including existing national policy, services, palliative care workforce and 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.

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 pain psychosocial assessment 3. Developing an advance directive function in patient and family caregiver 3. Co-ordinating PM family conferences 4. Integrate medical and psychosocial information and post acute care. Method: We reviewed 400 psychosocial assessment journals 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 4 domains of activity: 1. Psychological and emotional assessment and management, 2. Psychological and social evaluation, 3. Equipment and care planning, 4. Psychosocial information and post acute care. The impact of the recommendation was 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.

32. Emotional preparedness at the time of wifes death predicts psychological morbidity for widowers 4-5 years after the low - 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 2.1), and emotional numbness (RR 2.2), low level of self-assessed quality of life (RR 1.7), on or little with friends (RR 2.1), current 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 hopelessness (RR 1.6). Conclusions: Case finding 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 prevent emotional 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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Inspiried by the French neuropsychiatrist Rene Cyturiak research (Del Chiaro et al., June, 2006, 25?), we will present in this paper a new biology of attachment. The concept of resilience notably explains why for one or each of us, life is a permanent conquest, never fixed in advance. No variable among us nor our original environment prevent 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. Cyturiak argues that one can discover in himself and around himself the means that permit to come back to life and go about still keeping in mind and in flesh his life. Loss paths follow narrower 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. Unattended moments are the result of one capacity to master, indeed to overcome in oneself the matter of a constant reshaping of its biography, its attractiveness and its social-cultural environment. Without suffering, would one be able to love? When love poses, would one not feel safe? Life would be tasteless and one would possibly not have the appeal to savour it.

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

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4 Laval University, School of Social Work, Quebec City, Canada

Background: Demographic changes, new health technologies and increased patient and public approval expecting to have interventions which will safe? Life would be tasteless and one would possibly not have the appeal to savour it.

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

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2 Hospital University of Toulouse, Child and adolescent psychiatry, Toulouse, France

Background: Loss and mourning in children can lead to suffering and psychopathology. When a child loses a brother or sister, various supports are proposed but are rarely evaluated.

Aim: Description of care for observation and support. Collaboration with parents. Appropriate tools to evaluate the child's/peer's acceptability, feasibility and clinical interest.

Method: 3 groups of 4 to 8 children, from 6 to 16 years old, 10 to 16 months after their sibling's death. Before inclusion: family interview and child's interview by a psychologist and a psychiatric; collection of Child Behaviour Checklist and standardised general data. After inclusion: 4 meetings for each group, based on expressing and sharing experiments and emotions, with mediations, conduct by trained therapists, who also evaluate each child and group's dynamics; new evaluations by the psychologist 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.

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

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Methods: After the definition of the dying phase, the panel members were asked to describe unbearable suffering, without suffering, would one be able to love? When love poses, would one not feel safe? Life would be tasteless and one would possibly not have the appeal to savour it.

37. Defining Unbearable Suffering

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Introduction: The purpose of this study was: how do professionals and non professionals define unbearable suffering both for themselves and for terminally ill patients. In the Dutch jurisprudences for Medical Decisions End of Life unbearable suffering is mentioned but not defined. 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. 32 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 for their fellow human being terminally ill. Both the panel members mentioned different answers. In the 2nd round the panel members were asked to describe unbearable suffering as validated gold standard, pain correlated highly with hand pain score (r=0.90), and faces scale (0.84), less highly with the Gerry Can visual scale (r=0.73). In the Dutch, distress and suffering, both for themselves and for their fellow human being terminally ill. Both the panel members mentioned different answers. In the 2nd round, 25% of 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: there is no consensus about the definition of unbearable suffering. Unbearable suffering is not an unequivocal concept. Concerning the description of unbearable suffering, the majority provides several 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 patience. This study aimed to compare 4 methods. METHODS Patients in 5 African palliative care settings completed cross-sectional assessment for pain then symptoms using an APAC-African POS scored verbally and b scored using “hand” method, where a closed fist <1=no problem, 3 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 correlation coefficients reported strength of methods’ relationship. Graphs plotted scores by method and compared to each other. RESULTS 513 patients, 35.6% cancer, 49.2% rural. All associations significant at 0.1% level, 0.001 if correlation coefficients were .6 or above; consistent differences between methods. Taking POS verbal score as validated gold standard, pain was correlated highly with hand POS score (r=0.90), and faces scale (0.84), less highly with the Gerry Can visual scale (r=0.73). POS verbal symptom score was highly very highly to pos hand score (r=0.90) and faces scale (r=0.83), but relationship further weakened for Gerry can (r=0.73). Graph plots demonstrate POS, faces and Gerry can can differ at scale patient’s (non-visual, non-view, non-territorial, non-practice). Alternative methods offer high, but weaker, correlation.

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 delirium at the Palliative Care Unit of our cancer center are monitored for 2 hours using the Delirium Observation Screening (DOS) scale. In case of a DOS score ≥ 3, a diagnosis is established by a physician. We earlier assessed the change in opioids (shift or increase in dose) as a risk factor for the development of delirium and thus as an indication for readjustment. 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 risk factors of patients with an established diagnosis of delirium within 4 days after the start of the DOS were assessed for DOS scores ≥ 3 and ≤ 2, respectively.

Result: 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 opioid change were missing.

Conclusion: Delirium is a significant complication in the palliative phase of cancer patients and is often related to opioid use. Patients with a risk of delirium at the Palliative Care Unit of our cancer center are monitored for 2 hours using the Delirium Observation Screening (DOS) scale. In case of a DOS score ≥ 3, a diagnosis is established by a physician. We earlier assessed the change in opioids (shift or increase in dose) as a risk factor for the development of delirium and thus as an indication for readjustment. However, the DOS has never been evaluated for its use in cancer patients after a change in opioids.
40. Predictive value of the prognostic inflammatory and nutritional index (PINI) in terminally ill cancer patients

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3 VU University Medical Center, Department of Public and Palliative Medicine, Amsterdam, Netherlands

Aim: We aimed to identify biological markers correlated with the patients’ short-term life expectancy. For this purpose, we conducted a prospective study in a palliative care unit of a university hospital.

Methods: From January 2004 to May 2005, 285 patients with advanced cancer entering in a palliative care unit were prospectively analysed for inflammatory and nutritional markers (ferritin, fibrinogen, and PINI index = α1-acid glycoprotein x C-reactive protein(CRP) / albumin x prealbumin). Amongst 285 consecutive patients, 246 were evaluable. Uni- and multivariate analyses according a logistical regression used to estimate the relative risk (RR) of death within two weeks based on baseline patients characteristics at admission.

Results: 133 men and 112 women were analysed (mean age 64.9 ± 16.9 y). In univariate analysis, RR of death by within two weeks were 2.67 if CRP>150mg/l (95%CI, 1.36 to 5.23; p=0.001), 4.08 if ferritin>250ng/l (95%CI, 1.84 to 9.08; p=0.001), 2.85 if albumin<30g/l and<25g/l (95%CI, 1.11 to 6.92; p=0.008), 4.4 if prealbumin<0.5g/l (95%CI, 1.98 to 9.06; p=0.001), 3.88 if PINI=20 and>200 (95%CI, 1.77 to 8.48; p=0.002), 4.37 if PINI<100 (95%CI, 1.5 to 7.21; p = 0.002). In multivariate analysis, PINI (p=0.003) is a strong predictive factor.

Conclusion: The measurement of PINI may help physicians to evaluate the short-term life expectancy.

41. Use of the APA’s 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 increased significantly amongst patients and nurses, yet the majority have no palliative care training. APACA recognised the need to measure the ‘quality’ of care provided through the use of an outcome scale. Method: The APACA African POS, consisting of 10 patient assessment questions, was piloted in 8 African countries, and was subsequently used to assess the care provided by nurses to 460 terminally ill cancer patients. The POS was designed to be used by nurses in their daily practice.

Results: The POS was completed within 48 hours of admission. Patients were assessed on the domains relevant to palliative care, and the personal preferences of the members of a healthcare team. It is a priority for the nurse to frequently evaluate the comfort, mental status or survival time of dying patients, and the POS assists in this decision. Outcome evaluation 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.

Conclusion: The APCA POS is a powerful tool to improve the quality of care in palliative care patients. It is a priority for nurses to frequently evaluate the comfort, mental status or survival time of dying patients, and the POS assists in this decision.

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) is a network of eight palliative care research groups in the UK, Ireland, Switzerland, Germany, Austria, and Norway, coordinated by the Palliative Care Research Group at the Medical Faculty, NTNU, Trondheim. The collaborative proposal was successfully evaluated in 2005 by the EAPC Research Network and EAPC, and has been funded by the Norwegian Cancer Society for a 4 year period. Parts of the application are based upon previous experience from 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 different assessment and measurement of pain, depression and cachexia by computer assisted approaches. 3. To combine the new knowledge, genomics and assessment in an internet-based system for implementation of European evidence-based guidelines, which will include standardization, assessment and individualized treatment plans for pain, depression and cachexia, and 4. To develop a long-lasting European Collaborative in palliative care 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 be held to 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 the threat of one-experiencing dehydration. When a dying person becomes unable to express his or her needs, the question shifts from the patients to their caregivers, who are concerned to find the right intervention to ensure comfort at the end of life. 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, mental status or survival time of dying patients, and the POS assists in this decision. Outcome evaluation 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 indispensable precondition for ethically justifiable decision making.

Method: HOPE (Hospital 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 and 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 administration (46% / 47%). Conclusion: Hydration can be withheld or with the patient’s wishes, 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 approach. Decision making raises critical issues and care providers should be aware of the potential for legal actions.

48. Stopping hydration a step towards euthanasia

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Decisions to forgo potentially life-prolonging treatment are taken relatively frequently at the end of life. A Euroscan study on end-of-life decisions amongst terminally ill cancer patients in 11 European countries showed incidences ranging from 6% (in Italy) to 41% (in Switzerland) of all deaths, for most countries (Belgium, France, Germany, The Netherlands) above 20%. In 6 countries forgoing artificial 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 perception of family hydration among nurses of hospice 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 moral, legal and cultural considerations regarding the initiation and discontinuation of artificial hydration.

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

David Olivieri
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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 entertainment. The importance of practitioners being able to work with processes of resilience 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 the evidence from practice on promoting resilience; and make recommendations for practice with families/carers.

A series of nine day studies on resilience were conducted, with themes ranging across palliative care. Thirteen case presentations were made by international experts from psychology and academia from psychology, psychiatry, sociology, psychology. The project will use the knowledge base to develop 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 PINI have useful similarities or the multifaceted processes involved in how families cope, communicate and adapt to stress and end of life.

ORAL ABSTRACTS

10th Congress of the European Association for Palliative Care, Budapest, Hungary, 7–9 June 2007
50. Palliative care in a multi cultural society
Nathan Cherry
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Across all cultures, advanced cancer and terminal illness present a common set of challenges. Fear, uncertainty, loss, physical deterioration, intellectual deterioration, depression, physical suffering, emotional suffering of anxiety and depression, spiritual distress related to hope, meaning, and purpose. 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 descibing differences in a "Jewish approach to death and dying" the "Mediterrenean approach to issues of truth telling". Since similarities and overlap are so common, clinicians should be wary of reductive anthropologhy 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.

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

Method
We realized a correlational study on professionals group of 30 women who are working in palliative care units for children. For job satisfaction evaluation we used a "Satisfaction Inventory for 4 factors: emotional exhaustion, depersonalization, personal accomplishment and promotion, leadership and relationships."

Results
Death and dying represent a major source of job stress among professionals because the patients are also young and the professionals has formed a close relationship with them. Other stress sources are: several deaths of children coming 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%).

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

52. Burden and support needs of family caregivers of patients with malignant brain tumors
Maria Wasner, Britta Dierks, Gian Borsio
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Aim Many patients with malignant brain tumors suffer from depressive symptoms, fatigue, and other 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 were recruited with highly malignant brain tumors (astrocytoma III or glioblastoma) were asked to participate in a cross-sectional survey. Basic demographics and the data 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. Results 27 caregivers took part in the study. 50% 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 affective for the ill: 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.

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 6-38% in palliative care patients. The commonality 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 not validated 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 and not to 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.

Aim of study
To evaluate the burden and the support needs of family caregivers of patients with malignant brain tumors.

Method
We realized a correlational study on professionals group of 30 women who are working in palliative care units for children. For job satisfaction evaluation we used a "Satisfaction Inventory for 4 factors: emotional exhaustion, depersonalization, personal accomplishment and promotion, leadership and relationships."

Results
Death and dying represent a major source of job stress among professionals because the patients are also young and the professionals has formed a close relationship with them. Other stress sources are: several deaths of children coming 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%).

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

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. FSch'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 illness 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 2-5) there is 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.

References

55. Symptom prevalence amongst people affected by advanced and progressive neurological conditions - a systematic review
Taiq Saleem 1, Nigel Leigh 1, Irene Higginson 1
1 King’s College London, Department of Palliative care, Policy and Rehabilitation, London, United Kingdom
2 King’s College Hospital, Department of Neurology, London, United Kingdom

Background
In recent years, specialist palliative care services have increasingly recognised the needs of non- cancer patients. Aims: To determine whether patients with various different late stage neurological conditions have similar or different symptom profiles. Method: Articles reporting symptom prevalence in neurological conditions - motor neuron disease, psychiatric lateral sclerosis (MNDs), 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 searching of citation tracking. Results: 49 papers were identified. Eight symptoms were common across all the conditions: pain, nausea, appetite loss, fatigue, depression, communication (in ≥ 80%), bladder dysfunction, swallowing problems and depression varied between conditions (in 50-80%) and weakness, spasm, bowel problems (≤ 30%). Three conditions (MND, MS, PD) represented high levels of pain and fatigue ≤ (≥ 50%). Other symptoms including anxiety, memory problems, sleep disturbance, sexual dysfunction, shivering, debility, weight loss, 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.

57. Successful fundraising for palliative care
David Butland, Neelam Makijhani
Help the Hospices, National Centre, London, United Kingdom
A session hosted by Help Hospices on key fundraising issues for palliative care service.

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

Who: Who 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 support sessions on the Friday and Saturday mornings for more individual coaching. The session will also lead to a fundraising manual.
58. EEG FREQUENCIES OF CENTRAL ORIGIN OF CANCER RELATED FATIGUE
Dilara Khoshknabi 1, Meltar Davis 1, Vloek Sieremonnow 2, Deean Walsh 1, Vinroth Ranganathan 1, Guang Yue 2
1 Cleveland Clinic, Palliative Medicine, Cleveland, United States  
2 Cleveland Clinic, Nurse Control Laboratory, Department of Biomedical Engineering, The Lerner Research Institute, Cleveland, United States

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 underlying pathologies.

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 contracton at 30% maximal strength until fatigue. Electrical stimulation-evoked muscle response and continuous 12-channel scalp-EEG data were recorded, 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.

Results: Compared to controls, (B) CRF were more subjectively fatigued by BFI, but had less muscle fatigue (P<0.0001, (B)) relative power of gamma frequency between control and CRF control groups, (B) relative changes in gamma power between two hemispheres during sustained contration was still present in CRF (P<0.05). (B) 1st signal activity was higher in CRF during task when relative power of frequencies spectrum were compared, (B) post ipsilateral signal activity did not return to pre-fatigue levels during the 2 minutes rest period. Conclusion: CRF is associated with altered CNS signals during a standard motor task.

59. Symptom prevalence in patients with incurable cancer: a systemic review
Alexander De Graeff 1, Saskia Teunissen 1, Wendy Wesker 1, Henk Van Den Bergh 2, Emiel Verbeek 1
1 University Medical Center Utrecht, Department of Medical Oncology, Utrecht, Netherlands
2 Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands

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 the study: To obtain a reliable estimation of symptom prevalence in patients with incurable cancer.

Method: systematic review of studies of giving prevalence data (assessed by questionnaire, standardized interview or the medical record) on symptoms of palliative care cancer patients. Data collection (including 25047 patients) on overall symptom prevalence (Group 1) and 6 studies (including 2237 individuals) for the prevalence of the last 2 weeks of life (Group 2). We identified 37 symptoms assessed by study Group 1. Almost all symptoms occurred in 10% of the patients. Five symptoms (fatigue, pain, lack of energy, weakness and appetite) had an occurrence of 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 clinicians 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
Ingela Hennhof 1, Beng Bergman 1, Ella Danielson 1
1 Institute of Health and Care Sciences, Sahlgrenska Academy at Göteborg University, Göteborg, Sweden  
2 Sahlgrenska Academy at Göteborg University, Dept of Respiratory Medicine and Allergology, Sahlgrenska Academy at Göteborg University, Göteborg, Sweden

Aim: The aim was to describe dyspnea experience in patients with lung cancer in palliative care.

Methods: approached when active anti-cancer treatment was finished, 105 patients with lung cancer completed questionnaires concerning aspects of dyspnea perception, frequency, duration and severity, 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 0.36, between frequency and dyspnea qualities 0.93, between intensity, qualities and activity-related dyspnea ranging from 0.30 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 score.

Conclusions: Dyspnea is a multidimensional experience, with relations between different aspects of dyspnea and psychological and emotional distress, 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 a Palliative care region of Sweden? An inductive structured assessment approach
Carol Tishelman 1, 2, Iva Doskaila 1, Kristina Bertilsson 3, Mirjam Spring 2
1 Karolinska Institute, Department of neuroeconomics, care sciences and society, Stockholm, Sweden
2 Stockholm Institute for Research and Development, Stockholm, Sweden
3 Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands

In this study, we compiled 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 (2002) typology of effect sizes in mixed methods research. Somatic distress comprised 57-72% of issues reported, with dyspnea, pain & fatigue dominating, although even symptoms often not assessed were also reported. Distress related to living with cancer decreased from 38% at T1 to 23% at T3. 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 in an In-Patient unit
Sarah Wells
Maree Currie Hospice, Solihull, Solihull, United Kingdom

Background
Constipation is a frequent and disabling symptom in terminal ill patients. Studies have shown that around 50% of patients admitted to UK hospices complained of being constipated. To ensure optimal 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
Wherever possible this 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, Physician Assisted Suicide
Physician considered non-voluntary euthanasia never ethically justified. The statistical analysis of the results will be completed in February 2007. In January 2007 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.

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 3 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. 15% (77) of study patients said they were constipated during the previous week. 43% 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.

Conclusions: 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-fac torial, genetic variation in response to opioids may play an important role.

Conclusion: 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 Broekaert, Josi Geilen, Trudie Van Jerse, Stel Van den Branden
Katholieke Universiteit Leuven, Interdisciplinary Centre for the Study of Life and Death, Leuven, Belgium

Aim of the Study: Several studies have already addressed the attitudes and beliefs of medical professionals towards end-of-life issues. Less research has been conducted concerning ethical and religious beliefs of patients and caregivers. In 2006 the Interdisciplinary Centre for the Study of Religion and Life and Death views U.European Union and Flemish Federation for Palliative Care undertook a quantitative study of attitudes of palliative care physicians and nurses towards physician assisted suicide and 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 January 2007 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. The study is being funded by the Flemish Community of Belgium.

Aim: this paper identifies - and challenges - some key ethical parameters in conducting medical practice in a palliative care context. It argues for a revisioning of our understanding of childhood and for a more robust
negotiated construct, and that truth is always a challenge to palliative care, particularly as the determinants of the wish to hasten death in ALS are kept, and therefore almost inevitably leads to the problem of when and how to stop it. The advanced care planning process is a multi-layered and constantly negotiated construct, and that truth is always a challenge to palliative care, particularly as the determinants of the wish to hasten death in ALS are kept, and therefore almost inevitably leads to the problem of when and how to stop it. The advanced care planning process is a multi-layered and constantly negotiated construct, and that truth is always a challenge to palliative care, particularly as the determinants of the wish to hasten death in ALS are kept, and therefore almost inevitably leads to the problem of when and how to stop it. 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To examine the coverage and representations of University Hospital Goettingen, Department of Palliative University of Klagenfurt, IFF-Palliative Care and Baruch Padeh Medical Center, Department of Geriatric Curtin University, Division of Health Sciences, Perth, New Abstracts 14/5/07 11:30 Page 93

Aim: To examine the coverage and representations of cancer and dying in the news: a study on death and dying in the Portuguese press.

Method: 234 newspapers and magazines (98 with national coverage) were searched for all articles on cancer or dying (29 March to 8 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 311 articles issued in 44 different publications (daily newspapers, weeklies, 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 <100 words and only 14% had more than 1000 words. 37% reported research (mainly new treatments) and statistics, 27% were on policy developments and 23% on fund raising. 7% on health information (7%) and discussions on death and dying (1%) were rare. Palliative care was only mentioned in 11 (3.5%) articles.

Conclusion: Discussions of death and dying, descriptions of palliative care services and research on symptom control were not absent in the Portuguese print media. Ways to improve media coverage and improve opportunities for communication in health practice will be discussed.

74. The Battle for Palliative Care during Wartime

Amitai Oberman 1, Mali Sztalder 2

1 Baruch Padeh Medical Center, Department of Geriatric Medicine, Poriya, Israel
2 The Milton and Lois Safra House-Hospice in the Valleys, Clalit Health Services, Northern District, Israel

The recent military conflict in the northern part of Israel had a direct impact on our home and palliative care (PC) services. All patients were offered evacuation to safer areas. Despite the constant threat, many opted to stay at home and required PC provision. For the first time, our team had to provide care while under persistent threat and fear. We were faced with multiple new challenges and dimensions of care for which we were not trained. Travel in the region became dangerous due to unexpected missile attack. Occasionally, military restrictions did not permit travel to patients' homes. Despite the constant threat, many opted to stay at home and required PC provision. For the first time, our team had to provide care while under persistent threat and fear. We were faced with multiple new challenges and dimensions of care for which we were not trained. Travel in the region became dangerous due to unexpected missile attack. Occasionally, military restrictions did not permit travel to patients' homes. Medication accessibility was reduced due to limited pharmacy services and since local hospitals were constantly subjected to possible mass casualties, patients were discharged earlier or not admitted. For patients hospitalised, the main problem was临终关怀 patients' homes. Medication accessibility was reduced due to limited pharmacy services and since local hospitals were constantly subjected to possible mass casualties, patients were discharged earlier or not admitted. For patients hospitalised, the main problem was...
Friday 8 June

CONNECTING DIVERSITY

10th Congress of the European Association for Palliative Care
37. Reporting cancer and dying in the news: a study of Portuguese newspapers and magazines

Barbara Gomes, Marjolein Gysel, Irene Higginton
King’s College London, Palliative Care, Policy & Research, London, United Kingdom

Background: The media’s role in educating about cancer and dying is poorly understood yet these are leading sources of information for patients, families and general public.

Aim: To examine the coverage and representations of cancer and dying in the Portuguese press.

Method: 234 newspapers and magazines (98 with national coverage) were searched for all articles on cancer or dying (30 March-8 May 2006) using 10 keywords. Publication patterns and variations in articles’ length and themes were described. A qualitative analysis of a sub-sample explored discourses and reporting strategies employed to reflect media representations.

Results: We identified 331 articles issued in 41 different publications covering news, specialist journals, women’s magazines and sports press), with a mean per day of 5 articles on cancer (min=0, max=20, SD=5.3) and 2 on dying (min=0, max=9, SD=1.8). 40% of the articles had <100 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 funerals. Media health information (7%) and discussions on death and dying (1%) were rare. Palliative care was only mentioned in 11/331 articles.

Conclusion: Discussions of death and dying, descriptions of palliative care services and research on symptom control were absent in the Portuguese print media. Ways to improve media coverage and implement for communication in health practice will be discussed.

74. The Battle for Palliative Care during Wartime

Amati Obermann 1, Mali Sitalifer 2
1 Baruch Padil Medical Center, Department of Geriatric Medicine, Tel Aviv, Israel
2 The Milton and Lois Shiffman Home-Hospice in the Valley, Chad Health Services, Northern Eldrist, Israel

The recent military conflict in the northern part of Israel had a direct impact on our home and palliative care (PC) services. All patients were offered evacuation to safer areas. Despite the constant threat, many opted to stay at home and required PC provision. For the first time, our team had to provide care while under persistent threat and fear. We were faced with multiple new challenges and dimensions of care for which we were not trained. Travel in the region became dangerous due to unexpected missile attack. Occasionally, military restrictions forced the team to visit patients’ homes. Medication accessibility was reduced due to limited pharmacy services and since local hospitals were constantly on alert, possible mass casualties, patients were discharged earlier or not admitted. For patients’ relatives, in particular, it was distressing due to the fear of losing their loved ones. Anxieties to cope with the near death of their dying relatives and members often had to struggle with their own fears and sense of threat. Likewise, patients’ fears and concerns increased due to the threat to their loved ones. Additional challenges included PTSD reactions among team members, patients and families. The presentation will highlight the many challenges we faced emphasizing the need to develop additional training and support for PC providers in countries facing similar situations.

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

Lesia Renoenwax 1, Ben McNamara 2, Kirsten Auert 1
1 Curtin University, Division of Health Sciences, Perth, Australia
2 The University of Western Australia, Faculty of Medicine, Perth, Australia

Despite the existence of palliative care (PC) services in Australia, there is still a very heavy burden of physical and psychological suffering. There is a lack of awareness of the burden of suffering, and low expectations of service delivery. There is also a lack of knowledge about the current levels of suffering in our population. Our study is a descriptive population-based Australian study to investigate factors that contribute to unmet need of people in the last months of their lives. A retrospective telephone interview of 1,100 family caregivers of people who died of 10 conditions, considered experts to be able to accurately provide information on unmet need and survival time, was conducted. Most caregivers received information about demographics, symptom severity, quality of life, end of life care, and unmet needs pre death and organisational barriers to service delivery. The majority of caregivers reported that their relative was in pain, two-thirds thought he/she suffered in the three months before death, and 67% had bedsores and 22% of caregivers did not realise that their relative was going to die. With such high levels of unmet need, it is surprising to learn that only 38% of caregivers said they needed more support from health services. Of those caregivers that did not request support, the main reasons were that there was no available information about what might happen to their relative in the future and psychological support (21%). Even though 86% of caregivers knew of PC services, less than half of these interviewed accessed them. The study provides much needed information about unmet needs of palliative care patients and their families.

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.

Aim: 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 ten 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.

Method: 1) To explain 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 to participants three recent exhibitions and associated publications that have been produced from the archive and 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.

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

Sahine Pleschberger 1
1 University of Klagenfurt, IBI-Palliative Care and Organizational Ethics, Vienna, Austria

While it is rather short, the history of palliative and hospice care in Germany is essential to understanding the current situation, the possibilities and the challenges of 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 will feed into the International Hospice History Project, hosted by the International Observatory on End of Life Care, Lancaster (D. Clark). First results of the ongoing process as much as methodological aspects will be presented. The research approach is oral history, and data generation consists of about 80 qualitative narrative interviews focused 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 verbally. 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 standardizing the concepts have to be reconsidered.

78. Opioids - how to rotate

Per Spjórgyn 1, Franco De Conno 2
1 National Hospital, Multidisciplinary Pain Centre, Copenhagen, Denmark
2 National Cancer Institute of Milan, Palliative Care and Rehabilitation Medicine, Milan, Italy

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 dosage, more liberal use has resulted in reports of very high opioid doses causing new forms of side effects (e.g. opioid induced neurotoxicity). Oral morphine is widely used and remains the opioid of choice for its familiarity, availability and costs. For that reason, opioid rotation to morphine is frequently chosen as the route to alternative opioids. In these cases clinicians should be deliberately supporting and observing any potential side effects until available data, opioid rotation will in clinical important time at least in more than 50% of cases. Treatment with chronic pain presenting a poor response to one opioid. Despite the favourable effects morphine, opioid rotation, data are mainly based on open studies, most of them retrospective or small case series. Furthermore, 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.


79. Emergencies in Palliative Care

Friedemann Nauck 1, Stefan John 2, Eberhardt Kläsiick 1
1 University Hospital Geleen, Department of Palliative Medicine, Geleen, Germany
2 University Hospital Geleen, Department of Palliative Medicine, Göttingen, Germany

Introduction: Emergency situations (ES) in patients with advanced terminal disease can be extremely distressing for patients, caregivers, and health care personnel. Common emergencies to be addressed may be associated with acute pain, compression syndromes, hypercalcaemia, dyspnoea, seizures, acute urinary and bowel incontinence, massive haemorrhage, or other syndromes due to advanced malignancy.

Results: We surveyed and assessed quality of physician-delivered care in impatient hospices in the North Rhine-Westphalia. About half of all physicians felt to have deficits in dealing with ES. 58% of the surveyed physicians (45%) reported to be annually involved in 5 ES, 65% in more than 10. 70% of the physicians were related to malign 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. Some principles however, for the management of ES were widely accepted and include respect for the patient’s wishes and early documentation of wishes for probable ES. In many cases, these were not clearly defined. In the future, physicians and professionals can plan ahead to minimize distress. Clinical scenarios will be addressed in this session.

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 communal context. For a large proportion of the world’s population, religion is a vehicle through which individuals explain and understand 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 just the transition from health to illness and death. Palliative care includes this space and recognizes both the complex and powerful role that religion provides for its devotees, whether they are patients, significant others, health 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 collective, a group of values or a spiritual leader. It might also effect a coping strategy or the maintenance of a spiritual or religious culture. For family: the spiritual or religious care that patients receive, the religious beliefs which have been variably acknowledged as a source of motivation or sense of calling, a prompt to reflection and redemption through good works, and the sharing of the brokenness of humanity in the presence of God. These facets are present in the day-to-day lives of those
84. Beyond Words - making relationships in unique ways
Nigel Hartley, Lars Bjorklund, Peter Strange
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 families 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 discuss and present a number of years 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 debate and question and answers. It will be clear to focus on that 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 Strange
Karolinska Institutet, Stockholm, Sjukhus Foundation, Research and Development Unit, Stockholm, Sweden
Companion animals bring a lot of joy to their owner’s and the relationship can deepen at times of hardship. During this lecture I will describe results from an in-depth interview study with 10 very severely in cancer patients in palliative home care. The interviews focused on the support and needs of their dogs, as their dog, when they were diagnosed with disseminated cancer. The analysis revealed four main categories: 1) psychosocial support 2) communication 3) motivation, and 4) existential support. The first three categories were: expected: most dogs were healthy or not, normally described 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, dogs were a sense illness created meaning in a trying situation. When feeling existentially abandoned their dogs were the only available support, as they were experts on interpreting body language. Certain issues and experiences were so desperate to share even with family members. The most important was a good and safe enough listener in such situations. The lecture will be exemplified by case material of how the dog even relieves acute death anxiety.

88. Silence, a language beyond words
Lars Bjorklund
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 huddled 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 compounds or the 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 just picks up, and it is as if there was never 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. So 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 who knows I carry it myself, someone who shares the very insight and respects my silence and accepts me.

89. Genetic markers for opioid responses - Representing the EPCHR Group
Frank Skjøn
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 EPCHR project. The primary aim is to identify major genetic polymorphisms 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 variants that may contribute to interindividual variation in opioid response. Candidate genes are identified and isolated by thorough review of the literature, and experimentally by assessing the changes in global gene expression that can be monitored using microarray-based gene expression model systems. Our findings so far will be presented. In the next phase, candidate genes are classified and regard to informative genetic markers, using information from publicly available databases and the human HapMap project. In addition, SNPs associated with differences in opioid responses will be identified from whole genome scans (500K). Affymetrix SNP arrays, using a “pooleDNA” approach on groups of individuals classified as “opioids” and “poole responders” in large patient cohorts. A first version of “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 EPCHR 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 clinical 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, 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 of pain and recommendations for treatment based on the data.

A comprehensive pain assessment involves several dimensions other than the patient’s subjective feeling and pain intensity: i.e. disease and treatment-related variables, demographics, ethnicity, historical abuse, the genetic/interracial-individual variability in pain perception for which the understanding is inadequate. Only a few classification tools for cancer pain exist, and few tools for non-pharmacological pain.

Methods. It is time to develop a software solution for pain classification and assessment for practice and research. Pain can only be represented by a transdisciplinary 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 and construction systems and international consensus.

Status. A first version of the program is going to be developed, 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 Pingi
National Cancer Institute of Milan, Palliative Care Department, Milan, Italy
The European Palliative Care Research Collaborative 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 pain guidelines has been considered as 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. Preparation of a set of recommendations that summarize the needs of cancer pain patients worldwide starting from 300 methods for cancer pain relief 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 opioid morphine guideline as the first step in its work plan:
a) Two subsequent levels of expert groups have been appointed to cooperate with the different steps of literature review, evaluating, grading, formulating and assembling recommendations
b) Six topics have been defined
1. ABC (Analgesic, Anxiolytic, Corticosteroid)
2. Opioid change
3. Patient And Family Education
4. Pain Assessment
5. Supporting Care
6. Pain In Palliative Care

92. Pain in children's cancer - new strategies
Boris Zernikow
Children's Hospital Datteln - Witten/Herdecke University, Vodafone Foundation Institute 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 experience 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 and helped physicians get the most benefit from its use. Results will be presented. In the last week of the life the opioid dose in some children is hardly changes. One could hypothesize that fentanyl or buprenorphine TTS might be inadequate even if additional last fast acting opioids are given. Whether patient-controlled analgesia (PCA) might be a useful therapy option in those patients will be discussed in detail.

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 Mohlahlole
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 Manguing, Free State, South Africa, face many diverse problems and require coping skills to manage these. The provision of supportive care allows a child to 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 that includes training, 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, re-emergent strengthening and activities, will be identified.

94. END-OF-LIFE IN NICU: DIFFERENCES BETWEEN 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 neonates dying 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: N = 29.5 ± 5.2 weeks vs. N: 30.5 ± 2.3 weeks (NS). 12% of neonates receive CPR in delivery room (9% in group M, 19% in group N, p = 0.04). Periventricular leucomalacia is more frequent in group M (p = 0.004). The first visit of mother (p = 0.004) or father (p = 0.005) occurs later in group M than in group N. But in group M, 30% of mothers (p = 0.003) and 24% of fathers (p = 0.002) have never seen their child before death whereas none in group M. The number of visits of mothers is identical in both groups, whereas the number of visits of fathers in group M (p = 0.02). Almost all parents of group M meet a paediatrician vs. 75% in group N (p = 0.001). The age of death is 22.3 ± 5.3 days in group M vs. 9.3 ± 5.6 days in group N (p = 0.006). 48% of parents of group M are with their dying child vs. only 7% in group N (p = 0.05).
Conclusion: Parental presence is less important in group M, then decreased psychological and economical affordable support. This may lead to a difficult mourning process because lack of information and contact with reality. These results favour reinforcement of support before and after a natural death of a neonate.

95. The palliative care needs of Australian children who die from cancer and their families
Leanne Monterosso 1, Linda Kristjanson 1, Marianne Phillips 2, Kate White 2, Sue Rowell 2, Martin Watson 2
1 Edith Cowan University, Nursing, Midwifery and Postgraduate Medicine, Perth, Australia
2 Curtin University, Research and development, Perth, Australia
Aim: Despite extensive palliative care services large numbers of older people are admitted to hospital 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.
Results: A descriptive case-note review of hospital inpatients aged 65 years and over, who died between October 2004/March 2005, was undertaken. Ethical approval was obtained. 196 case-notes were randomly sampled. Data were coded and entered on to SPSS. Descriptive and inferential analysis was undertaken. Significant patterns and relationships between the different death trajectories were identified (Lanney et al 2002). Descriptive and comparative analysis was undertaken.
Conclusion: Core elements have been identified for consideration in the future development of an integrated palliative and supportive care services.

96. Caring for life: The palliative and supportive care needs of children and families in Western Australia
Leanne Monterosso 1, Linda Kristjanson 1, Marianne Phillips 2, Rosemary McPherson 2, Martin Watson 2
1 Edith Cowan University, Nursing, Midwifery and Postgraduate Medicine, Perth, Australia
2 Curtin University, Research and development, Perth, Australia
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: Participants 144 parents and 20 service providers.
Results: Analysis indicated the key aspect of palliative care is poorly understood by health professionals and by parents. Families are affected emotionally; finance and physically by the burden of caring for children with life threatening or chronic conditions. Many complex cases at home. Families need the clear and honest information about their children's situation 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 described wanting more practical resources and information to assist in the effective management of their children and parents, as well as support for their other children. The research process became a positive and resourceful experience as they were insufficient and inequitable. Parents also reported access to, and advice from, multidisciplinary health professionals when caring for their child was limited. There was a perceived lack of coordination between community services and the hospital. Setting: 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.
Conclusion: Multi-disciplinary community services including practical aids and respite care. Key elements for care models will be presented.

97. Dying in old age: how illness trajectories influence place of death
Julie Skillebek, 1 Sheila Payne 2, David Reid 3, Grace Davis 4
1 Sheffield Hallam University, Health and Wellbeing, Sheffield, United Kingdom
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.
Aim: 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. 196 case-notes were randomly sampled. Data were coded and entered on to SPSS. Descriptive and inferential analysis was undertaken. Significant patterns and relationships between the different death trajectories were identified (Lanney et al 2002). Descriptive and comparative analysis was undertaken.
Conclusion: Core elements have been identified for consideration in the future development of an integrated palliative and supportive care services.

Cerebrovascular disease and Multiple Pathology. 33% were identified as Frail Older (VO) 28% Organs System Failure (OSF), 50% lived at home prior to final admission; 31% in care homes. 24% of FO, 43% with OSF died within 7 days of admission. 50% of FO, 57% with OSF died after 1 month. Discussion: These findings identified the ‘oldest old’, considered to be FO or with OSF, are admitted to hospital and died within 1 week or less, Often following admission. Studies on the nature of palliative care that older people receive at hospital 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 some settings and awareness of end-of-life care trajectories of these two types of older people.
98. Opening the door for older people to explore end of life issues.
Jane Seymour 1, Amanda Clarke 2
1 University of Nottingham, School of Nursing, Nottingham, United Kingdom
2 Sheffield Hallam University, Faculty of Health, Sheffield, United Kingdom

Aims: to understand the concerns of older people about end-of-life care and assess the utility and acceptability of information materials

Methods: a random sample of 118 older people was selected from a care home and a day centre. Participants were invited to participate in a focus group discussion. Participants rated sheets of paper relating to the topics of terminal illness, death and dying, palliative care,Advance Care Planning, and the use of the Advance Decision tool.

Results: Positive reactions to the information materials were received from most participants. The majority of participants were interested in receiving more information about Advance Care Planning.

Conclusions: These findings suggest that providing information and education to older people about end-of-life care is an important issue. Further research is needed to determine the most effective way to deliver this information.

99. End-of-life care for heart failure in acute Care for Elders Unit: a retrospective case series
Vito Corato, Camilla Pire, Stefano Tracatelli
E.O. Ospedali Galliera, Dipartimento di Genitourlogia e Scienze Motorie - Struttura Completa di Geriatria, Genova, Italy

Aim: to observe the effects of end-of-life care for terminal heart failure patients admitted in an Acute Care for Elders (ACE) Unit.

Methods and materials. We reviewed 19 consecutive patients who died of heart failure over a 1-year period and who had been provided by the Local Health Authority with antithrombotics, antimicrobial, communication disability, symptoms, use of cardiovascular, support, palliative or sedation therapies, and their impact. Result: At 24; 63 yrs (mean), hospital stay 2 days, severity and comorbidity index (13-item Cumulative Illness Rating Scale) 2.21, bowel and bladder (17.6, 3.6), communication disability score 3 (0-4). 14 patients had symptoms. All patients received antithrombosis, 13 parenteral hydration, 10 furosemide, 9 vasoactive drugs, 3 ACE inhibitors, 3 beta-blockers, 3 digoxin, 3 nitro-derivatives. 11 patients underwent palliative therapy subcutaneously (mean 3.6, 4.6 days) with morphine hydrochloride (mean 1.45 mg/day), fentanyl (132.2 mg), hydromorphone (140 mg), midazolam (8.5, 2), metoclopramide (35). 30 patients were in 9 of 13.93 patients were in 2.2, 2.5 days in 2/3, nausea and vomiting in 2/2, and death rattle in 4/6. 4 patients were terminal, 5 were treated with an association of morphine (mean 22.5 mg/day), midazolam (30) and haloperidol (3.5), which was effective in all cases. Conclusions. Low-dose parenteral drugs controlled the symptoms in the most of the oldest-old patients dying from heart failure in ACE Unit. Terminal sedation was effective and needed a slight increase in doses.

100. Improving End of Life care in care homes in England: an observational study
Frances Badger 1, Collette Clifford 2, Ken Thomas 2, Gillian Plumridge 1, Alistair Hewison 3, Karen Shaw 4
1 University of Birmingham, School of Health Sciences, Birmingham, United Kingdom
2 National Institute for Health Research, NER End of Life Care Programme, Department of Primary Care and General Practice, Birmingham, United Kingdom
3 University of Birmingham, 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 improve primary care in the UK. It has been adapted into the GSFCH programme which supports care homes. Phase 2 of the study involved 95 homes.

Aim: to evaluate the introduction of GSF into care homes.

Methods: 1. Quantitative survey data before GSFCH introduction and following the programme completed pre and post surveys. 2. Case studies (10 homes) admitted in-depth qualitative explorations with residents, families and staff of relevant issues.

Results: Quantitative data: homes demonstrated significant improvements in the following indicators:

- Reduced number of resuscitations
- Unprompted discussion of plans for resuscitation
- Number of homes who provided pre and post advanced care planning

Discussion with residents of plans for resuscitation; Number of homes with a coordinator for End of life care. Ability to make informed decisions about spiritual needs. Case study data showed GSFCH improved communications between residents, health practitioners and care home staff. Reasons for homes to complete objectives and suggested improvements have been identified.

Conclusions: 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

101. Analysing End of Life care in care homes: After Death Analysis tool
Kerr Thomas 1, Frances Badger 1, Collette Clifford 2, Karen Shaw 3, Alistair Hewison 4
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 to improve quality of end of life care. As part of the evaluation of the GSFCH, the "After Death Analysis" tool (ADA) was developed to examine the impact of GSFCH on end of life care.

Aim: of the ADA was to:

1. Gather quantitative data to provide details of deaths including: location; need for hospital admissions; and advanced care planning.
2. Compare End of Life care pre and post implementation of GSFCH. 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 were performed using SPSS.

Results: 44 homes completed pre and post GSFCH ADA.

Data revealed positive changes in end of life care following GSFCH implementation, indicating success of GSFCH in improving End of Life care. 6 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.

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: to explore the attitude of clergy to the pastoral care of the elderly.

Methods: A pasteur was interviewed in depth.

Results: 1) To demonstrate and validate that grieving is a natural, healthy, spiritual 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.

103. The Gifts of Grief
Nancie Solonyna
Shining Light Productions, Oakland, United States

The Gifts of Grief: This 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 help identify the physical, emotional and spiritual affects of grief, that the resources that help us through grief and loss and discover 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, live to learn from their loss and now engage in life with more compassion, courage and depth. The personal and moving stories include author, Isabel Allende; Reverend Cecil Williams; Zen Monk /Vietnam Veteran, Claude Aranishi Thomas; filmmaker, Lee Mun Web, 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, spiritual 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.

104. “to care at home: a journey through the experience”
Massimo Melo, Stefania Bullo, Teresa Selian, Sofia Rasini
A.V.A.P.O., VOLUNTARY 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 overcome difficulties that may arise in their life for the first time. These critical moments can be overcome with one’s own interior strength supported by the help of the Local Health Service and the social support network. Local volunteers associations can provide aids, helping families with organizational, social, spiritual, financial support and, in some cases, complex health care which may substitutes or act in addition to the care provided by the Local Health Service. The 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, and ethical and spiritual questions. We feel that conveying these experiences will enhance the possibility of caring at home for terminal patients, as well as advancing a sense of solidarity.

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 skilled 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 (Clinical 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 a space where people can grow and develop. We must increase our understanding of the things that happen within teams in order to identify the creative and positive, 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 our own work, with partners and colleagues.
106. SOURCES OF STRESS AND REACTIVE BEHAVIOURS IN THE PC TEAM
Oscar Cotli, Maria Giulia Marinis1, Massimo Pizzuto1, Giandomenica Andreoli1
1 Osservatorio Italiano Cure Palliative (OICP), Milan, Italy
2 Osservatorio Italiano Cure Palliative (OICP), Milan, Italy
3 ISTUD Foundation, Stresa (Verbano, Italy)

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 an age mean of 43.3 years (SD: +/- 10,0), composed by 30 % physicians, 40% nurses, 6% psychologists, 13% volunteers and 13 % other roles, participated to the study. The investigation has been leaded by O.I.C.P. (Osservatorio Italiano Cure Palliative) and ISTUD (Istituto Studi Dimoniali) Foundation. The main tools for investigation were: an expressly set up questionnaire- a description, through metatheses, of the point of view of the interviewed people about the work environment, and about patients and relatives- analysis of the burn out data through the Maslach Burnout Inventory. Results: the peramorphosis, implication according to the Pygmalion tales structure, of the creative, emotive and moral features of the nurses' professional experience. The results sprung out from this complex of sub-investigations strata allowed the definition of the problem of the work environment, including the profile of the palliative care team, the equipe working condition, the positiveness of the relationship and the reasons for the different evaluation referred to the professional experience: and, most important, the main behind the choice of working and continuing to work in this field.

107. When the team is limited
Daniela Mosnica

Hospice, Education and Training, BRASIL, Romania

Palliative care aims to alleviate suffering and to offer comfort by addressing holistic the needs of patients and their relatives. The joint expertise 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: 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 of social worker, 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 hospices. The palliative care model has been frequently created by NGO's outside the public health system. Consequently the palliative care model is not defined in these countries, the minimum competencies for different staff working in palliative care and standards concerning training, discussion of these challenges and adopted solutions in different countries will be presented.

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 including consent and resuscitation decisions, which do not include asking the patient when requested, the procedure is likely to be futile. Such issues include legal and ethical issues, getting the patient's views if resuscitation is needed or desired (as stated by the patient or their carers what the patient wanted, if they are not mentally competent at the time), Human Rights, quality of life, in making the decision, it is unethical for blanket policies to exist. Approaching such discussions with patients and family is a difficult task that 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 opinion. 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 many healthcare staff to ensure the patient should not be asked whether they want resuscitation if it is going to be futile. Although the National Guidance state that it is important to discuss each decision with the patient if they agree to, discussion should not be interpreted to mean asking the patient. If a patient has a right to demand any futile treatment form a docet, and no doctor is obliged to go on.

The only person who can legally make the final resuscitation decision is 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.

109. The End of Life Nursing Education Consortium (ELNEC) Salzburg Institute for Nurses in Eastern Europe
Betti Ferrell1, Nessa Coley2, Patrick Coyne3, Judith Pafe4, Mary Callaway5
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 Aim: The ELNEC project (www.aacn.nche.edu/ELNEC) was initiated in 2000 in the United States, and it involved a very successful effort to improve palliative care through education of nurses. The ELNEC project is a unique, multi-disciplinary, and evidence-based approach and has trained over 3000 nurses to educate their colleagues.

Sample: In full 2006 the ELNEC project, held it 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 will be tremendous opportunities for international collaboration in palliative care education. Nurses are vital leaders in improving care for patients and families.

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.
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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, Tromsøm, 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, Iceland), although the situation varies a lot. Palliative medicine has not been recognized as a specialty in the Nordic countries. In 2002 the first Nordic Specialist Course in Palliative Medicine was established in Tromsø, Norway, as a part of the Associations for Palliative Medicine in the five Nordic countries. The course content covers the theoretical part of the curriculum for past patient medicine from EAPM and APM, and the course last 2 years, consists of 6 modules, and takes place in 3-4 weeks per module in the Nordic countries. Only doctors who had obtained a speciality authorization 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 role in palliative medicine, research activities and publications was sent to the students 1 year after the course. The overall evaluation of the course and the main results from the two surveys will be presented at the conference.

111. The Association for Palliative Medicine (APM) Consensus Syllabus for Undergraduate Palliative Medicine
Paul Pae1, Joe Wren2
1 Marie Curie Hospice, Palliative Medicine, Newcastle upon Tyne, United Kingdom
2 Department of Medicine, Fall, Palliative Medicine, Oxford, United Kingdom

Aim of study
The development of the APM undergraduate syllabus for palliative medicine

Background
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
42 participants agreed to take part. 3 rounds of the Delphi study took place. Consensus (75% agreement) was set at round 2. There was agreement in 90% of the syllabus. The syllabus is broken down into the following sections: basic knowledge, psychological care, multidisciplinary care, ethical and cultural, language, religious and spiritual issues, ethics and legal framework. 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 the learning outcomes are set for those institutions who are able to deliver more than the minimum level, for example through special study options.

112. Evolution of the Subspecialty of Hospice and Palliative Medicine in the United States: The Role of Accreditation and Certification
Steven Radwan1, Dale Lupe1, Dorothy Moga2
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 Care Review Committee, Alpharetta, 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 2,500 physicians who had achieved board certification. As formal training programs (fellowships) began to emerge, the need for accreditation of the training programs became apparent. Beginning in 2004, the ABHPM, in cooperation with the professional organizations, the American Academy of Hospice and Palliative Care, began to accredit training programs. A committee, the Palliative Medicine Review committee (PMRC), was appointed to adopt standards based on recommendations from the field for a new specialty. 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 accrediting body. Both PMRC-accreditation and ABHPM board certification will play key roles in 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 Kavuma 2
1 African Palliative Care Association, Kampala, Uganda
2 The Mildani Centre, Kampala, Uganda
Aim of Study There is minimal literature on the evaluation of palliative care training in Uganda. The Mildani Centre conducts a 1-year modular run 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 recognised and they were used as trainers in the district. Participants found the training demanding and challenging with regards to working with the dying, with families, forming multi-disciplinary teams, and implementing their action plans. Conclusion Strengths and limitations of the evaluation were discussed with health care planners for future evaluations. The evaluation demonstrated the potential of this programme impacting on the provision of palliative care at different levels. Further work has been identified for future programmes, research and evaluation.

114. Bridging the gap between oncology and palliative care. Presentation of an interactive educational program
Diede Von Zabern 1, Frank Eiken 2, Jen Lone 3, Marie Fallon 4, Xavier Gomez-Batiste 5, Daniela Mosoiu 6
1 Grunenthal GmbH, Medical Marketing, Aachen, Germany
2 INHT Aachen University, scientific, Aachen, Germany
3 Health Care & Science, Aarhus, Denmark
4 University of Oslo, Behavioural Science, Oslo, Norway
5 Cancer Research UK, Palliative Medicine, Edinburgh, United Kingdom
6 Hospital Clinic de Barcelona, Oncology, Palliative Care Service, Barcelona, Spain
7 Hospice, Palliative Care, BRR/AV, 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 6.5 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 HPRA. It is in print, as well as further educational materials are reviewer interviews and brief guides for use in daily practice. The state of the art educational tool, including didactical units such as voting system, group work and role plays, has been successfully piloted. In the workshops 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. The course is designed as educational concept, including didactical tools such as application. Demonstration videos will illustrate techniques. Role play will take therapists through assessment to practical measures of family engagement, it will demonstrate the use of linear, circular, & square questions, the role of risk assessment and how it strengthens the use of inclusive summaries to promote family motivation towards greater teamwork & mutual care & support.

115. Wound Care 1 - Practical Approaches to Palliative Wound Care
Frank Ferris, Rosene Perrelli
San Diego Hospice and Palliative Care, Center for Palliative Wound Care, 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 health care team. During this interactive, hands-on workshop, the participants will understand the pathophysiology of chronic healable and non-healable wounds. We will use clinical cases to discuss effective assessment and management, including debridement, cleansing, and most interactive workshop exercises for handling of both healable and non-healable wounds.

116. Family Focused Grief Therapy (FFGT) during Palliative Care & Bereavement - a model of family-centered care to optimize adaptation and coping
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 FKI to identify at risk families, (2) understand the FFGT model of assessment, engagement, focused treatment, consolidation & termination of therapy. This hour-long experiential workshop provides an overview of FFGT & introduces techniques & tools 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, formulation & description of the FFGT model of care. Application demonstrates will illustrate techniques. Role play will take therapists through assessment to practical measures of family engagement, it will demonstrate the use of linear, circular & square questions, the role of risk assessment and how it strengthens the use of inclusive summaries to promote family motivation towards greater teamwork & mutual care & support.

117. See page 73

118. See page 74

119. Solid facts in Paediatric Palliative Care - A new EAPC Taskforce
Franca Benini
University of Padua, Pain and Palliative Care Unit, Padua, Italy
In the last decade palliative care has witnessed an expansion in knowledge and service provision. 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, a large number of children die 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 similar and widespread 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 terminally ill children requires an effort on many fronts: on the health care organization 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 childhood 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 practitioners would be considerably facilitated by having access to such a document. In particular, this Taskforce will contribute to the develop the absence of adequate national health care strategy devised to establish costs and to determine problems which face caregivers or family members. When these are not forthcoming they may blame their parents or their God, directing their disappointment and fury against caregivers or family members.

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. Variations from a context of uncertainty and is so vital to human well-being that its absence equates to a loss of life 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 ruminated, and也希望 suggests that its status changes as physical symptoms fluctuate. Two types of hope have been identified: particularized hope (such as seeing a newborn grandchild), and generalized hope (a condition of being hopeful). Particularized 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 care. This perception of 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-focused when the possibility of a cure has passed? Meanwhile, an approach to patients which acknowledges the being and doing aspects of hope, while recognizing that within the parameters of supportive care, is likely to maximize any benefits that hope offers to patients.

122. The existential dimension of faith
Piotr Krakowiak
Hospice Foundation, Social Education about Hospice, Gdańsk, 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 easier or easier, though it may make both meaningful. Any of religion system does not systematically allow the answers persons may be looking for. Unanswerable questions of their religion are usually disappointed, especially expecting miracles or immortality and symbolic immortality. Religion itself can be a source of comfort and of transition through. Can religious faith help the dying patient who trust their God, directing their disappointment and fury against caregivers or family members. How can religious faith 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 which religious matters they want to discuss. The health care team should not provide all the answers people seek. People with religious faith can have a meaningful life which is neither well understood nor well researched. It is often linked to the possibility of a cure, even among patients who are most ruminated, and hopes suggests that its status changes as physical symptoms fluctuate. Two types of hope have been identified: particularized hope (such as seeing a newborn grandchild), and generalized hope (a condition of being hopeful). Particularized 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 care. This perception of 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-focused when the possibility of a cure has passed? Meanwhile, an approach to patients which acknowledges the being and doing aspects of hope, while recognizing that within the parameters of supportive care, is likely to maximize any benefits that hope offers to patients.
124. EPCRC - Session: Cachexia in cancer patients • Clinical aspects, what difference does it make?
Florian Stassen
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 in its consequences, such as associated eating-related symptoms, impaired physical function, psychosocial and existential distress, and malnutrition-associated complications. Since eating is a central issue in cancer care and most often play a role in modifying (deteriorating or alleviating) the consequences of cachexia. A useful classification system for cachexia in clinical research context requires to acknowledge the peculiarities of palliative care (i.e., short-term, terminal diagnosis, suffering, b) the unity of care involving family members in care concepts, c) goal-, and suffering-directed (not primarily etiology directed) diagnostic and therapeutic concepts, and d) fluctuating trajectories of illness, in particular in many patients until immediately before death. Define 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 consensus (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 (i.e., nutritional intake) or newly developed (i.e., psychosocial and functional assessment with eating-related causes for anaemia and cachexia) for palliative care. For practice-guiding use in everyday palliative care including clinical research an “EPCRC – Cachexia Classification” requires to be pragmatic and practical, taking into account the specific aspect of etiology and pathological processes tailored to the palliative care context.

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

125. Cachexia in cancer patients: Inevitable or treatable? Research proposals from the EPCRC.
Lukas Radbruch
Dip Palliativmed, 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 current state of the knowledge and future directions of classification systems based on etiology and pathophysiology and their potential impact on treatment decision will be discussed. The scope of a clinical guideline to be prepared by EPCRC will be introduced. The methodological principles 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 this 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!

126. Developing a common language towards consensus-based definition of 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 of different terms are used to mean the same thing and when there are variations in the understanding of the same term.

130. Grieving is a Family Affair
Pam Birt
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 we if we provide 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 will vary according to family history, culture as well as the current family situation. The story of the death becomes important as the individuals within the family begin to make sense of the process. This is particularly true for children whose role of the family is often excluded from parts of the story of the death. They are particularly affected by the loss of the纽带 of the chain of the death process to the future and to the parent. The parents of the future.

Discussion Ideas from systemic thinking will underpin the sessions 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 Birt, Head of Family Support, Isabel Hospice, Welwyn Garden City, UK.

131. The cultural determinants of grief
Eszter Biro
Hungarian Hospice Foundation, Psychosomatic, 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 measure in a cultural context signs of weakness, is even harder. The psycho-ontological service of Hungarian Hospice Foundation helps the deceased to find his/her own rituals and ways 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 interviews. In the first interview – as the 1st step of our eight-step protocol – we conclude to a contract on 8 to 16 fifty-minute interviews. In the second step we establish individual arrangements for the family and the deceased, 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.

We believe a carefully-considered consensus-building process, could we develop one common language for hospice palliative care that is accepted and used internationally?
132. Decision-making in end-of-life care: a pilot study on the attitudes, knowledge and medical acts of 602 Belgian GPs

Marc Couyn1, Myrtum Deveugle2, Jan De Maesenaere3, Roland Boland4, Brésidette Abobda3
1 University of gent, General Practice, gent, Belgium
2 Vrije Universiteit Brussel, family medicine, Brussels, Belgium
3 Bispebjerg hospital, Chaplaincy, Copenhagen, Denmark

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 style. 4. decision-making process and medical acts towards the patient at the end of his/her life.

Methods/Intervention A 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 included; hospital with a co-operation from GPs in homes for elderly and physicians in palliative care units. There was also a semi-qualitative research by peer-group and qualitative teams.

Preliminary results The questionnaire was returned by 602 GPs, 66% men on 24% women. Only 14% of them followed an institutionalized education in palliative care. Less than 30% 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 medical acts without the consent of the patient or his representative.

Interdisciplinary decision making is registered in 28% of the retrospective cases.

133. The care giver’s point of view in the approach of sexual concerns in palliative cancer patients.

Mario BARMAKI, Aurélie LAURENT, Henri Met, Venise 2006).

Methodology: A theoretical model emerged about optimizing family communication. It shows the change in the quality of breaking bad news (BBN) to people with learning disabilities (LD) 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 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 transcribed and analysed by the team. People with LD said the way 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 models can hinder communication with people with LD, collaborative working between palliative care and LD healthcare can overcome this and prevent increased psychological distress. Adaptations to the BBN Model and models are easily included in existing communication training and have transferability for a range of people with cognitive impairments.

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

Jacqueline Saunders1, 2, Linda McFerrill2, 3
1 St Nicholas Hospice, Education, Bury St Edmunds, United Kingdom
2 Christopher’s Hospice, London, United Kingdom
3 National Network for the Palliative Care of People with Learning Disabilities, Cambridge, United Kingdom

“The Helpings, Education and Training, London, United Kingdom

Introduction: 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 video, video content transcripts, and interview transcripts using Atlas.ti software to facilitate the coding process. A team of 5 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.

135. Family-Oriented Communication in Palliative Care

Iris Cohen Fieuxberg1, Steven Ash2
1 Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom
2 Vrije Universiteit Brussel, School of Social Sciences and Public Management, Brussels, Belgium

Aim of study: Effective communication with families is an important component of palliative and of 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.

Methods: 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 video, video content transcripts, and interview transcripts using Atlas.ti software to facilitate the coding process. A team of 5 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 (PFHCQ)

Jennifer Abbey, 1 Barry Rosenberg1, Hayley Pessin2
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2 Memorial Sloan-Kettering Cancer Center, Psychiatry & Behavioral Sciences, New York City, United States

Purpose: The goal of this study was to develop and pilot test a measure of patient-family communication about EOL topics, the Family Illness Communication Questionnaire (PFHCQ).

Method: A literature review was conducted to identify salient themes for those at the EOL. Palliative care experts provided input 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).

This last step was with the PFHCQ 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: r = .923, b: r = .913). There was no noteworthy improvement in the internal consistency levels of the subscales due to the elimination of any items. A low spearman correlation coefficient was documented between the 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

Helte Jensen1, Steen Nielsen1
1 Nyhøjegy hospit, Chaplaincy, Copenhagen, Denmark
2 Nyhøjegy hospit, Palliative care unit, Copenhagen, Denmark

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

Pastoral theory and theology are often incompatible due to their different perspectives on man but in a palliative context it can be important to both perspectives simultaneously. For this reason we conducted three psychotherapy and pastoral care meetings with both teams meeting the patient and team initially together and finally with a 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. Firstly, that body images are universal and need no particular educational or 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 potential 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

Wadh RHONDA1, Marilene FILBET, Aurelie LAURENT, Mario BABMAKI, Isabelle BRABANT
1 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 the team in the course of the session. The video are edited around a case studies.

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

Anna Sandgren1, Hans Thulesius1, Kerstin Petersson2, Bengt Fredlund3
1 Kronoberg County, Kronoberg County Research Center, Västervik, Sweden
2 Västergöt University, School of Health Sciences and Social work, Västervik, Sweden

Lately, in Sweden, more and more people die in nursing homes and homes and fewer die in hospital. 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 Matriated care, by which nurses organize 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 and involving the family. But in a palliative context it can be important to offer Anticipatory care by giving recognition, offering support and Resigning. Depending on the circumstances nurses can choose one of these different caring behaviors. Healthcare providers need to increase the knowledge of palliative care and to be more give Anticipatory care by giving recognition, offering education and providing adequate resources.
Aim: To determine the willingness of patients and relatives to participate in palliative care research, in particular randomised controlled trials (RCTs), and determine any influence parent factors.

Methods: A questionnaire was developed and modified through 4 focus groups with a palliative care-stable group of patients, relatives and patients. The final questionnaire assessed issues affecting willingness to participate (WTP), trial complexity and inconvenience tolerated using modified Leikart scale. 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 determined to identify demographic and other factors that can predict WTP.

Results: 125 patients were screened, 101 patients and 108 relatives completed the questionnaire. 88% of patients and 95% of relatives were interested in participating 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?
Paul Perkins1, Sara Booth2, Sarah Vowler3, Stephen Barlow4
1 Sue Ryder Care St. John’s Hospice, Moggerhanger, United Kingdom
2 Addenbrooke’s Hospital, Palliative Medicine, Cambridge, United Kingdom
3 University of Cambridge, Department of Public Health and Primary Health Care, Cambridge, United Kingdom

Aims: To elucidate which areas patients think should be research priorities for palliative care.

Method: A 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: 18 years or older, cancer diagnosis. In each stage, 4 focus groups with a total of 19 patients. A total of 1000m, reported that they had no difficulties doing this. 6% reported that they could not walk 20m, 20% and 47% could not walk 100m and 1000m. (20-100). Six% reported that they could not walk 20m, 20% and 47% could not walk 100m and 1000m. (20-100). Six% reported that they could not walk 20m, 20% and 47% could not walk 100m and 1000m.

Possible attitudinal barriers need to be proactively addressed. A method of assessing the patients’ spiritual needs.

142. Self reported mobility in palliative patients: Does wording of items matter?
Jorunn Helbostad1, Line Oldervoll2, Marit Jondal1, Gerd Inger Ringsdal3, Jon Håvad Loge3, Stein Kaasa4
1 Norwegian University of science and Technology, Dept. of Neurobiology, Trondheim, Norway
2: Norwegian University of science and Technology, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Trondheim, Norway
3: Norwegian University of science and Technology, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Trondheim, Norway
4: Norwegian University of science and Technology, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Trondheim, Norway

Aim: To explore the willingness of patients and professionals to participate in palliative care research.

Method: A self-report questionnaire on functional and symptomatic treatments, physical and psychological distress was developed. The questionnaire was completed by 1000m, reported that they had no difficulties doing this. 20% and 47% could not walk 100m and 1000m. (20-100). Six% reported that they could not walk 20m, 20% and 47% could not walk 100m and 1000m. A method of assessing the patients’ spiritual needs.

143. Assessment of the patients’ spiritual needs: the influence of investigators’ attitudes on patient drop-out rates
Gian Domenico Borasio1, Martin Fegg2, Thomas Hagen3, Traagott Roser4, Gudrun Linke3, Caro anla Redman1
1 University of Munich, Interdisziplinäres Zentrum für Palliativmedizin, München, Germany
2 University of Munich, Department of Psychotherapy and Psychosomatics, Munich, Germany

Aim: To elucidate which areas patients think should be research priorities for palliative care.

Method: A 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: 18 years or older, cancer diagnosis. In each stage, 4 focus groups with a total of 19 patients. A total of

144. Combining Patient & Professional Perspectives Using “Speed Dating”
Jane Maher1, 2, Sara Booth2, Jane Gwilliam1
1 University of Hertfordshire, Complexity and Management of Care Studies, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Trondheim, Norway
2 University Hospital Birmingham, Birmingham, United Kingdom

Aim: To determine if demographic and other factors can predict complexity and inconvenience tolerated using modified Leikart scale. 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 determined to identify demographic and other factors that can predict WTP.

Results: 125 patients were screened, 101 patients and 108 relatives completed the questionnaire. 88% of patients and 95% of relatives were interested in participating in research trials. The level of inconvenience and trial complexity tolerated may aid the development of future studies.

145. The Coordination Centre for Pediatric Palliative Medicine in Munich - a model for the future
Monika Haefner1, Barbara Klein2, Klaus Kiernan3, Ayda Dorou4, Gian Domenico Borasio1
1 De von Haunersches Kinderhospital, Pädiatrische Onkologie und Hämatologie, München, Germany
2 Interdisciplinary Centre for Palliative Medicine, Coordination Centre for Pediatric Palliative Care, Munich, Germany
3 Interdisciplinary Centre for Palliative Medicine, Munich, Germany

Aim: The Coordination Centre for Pediatric Palliative Medicine (KPiP) was established 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’s files and patient’s documentation.

Results: From 304.46 06.16 patients (age 0-35 yrs) were enrolled in the programme. 36% (62%) have died so far, 36% of the patients are still living at home. The first hospice staff in 69%, in 27% the family contacted the KPiP. 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 79% 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 (2-273 d).

Discussion: The work of the KPiP was highly accepted by children and families. Most children could die at home. This could be achieved by a critical mass of 24/7 availability of a specially trained pediatrician. A network of similar coordination centres could be helpful in improving care for patients with bone metastases or late effects of radiotherapy.

146. Si closing project - A German project for healthy siblings of chronically ill children
Wilma Henkel1, Bettina Hühner2, Boris Zernikow3
1: Verstehende Kinder- und Jugendklinik Datteln, Vodafone Stiftungsinstitut für Kinderpsychiatrie und Palliativmedizin, Datteln, Deutschland
2: Verstehende Kinder- und Jugendklinik Datteln, Vodafone Stiftungsinstitut für Kinderpsychiatrie und Palliativmedizin, Datteln, Deutschland
3: Verstehende Kinder- und Jugendklinik Datteln, Vodafone Stiftungsinstitut für Kinderpsychiatrie und Palliativmedizin, Datteln, Deutschland

Aim: To explore healthy siblings’ needs. 2) To provide social support for healthy siblings. 3) To provide guidance for further interventions.

Method: Intervention: Fifteen siblings aged 6 to 11 y of chronically ill children with life-limiting diseases, who had to face the threat of losing a sibling. Thalidomide-threatening conditions took part in weekly group activities. They were encouraged to share their own needs, to express their feelings and bond with other group members. 2) Study: Thirteen children participated as a control intervention. Questionnaires on the children’s feelings, thoughts, and concerns was collected from parents (CRL) and children > 8 y.

Focus group interviews with all children generated

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: A user involvement facilitator works with parents to identify “real world” problems which can be told in 2-4 minutes. 2) Each pair host a table with 5-6 “presenters”. The latter move to different tables every 12 minutes after discussing each story. A team of facilitator/writers captures ideas and quotations illustrating different perspectives.

3) Results: Insightful use are refined models of care and patient goals.

4) Conclusion: This is a useful tool to draw ideas from multiple stakeholders. It is highly valued by patients but requires skilled organisation and facilitation.

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Healthcare siblings tend to be unintentionally neglected which may have negative impact on their physical and mental well being. Studies demonstrated that healthcare 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 Munich.

Aims: 1) To explore healthy siblings’ needs. 2) To provide social support for healthy siblings. 3) To provide guidance for further interventions.

Method: Intervention: Fifteen siblings aged 6 to 11 y of chronically ill children with life-limiting diseases, who had to face the threat of losing a sibling. Thalidomide-threatening conditions took part in weekly group activities. They were encouraged to share their own needs, to express their feelings and bond with other group members. 2) Study: Thirteen children participated as a control intervention. Questionnaires on the children’s feelings, thoughts, and concerns was collected from parents (CRL) and children > 8 y.

Focus group interviews with all children generated

10th Congress of the European Association for Palliative Care, Budapest, Hungary, 7–9 June 2007
Oral abstracts

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

We have been developing pediatric hospice care for the past 3 years.

Aim: To evaluate parents' feelings and the impact of our hospital team on pediatric hospice care.

Methods: We sent an anonymous questionnaire to 33 parents of children (1 to 12 years old) who died at home or had no regret for their decision. 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 had no doubt regarding rehospitalisation. Interestingly, for none of them were their family physician and local hospice care providers and we didn’t organise any visit at the child’s home.

Local home care providers who met with our hospital-based palliative care team had to face the most frequent parental requests regarding their competence, quality of care, accessibility, as well as to show management of end of life symptoms with the highest impact on parents were their child’s fatigue and pain. Parents cited loneliness, 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 home-based palliative care. The degree of commitment from the primary hospital-based team seems to be critical in paediatric palliative care.

150. Pediatric Advanced Care Team: one of the models of delivery of pediatric palliative care in the UK - Tamara Vesel

Palliative Pediatric Care focuses on optimizing the care of children whose survival is limited. Dr Vesel will introduce you to the Pediatric Advanced Palliative Care Team (PACT), one of the models of delivery of pediatric palliative care in the UK. 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 threatening illnesses and families to identify goals of care, intensive symptom management, coordination of care between families, hospital, 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 palliative care advice. 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 possible for as long as possible.

151. Quality of life - a valuable concept? - Raymond Voltz

In this wake-up session, participants will have the chance to 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 definitive answer.

152. Nutrition - Meet the expert - morning session

Florian Stasser, Yva Oterrell

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

Deceased 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 the care of 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, by facilitating the patient’s autonomy 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 eating problems and their consequences; 2) assessment of secondary reversible causes; 3) estimation of severity of underlying anaemia (anaemia), 4) prioritisation in the overall context of patients’ illness burden, appropriation of specific goals (and no-go’s) of pharmacological, nutritional, and psychosocial interventions, 6) best interventions and expected time needed to reach these goals, and 7) well balanced diet avoiding 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”.


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 the standard of care evaluation. The session will provide an overview of those key recommendations and points 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 - Ruthamkaja Smeding, John Ellershaw

Ruthamkaja 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, Sheila Payne

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 user-based activities carried out by Sheila Payne at the University of Sheffield about user involvement in palliative care. This study reviewed palliative care literature, policy and practice literature, to identify methods of accessing user views and eliciting the views of key informants and highlighted best practice.

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

A facilitated discussion will identify the key themes and experiences of user involvement in their own settings and suggest how developments might be initiated. The session will demonstrate a user involvement meeting.
Saturday 9 June

CONNECTING DIVERSITY

10th Congress of the European Association for Palliative Care
147. An Ethical Framework for Pediatric End-of-Life Decision Making 1, 2

Mildred Solomon 1, Cyndie Raubach 2, Laura Rieghaupt 1, Alan Fleischman 2

1 Harvard Medical School, Division of Medical Ethics, Boston, United States
2 Education Development Center, City for Applied Ethics, Newton, United States

Background: Few ethical frameworks guide decision making regarding rehospitalization. In addition, they overlook the role of the patient’s family in the decision and are not age-appropriate. The present framework addresses the decision of the patient’s family as well as the patient to rehospitalize. The present framework provides guidance for rehospitalization. It addresses the decision of the patient’s family as well as the patient to rehospitalize. The present framework provides guidance for rehospitalization.

Methods: We conducted a literature review of the existing ethical frameworks for rehospitalization. We then developed a new framework that addresses the specific needs of pediatric patients and their families. The framework is based on the principles of respect, beneficence, nonmaleficence, and justice.

Results: The framework provides a structured approach for rehospitalization decisions. It highlights the role of the patient’s family in the decision and is age-appropriate.

Conclusion: The framework provides a useful tool for clinicians and families in making decisions about rehospitalization.

150. Pediatric Palliative Care: one of the models of delivery of pediatric palliative care in the UK

Tamara Vesel

Dana Farber Cancer Institute and Children Hospital, Pediatric palliative care/Palliative oncology, Boston, United States

Pediatric Palliative Care focuses on the care of children whose lives may be limited. Dr Vesel will introduce 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 that works with families, hospital staff, and patients to provide comprehensive care for children with life-limiting illnesses. The session will demonstrate the use of PACT to deliver high-quality palliative care to children and their families in a variety of settings.

Conclusion: Pediatric Palliative Care is a model of care that is increasingly being adopted in the UK. By providing a structured approach to the delivery of palliative care, it has the potential to improve the quality of care for children with life-limiting illnesses and their families.
Neurotoxicity, side effect of analgesic adjuvants or other drugs, would need more detailed assessment to identify those in need in their own villages and facilitate the barriers to volunteering and action to remove them, supported activity. Challenges include understanding use as a route to employment and increases in employer compliance, and relationship with relatives and carers. Delirium is the most prevalent condition with CF in palliative care [1]. It can be a general medical condition and presents as an agitated, a hypoactive or a mixed form.

Discussion
The 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 gets untreated. The high non-detection rates point to the urgent need to raise the awareness of delirium in PC, nurses and home care.

Results
A review (2004) revealed an increasing interest in delirium (2 in PC, 22 studies were published from 2000 to 2003). The interchangeable use of CF to describe specific diagnoses makes form 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. 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 aim to identify patients who need more detailed assessment.

Defining and principles of palliative sedation therapy
Alexandre De Graeff 1, 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 (most delirium, dyspnoea and/or pain). It use varies between centers and countries and may be recognized.

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 treatment has failed within a reasonable time frame and/or is accompanied by unacceptable side effects.

Principle: 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 death considered a necessary sedation requirement. In that case, the disease should be irreversible and/or is accompanied by unacceptable side effects.

Discussion
Since extreme suffering calls for extreme measures, it may only be used when all other, conventional strategies to relieve intractable symptoms either fail or are deemed inappropriate. Thus, patients eligible for palliative sedation find themselves in an emergency situation. When other treatments fail to relieve suffering in the imminently dying patient, PST is a valid palliative care option.

Conclusions: When other treatments fail to relieve suffering in the immiently dying patient, PST is a valid palliative care option.
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 a core specialty of care. Drawing on a survey conducted by the EAPC Taskforce on Education and Development, an overview of the current landscape for 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-speciality, for which a second certification is required. Poland, Romania, Slovakia and Germany. Some 10-12 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 processes in that are made in order to achieve certification. Further studies are essential to determine the impact 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 status and the improved recognition of palliative care as a discipline.

167. Suggestions in the communication with cancer patients

Eva Bánysy
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 person's reference frame. Since patients become very vulnerable and develop a feeling of being at the mercy of their dependence, the communication often results in a relinquishment of control function. All this leads to increased susceptibility to suggestions. In this situation, suggestions with clearly defined rhetorical 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 specifically designed suggestive technique recommended to help professionals in recognizing spontaneous trance states, in phrases and gestures of a fashion that is likely to do good than unintended harm, and in formulating emotional suggestions (often unintended) made by authority figures, patients sense they are left alone and shut out from life. A specifically designed suggestive technique recommended to help professionals in recognizing spontaneous trance states, in phrases and gestures of a fashion that is likely to do good than unintended harm, and in formulating emotional suggestions (often unintended) made by authority figures. 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 morbidities. 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 palliative care, i.e. to 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 morbidities. 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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).
174. Measuring Attitudes to Change and Relation Competence in a Palliative Medicine Unit

Beate André a, b, c, Endre Svoreid a, d, Gerd Ringdal a, e, Jon Loge a, f, Marte Holmelo a, f, Stein Kaasa a, e

a. Norwegian University of Science and Technology, Vrije Universiteit Brussel, Vrije University Budapest, Trondheim, Norway
b. 2 Norwegian University of Science and Technology, Vrije Universiteit Brussels, Psychosomatic Medicine, Trondheim, Norway
c. 3 Norwegian University of Science and Technology, Vrije Universiteit Brussel, End-of-Life Care Research Group, Trondheim, Norway
d. 4 University of Southampton, School of Nursing and Midwifery, Southampton, United Kingdom
e. 5 Karolinska Institutet and Uppsala University, Centre for Bioethics, LIME, Stockholm, Sweden
f. 6 St. Olavs University Hospital, Trondheim, Pain and Palliation Research Group, Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Trondheim, Norway

Background: Understanding a work group’s culture can facilitate the change process. In this study the respondents on organization relation level were subject to interview.

Methods: Health care personnel (N=25) at the Palliative Medicine Unit (PMU) answered a questionnaire. The respondents 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 key difference between the today and desire 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 own influence on the future. This resignation may also be heavily influenced by the work situations. The passive respondents with close relation to patients with short expected time to live. Implications are discussed.

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

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b. University of Southampton, School of Nursing and Midwifery, Southampton, United Kingdom
c. Karolinska Institutet and Uppsala University, Centre for Bioethics, Stockholm, Sweden
d. Centre for Study and Prevention of Cancer, Florence, Italy
e. Norwegian University of Science and Technology, VrijeUniversiteit Brussels, Vrije University Budapest, Trondheim, Norway
f. St. Olavs University Hospital, Trondheim, Pain and Palliation Research Group, Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Trondheim, Norway

Aim: To describe a new integrated palliative care model

Gunnhild Jakobsen a, Anne Kvikstad a, Stein Kaasa e

a. Norwegian University of science and Technology, Pain and Palliation Research Group, Department of Cancer Research and Molecular Medicine, Faculty of Medicine, Trondheim, Norway

Background: Palliative care needs to develop and evaluate new models for implementation of care. 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), Hassan 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: A pretest intervention: Patients who were admitted to and died in the PCU (n=685) and in the PMU (n=188) January 2002 to 31 December 2003 were consecutively included.

Results: Patients who died in the PCU were significantly older (70% 75+, p<0.001). The majority of the entire cohort had gastrointestinal cancer, 45% PCU, and 85% PMU. There were significant differences in the number of cancer units, assessed during the last week of patients life, in use of indwelling bladder catheter (36% PCU, 60% PMU), oxygen treatment (24% PCU, 50% PMU), intravenous treatment (46% PCU, 78% PMU) and central venous catheter (2% PCU, 12%PMU) (p<0.001). PCU had a median survival of 30 days (95% CI 5.59-44.05) versus to 11 days (95% CI 5.91-12.99) 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 different selection and/or medical preferences guided by site.

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

Joachim Cohen 1, Johan Bilsen 1, Julia Addington-Hall 3, Burik Lőkk 4, Guido Miccinesi 5, 6, Stein Kaasa 7, Anna Kvikstad 8

1 Yale University, USA, 2 University of Brussels, Belgium, 3 University of Southampton, School of Nursing and Midwifery, Southampton, United Kingdom, 4 Karolinska Institutet, Sweden, 5 University of Naples, Italy, 6 University of Amsterdam, Netherlands

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) in hospital, at home, and the determinants of their choice.

Methods: This is a mortality follow-back survey of 2,000 cancer deaths identified with a Swedish national cancer death 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 (93%) 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 (46% in the South and 25% in the North). Significant determinants of referral were (P=0.01) a long interval between diagnosis and death (birth) 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.
Oral abstracts

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 perceptions of deceased relatives: results from a survey using the VOICES questionnaire.
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1 Sir Michael Sobell House, Nursing, Midwifery and Postgraduate Medicine, Southampton, United Kingdom
2 Sir Michael Sobell House, Nursing, Midwifery and Postgraduate Medicine, Southampton, United Kingdom

Background: Accounts of care at the end of life are variously 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 measurement questionnaires 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 experienced by patients in hospices exceeded that of care provided in hospitals. Further research is needed to identify the 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.

180. SPECIALIST PALLIATIVE CARE SERVICES (PCS) AT HOME IN SPAIN: STRATEGY, OUTPUTS, AND OUTCOMES.
Jose Espinosa 1, Xavier Gómez-Batiste 1, Silvia Paz 2, Josep maria Picaza 1
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2 Asociación Espanola Contra el Cancer, Home Care Support Team, Ceuta, Spain
Paliative Care Programme, Home Care Support Team, Mataró, Spain

Introduction: The delivery of palliative care at home in Spain is still in its infancy but has been put in place. A National Surveillance and Monitoring Program has shown that 37% of patients, representing the largest 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 Centres. 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 life 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 other directions should be pursued to obtain a better efficiency, some of these directions pertain to the domain of palliative care: specialization home-based palliative services for the HIV / AIDS patients, evaluate the needs of palliative care 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.

181. Cultural Pain and its impact on patient and family care: Connecting diversity in culture, policy and practice
Anne Merriman
Hospice Africa Uganda, 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 this cultural challenge:
- 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 new and still emerging field in Uganda. 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 and neuropathy
  - Patients who are too sick to receive ART
  - Patients who present too late for ART
  - Patients who are overwhelmed by side effects of ART
  - Patients with opportunistic infections for which there is no treatment or care
  - Patients with side effects of ART
- Interaction with ART
  - Psychological and spiritual distress
  - Poverty and other factors limiting access to ART

182. AIDS challenges for palliative care in Uganda

183. HIV infection and AIDS challenges for palliative care in Romania
Ovidiu Popa Velea
University of Medicine and Pharmacy, Medical Psychology, Bucharest, Romania

HIV / AIDS infection is a major public health problem in Romania, and it has several implications, affecting, and at the end of 2006, a total number of 963 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, the 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 Centres. 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 life 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 other directions should be pursued to obtain a better efficiency, some of these directions pertain to the domain of palliative care: specialization home-based palliative services for the HIV / AIDS patients, evaluate the needs of palliative care 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.

184. AIDS and Palliative Care in France: new challenges
Jean-Michel LIVROZET 1, Marilène FLIBERT 1
1 Hôpital Edouard Herriot, Pavillon P, Lyon, France

CENTRE HOSPITALIER LION LYON Sud, Sables Palliatifs, LYON, France

Epidemiology
In France, they reported 60 212 AIDS cases (24% IV drug users, 43% Men having Sex with Men and 27% heterosexual contact) and 14 313 AIDS deaths. Out of an estimated 85 000 patients in 2005, 58 000 were on antiretroviral 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. Nowadays, (166 C’Vincent 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; carcinoïd; 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
Hospices were opened in response to the epidemic in our country and also in Switzerland or the 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 Lyon welcoming terminal patients at the beginning and now more patients with social problems. Some familiar cars Units were involved at the same time in the care of AIDS patients in major cities.

Respect and 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.

185. The Song Rooms
Lucinda Jarrett Jarrett

The Song Rooms

Breakout: Life, Health and Wellbeing, London, United Kingdom

Rosetta Life has pioneered an innovative music composition site that uses state of the art technology to enable children with paediatric palliative care across the world to participate in music making and upload music directly to a site where others can respond and remark.
Children will make music using the interactive site and videos produced by the BBC that record the concert and the friendships made. They hope to present the interactive site and videos produced by the BBC that record the concert and the friendships made online.

186. Wound Care Part 2 - Wound Pain and Other Symptoms Associated with Wound Care
Frank Ferris, Roseme Piretto
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, uncontrollable bleeding, and the accompanying anxiety, depression and delirium can cause suffering and lead to avoidable deconditioning.
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 intercurrent pain associated with dressing changes. We will use clinical case discussions to explore approaches to wound pain assessment and management, including both systems-based and topical analogues and anesthetic techniques.

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

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

Lukas Radbruch, Florian Strasser, Frank Elner

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Fatigue is one of the most frequent symptoms in palliative care patients. However, diagnosis and treatment of this symptom is often neglected. The Research Network of the EAPC has initiated an expert working group to produce recommendations on 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, while others have used it as a behavioral construct. There is broad consensus that fatigue has to be considered 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 authors have identified other dimensions on which fatigue has been predominantly in oncology patients, and the results may not be transferable to palliative care.

188. Distress or just a symptom?

Carol Tishelman

Karolinska Institutet, Stockholm, Sjukhem, Department of Nursing Science and Society, Direktion 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 meaning and consequence of 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, base this argument primarily on data from a six-month study, and discuss the potential of a behavioral construct which may not only be more meaningful, but also may be more useful in guiding our research into symptom experiences in 400 men and women with inoperable lung cancer who entered the dying phase. The study was also an original investigation on how symptom experiences in end-of-life care influence the burden of care for family caregivers.

189. An integrated care pathway - overview

Massimiliano Panella,1 Kris Vanhaecke,2 Sara Marchisio

1 University of Eastern Piedmont, Clinical and Experimental Medicine, Novara, Italy
2 Katholieke Universiteit Leuven, Leuven, Belgium

The European Pathway Association (www.E-P-A.org) definition of care pathway includes an explicit statement of the goals and key elements of care based on clinical and patient experience, and patient outcomes. 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 variables 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 care and clinical management tools can be defined in the best process in their organisation, with the best process in different countries, with different patients, with specific diagnoses or conditions according to Evidence Based Medicine. To build the clinical care pathway, the following steps, based on PDSA cycle can be used:

1. Select the area of practice.
2. Identify the multidisciplinary care 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.

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

John Ellershaw

Matere Care Palliative Care Institute Liverpool, Department of Palliative Medicine, Liverpool, United Kingdom

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 end of life 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 Health settings. The LCP was 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.

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

Lia Van Zuylen1, Laetitia Veerkamp2, Siebe Swart3, Agnes Van Der Heide4

1 Eunosis MC, Medical Oncology, Rotterdam, Netherlands
2 Eunosis MC, Public Health Sciences, Rotterdam, Netherlands
3 Nursing Home Antonius Boezemmond, Rotterdam, Netherlands
4 Comprehensive Care Centre South, Rotterdam, Netherlands

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 Centre Rotterdam (CCCR) supported the implementation of the LCP. Methods: Two home care organisations, 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) 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, 35.5 h in nursing home and 16 h in hospital. In the intervention period the documentation was 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 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.

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

Branka Cervl,1 Urska Lunder2

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

Background: Main difficulties of the implementation of palliative care (PC) in 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 health care sectors. 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 was 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 above. The process was complicated, was time consuming, and was easily achieved, on the local level the implementation was much harder than on the national level. The authors present some selected and important information about challenges and solutions in the implementation process.

Conclusion: 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.

193. PALLIATIVE CARE IN GEORGIA

Sema Ghvamishvili

Oncology Institute, PALLIATIVE CARE UNIT, Tbilisi, Gabun Republic

First palliative care clinic for advanced cancer patients in Georgia was opened in January 2001 and served 236 patients. During 2006, 261 patients have been hospitalized: 64% women, 36% men; median age 57, average 57.3. Average duration of hospitalization 17.5 days. The reason of incurability was metastasis, in 10% the locally spread tumors. Most common localizations - colorectal (28%), breast (25.3%), lung (76%), cervical (4.6%), ovarian (8.4%), gastrointestinal (15%). Cost of care (55 GEL) was covered by the State Program on Oncology (70%), the patients pay 30%.

182. Fatigue in patients with advanced cancer in Slovenia during first year of implementation of EAPC workgroup position paper

Karla Rebernik1,2, Iztok Filogenerits1,2, Karen Tratnik1,2, Rasov Ercolani1,2, Anja Vukovic1,2, Sonja Suplican1,2,3, Mary Pernkopf4,5, Carin van Der Rijt3

1 Comprehensive Cancer Center Rotterdam (CCCR), Rotterdam, The Netherlands
2 Comprehensive Care Centre South, Rotterdam, Netherlands
3 Comprehensive Care Centre North, Rotterdam, Netherlands
4 Comprehensive Care Centre West, Amsterdam, Amsterdam, Netherlands
5 Comprehensive Care Centre East, Amsterdam, Amsterdam, Netherlands

Background: This study was designed to evaluate the implementation of the EAPC position paper highlighting the problems and incongruities working group to produce recommendations for treatment of this symptom are often neglected. The implementation was much harder discussed; the most obvious feature in our findings. Development of 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.

183. Palliative Care in the Geographical Region of Klagenfurt

Bogdan Radu1,2,3

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3 Comprehensive Care Centre South, Rotterdam, Netherlands

The European Pathway Association (www.E-P-A.org) definition of care pathway includes an explicit statement of the goals and key elements of care based on clinical and patient experience, and patient outcomes. 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 variables 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.

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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.
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 (I), work both in the hospice and in 80% of the cases in the home of the Italian Society for Palliative Care (I). The UCP takes part in the national and regional project of the Hospital without Pain (C), the Director coordinates the local Committee for OSD.

195. The regional palliative care programme of Extremadura
Javier Rocafort
Regional Palliative Care Programme of Extremadura, Mérida, Spain

More than a single service, the Regional Palliative Care Programme (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 not have to pay for any service. The annual cost of the program around 3 million € (equivalent to 3 $ per inhabitant per year).

**Objective:** Creating a Regional Palliative Care Programme for the public Health System in Extremadura (equivalent to 3 $ in the public insurance system, and patients not have to pay). The need for lifelong palliative care is a major need and challenge for health care. Thus, WHO edited some essential ideas under the title “Learning together to work for health”. Some large proposals by this paper have been integrated in more recent educational strategies, mainly in the “5-steps-doctor” framework defined by Ch. Bölen, and more explicit, in the Palliative Care Network. They were asked to state the drugs they would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life. They would use to manage symptoms arising in the last days of life.
204. Categorising palliative care development: a global perspective
Michael Wright, Justin Wood, Tom Lynch, David Clark

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

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 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 113/234 countries. Total countries in each category were 31 (13%); 78 (33%); 21 (9%); and 22 (9%).

Aims: 1) To categorise hospice/palliative care development 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 113/234 countries. Total countries in each category were 31 (13%); 78 (33%); 21 (9%); and 22 (9%).

Aims: 1) To categorise hospice/palliative care development by country, throughout the world and 2) to depict this development through world and regional maps.
210. Addressing the diversity of symptoms in every day life in end-stage COPD patients

Jolanda Habraken1, Dick Willems2, Els Weersink3, Patrick Bink3
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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 understanding and 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 with 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.

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: NYHA class 4, 72.4% (91.6%), 76% male. Mean systolic ejection fraction: 27.7% (8.1%). Mean ESAS symptom distress score: 4.3 (11.32). HAOS: mean anxiety score: 5-4.35, mean depression score 6.25-3.4. Mean SEIQoL score: 79.21.9 4. Mean Minnesota 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.

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

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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 (PCVS) 110 patients 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 included: 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 concerns.

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 PCVS 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.

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 by clinician’s and patient’s perspectives of factors contributing to nausea in advanced cancer.

Methods: 4468 screened experiencing nausea were recruited from palliative care services. Patients completed an interviewer-administered questionnaire comprising rating scales to assess nausea severity and impact (NRS 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 had GI cancer accounting for 17.6% of the variance. Emotional factors made the largest unique contribution (36%, sr2=0.36), while the contribution of primary GI cancer (sz=0.17, 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 (sz=0.53) while the contribution of age (sz=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.

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 behavior 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 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, venting 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 coping 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.

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 385 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 scripts, authentications, soft-guardians, use of positive words and focusing on the positive. Conclusion: Physicians apply a range of sophisticated communication strategies in prognostic disclosure. The appropriateness of such strategy as well as new alternative ways should be researched for different patient populations.

216. See page 79

217. See page 81