Oral abstracts

Thursday 7 June

CONNECTING DIVERSITY

10th Congress of the
European Association for Palliative Care

1. See page 66

---

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

---

3. Access to controlled medications: impact for millions

Willem 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 treaties. The result is very scaring: consequences are unnecessary suffering from pain and preventable HIV-transmission. Women die in delivery by lack of access to ephedrine and ergometrine. WHO estimates that altogether over 600 million people will be affected during their lifetime.The drug conventions' aims are to ensure availability for medical use as well as the prevention of abuse but many countries enacted stricter measures than those required by the Conventions. Additional barriers are failure to develop and submit accurate estimates and statistics to the INCB, inappropriate medical practices and insufficient recognition of the therapeutic usefulness of controlled medicines by medical professionals and law enforcement officers. In developing countries procurement, available funds and infrastructure are additional barriers.The World Health Organization set up the Access to Controlled Medications Programme to deal with these barriers. Its activities will assist the countries when reviewing legislation, train officers responsible for statistics and estimates, and provide medical professionals with information and training on the rational use of these medicines. The optimal balance between access for medical use and prevention of abuse needs to be restored.

---

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

Eugene Murray

Irish Hospice Foundation, VOLOUNTARY ORGANIZATION, Dublin, Ireland

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

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

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

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

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

---

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

David Oliver [1], Rachel Forrester-Jones [2], Lisa Duplock [2]

[1] *Kent University, Kent Institute of Medicine and Health Sciences, Canterbury, United Kingdom*
[2] *Kent University, Tizard 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. The involvement of palliative care services with this group of patients appears to be small and this study aims to investigate the knowledge of health care professionals working in specialist palliative care in the care of people with intellectual disability.

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

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

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

---

6. "The Veronica Project": An ethnographic study into the experiences of people with Intellectual Disabilities (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' notes, attending case conferences, and writing extensive field notes, including the researcher's own reflections. Data are analysed using grounded theory. Ethical issues are carefully considered.

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

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

---

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

---

8. Social resurrectionists: death in a disabilty context

STUART TODD

Cardiff University, University hospital, Cardiff, United Kingdom

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

---

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

Noelle Blackman

Respond, Directorship, London, United Kingdom

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

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

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

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

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

Torkel Falkenberg

Karolinska Institutet, Department of Neurobiology, Care Sciences and Society, Division of Nursing, Center for Studies of Complementary Medicine, Huddinge, Sweden

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

---

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

---

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

Adriaan Visser [1], Machteld Van den Berg [2]

[1] *Helen Dowling Institute, Research, Rotterdam, Netherlands*
[2] *University Medical Center Utrecht, Research, utrecht, 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 31 patients in the experimental group and 26 in the control group. Patients in the control group were matched with patients in the experimental condition with respect to age, gender, type of cancer, type of chemotherapy, prognosis and the period between pretest and posttest. Standardized questionnaires were used measuring quality of life, mood, meaning of life, general functioning, symptoms, sleep quality, body awareness, and satisfaction with care. The intervention consisted of five haptotherapy sessions of 45 minutes each. Patients in the control condition received standard medical care. Results Most of the patients (61%) have a metastasized or palliative stage of cancer. Patients highly valued the haptotherapy treatment, and were satisfied with the personal attention and the relaxation they experienced. The haptotherapy treatment improved both the general quality of life and the cognitive and social functioning of patients. **Conclusion** Haptotherapy positively contributes to the of life of cancer patients during the period they receive chemotherapy. Haptotherapy as a type of complementary medicine is a potential valuable and effective intervention to raise the well-being of cancer patients undergoing invasive treatments.

---

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

Petra Plunger

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

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

---

14. Oral problems - assessment and treatment Overview

Andrew Davies

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

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

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

15. Oral Hygiene

Margaret Sweeney

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 problems often assume low priority within palliative care settings and other medical specialties. The management of oral problems is often anecdotal rather than evidence-based and there is a dearth of reliable research on this topic.

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

---

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

Fred Spijkervet

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. Mucositis is associated with an increase of systemic infections, days in hospital and overall costs, and these aspects have a negative impact on health related quality of life.Many studies have been published on intervention possibilities for prevention of mucositis, but most of these had small sample sizes, or used different scoring methods, which make comparison of outcomes difficult. Insufficient sample power, lack of sensitivity of the outcome measures, and study design flaws, make it hard to provide evidence-based guidelines on oral mucositis.This presentation will discuss meta-analyses of randomized clinical trials of intervention on prevention of oral mucositis and available guidelines.

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

---

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 incident to the teeth. In addition bacterial superinfections deteriorate the complication. No convincing data supports a relationship between the incidence of ON and demographic parameters, primary tumor, dosing interval, or cumulative drug dose, but it seems that patients who develop ON had longer infusion time and a higher number of infusions over long periods of time (> 2 years).

As practical management approach, before initiation of bisphosphonate treatment a careful dental-oral history should be undertaken and identified dental comordidity treated. Patients should maintain a good dental hygiene and undergo regular dental assessments. For patients who develop ON, a conservative, non-surgical approach is strongly recommended. A close interdisciplinary approach including the palliative care team, oncologist, dental specialist and oral surgeon should be cultivated.

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

Katherine Froggatt

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

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

---

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

Katharina Heimerl

University of Klagenfurt, IFF-Palliative Care and Organizational Ethics, Vienna, Austria

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

---

20. Nursing homes and hospice - needs fulfilled?

Friedemann Nauck [1], Stefan John [2], Eberhardt Klaschik [3]

[1] *University Hospital Goettingen, Department of Palliative Medicine, Goettingen, Germany*
[2] *University Hospital Goettingen, Department of Palliative Medicine, Göttingen, Germany*
[3] *University of Bonn, Department of Palliative Medicine, Bonn, Germany*

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

---

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

Elena Vvedenskaya [1], Alexander Isaev [2], Galina Larina [2], Irina Vvedenskaya [1], Boris Tolchenov [2]

[1] *Nizhny Novgorod State Medical Academy, Nizhny Novgorod, Russian Federation*
[2] *Gerontologic Institute, Nizhny Novgorod, Russian Federation*

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

---

22. THE INTRAVENOUS TO ORAL MILLIGRAM POTENCY RATIO OF MORPHINE

WAEL LASHEEN, FADE MAHMOUD, DECLAN WALSH, NABEEL SARHILL, MELLAR DAVIS, RUTH LAGMAN, SUSAN LEGRAND

Cleveland Clinic, Palliative Medicine, Cleveland, United States

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

---

23. INTERMITTENT CANCER PAIN: CLINICAL IMPORTANCE AND CLASSIFICATION

WAEL LASHEEN, DECLAN WALSH, MELLAR DAVIS, NABEEL SARHILL

Cleveland Clinic, Palliative Medicine, Cleveland, United States

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

---

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

---

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

Geoffrey Davis [1], Anthony Fisher [2], Andrew Knight [1], Robin Love [1]

[1] *St. Josephs Hospital, Thunder Bay, Canada*
[2] *Régional de Sudbury Region, Thunder Bay, Canada*

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

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

---

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

Bernard Wary, Giséle Pickering, Said Serbouti

CHR Metz-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 scale. Doloplus® has been one of the first scales to be published and statistically validated in 1999 by B Wary and the Doloplus® team. The validation characteristics are available on the Doloplus® site "doloplus.com . Translation in other languages was however missing and awaited by the geriatrics community. Considering the need for validated tools at an international level and the frequent request from many practitioners worldwide (more than 20 countries have contacted us since the creation of our web site in 2000), Doloplus® has been translated and validated in six languages, English, Dutch, German, Italian, Spanish and Portuguese and this study reports its validation. Twelve teams (two for each language) have been selected on the basis of their experience and competence in geriatrics and in pain evaluation of elderly patients with communication disorders. Each team tested the scale in her/his native language with 20 elderly persons. Test-retest reliability and inter-rater reliability have been analysed and showed excellent results in every language. The validation of this scale will allow its use on a broader scale in the evaluation of pain of elderly persons with communication disorders.

---

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

---

28. View from the Observatory

David Clark

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

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

---

29. Palliative Care in Europe are moving forward

Carlos Centeno

University of Navarra, Palliative Medicine, PAMPLONA, Spain

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

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

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

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

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

---

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

Natasa Milicevic

BELhospice, Belgrade, Serbia

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

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

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

---

31. The Social Worker in Palliative Medicine

Ruth Powazki, Mellar Davis, Declan Walsh

Cleveland Clinic, Palliative Medicine, Cleveland, United States

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

---

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

Arna Hauksdottir[1], Gunnar Steineck[2], Carl Johan Fürst[3], Unnur Valdimarsdottir[4]

[1] *Karolinska Institutet, Department of Oncology, Stockholm, Sweden*
[2] *Karolinska Institutet, Department of Oncology, Stockholm, Sweden*
[3] *Stockholms Sjukhem Foundation, Stockholm, Sweden*
[4] *Karolinska Institutet, Department of Oncology, Stockholm, Sweden*

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

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

Hugues Cormier [1], David Oliviere [2]

[1] *University of Montreal, Montreal, Canada*
[2] *St Christopher's Hospice, London, United Kingdom*

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

---

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

Serge Dumont [1], Konrad Fassbender [2], Philip Jacobs [2], Patrick Villeneuve [1], Donna Anderson [1]

[1] *Laval University, School of Social Work, Quebec City, Canada*
[2] *University of Alberta, Palliative Medicine, Edmonton, Canada*
[3] *University of Alberta, Public Health Sciences, Edmonton, Canada*
[4] *Laval University, School of Social Work, Quebec City, Canada*
[5] *Laval University, School of Social Work, Quebec City, Canada*

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

---

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

Agnes Suc [1], Michel Vignes [2], Isabelle Blandin [1], Veronique Lutgen [1], Jean-Philippe Raynaud [2]

[1] *University Hospital of Toulouse, Pain and Palliative Care Unit, Toulouse, France*
[2] *University Hospital of Toulouse, Child and adolescent psychiatry, Toulouse, France*

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

---

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

Laetitia Veerbeek [1], Lia Van Zuylen [2], Siebe Swart [3], Paul Van der Maas [1], Agnes Van der Heide [1]

[1] *Erasmus MC University Medical Center, Dept. of Public Health, rotterdam, Netherlands*
[2] *Erasmus MC University Medical Center, Department of Medical Oncology, rotterdam, Netherlands*
[3] *Nursing Home Antonius IJsselmonde, Rotterdam, Netherlands*

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

---

37. Defining Unbearable Suffering

Jaap Gootjes [1], Wouter Zuurmond [1, 2], Corry Van Tol [1], Roberto Perez [2]

[1] *Hospice Kuria, Amsterdam, Netherlands*
[2] *VU University Medical Center, Amsterdam, Netherlands*

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

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

Richard Harding [1], Barbara Panatovic [2], Godfrey Agupio [3], Claire Gillespie [2], Thandi Mashao [6], Keletso Mmoledi [4], Patricia Ndlovu [5], Natalya Dinat [4], Liz Gwyther [6], Lydia Mpanga-Sebuyira [3]

[1] *King's College London, Department of Palliative care, Policy and Rehabilitation, London, United Kingdom*
[2] *South Coast Hospice, Durban, South Africa*
[3] *Hospice Africa Uganda, Kampala, Uganda*
[4] *Witwatersand Palliative Care, Johannesburg, South Africa*
[5] *Philanjalo Hospice, Tugela Ferry, South Africa*
[6] *Hospice Palliative Care Association of South Africa, Cape Town, South Africa*

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

---

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

Lia Van Zuylen [1], Hetty Van Veluw [1], Marjolein Bannink [2], Paul Lieverse [3], Walter Taal [4], Carin Van der Rijt [1]

[1] *Erasmus MC - Daniel den Hoed, Medical Oncology, rotterdam, Netherlands*
[2] *Erasmus MC - Daniel den Hoed, Psychiatry, rotterdam, Netherlands*
[3] *Erasmus MC - Daniel den Hoed, Anaesthesiology, rotterdam, Netherlands*
[4] *Erasmus MC - Daniel den Hoed, Neurology, rotterdam, Netherlands*

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

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

Jean-Philippe DURAND [1], Georges CZAPIUK [2], Sylvain POURCHET [2], François GOLDWASSER [1]

[1] *Cochin University Hospital, Medical Oncology, Paris, France*
[2] *Paul Brousse Hospital, Palliative Care, Villejuif, France*

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

---

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

Julia Downing [1], Richard Harding [2], Richard Powell [1], Carla Alexandra [3], Sue Cameron [1], Stephen Connor [3], Kath Defilippi [1], Eunice Garanganga [1], Ekiria Kikule [1], Faith Mwangi-Powell [1]

[1] *African Palliative Care Association, Kampala, Uganda*
[2] *King's College London, London, United Kingdom*
[3]*NHPCO, Washington, United States*

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

---

42. See page 67

---

43. See page 69

---

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

Stein Kaasa

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

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

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

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

---

45. Hydration attitudes and practice: The nursing perspective.

Esther Schmidlin

Fondation Rive-Neuve, Soins Palliatifs, Villeneuve (VD)-Suisse, Switzerland

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

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

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

---

46. Hydration attitudes and practice Ethical decision-making

Friedemann Nauck [1], Birgit Jaspers [2], Lukas Radbruch [3]

[1] *University Hospital Goettingen, Department of Palliative Medicine, Goettingen, Germany*
[2] *University of Bonn, Department of Palliative Medicine, Bonn, Germany*
[3] *RWTH Aachen University, Department of Palliative Medicine, Aachen, Germany*

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

---

47. When Is It Time To Stop - Cultural Perspectives

Eduardo Bruera

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

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

---

48. Stopping hydration a step towards euthanasia

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

[1] *VU University Medical Center, Department of Public and Occupational Health, EMGO Institute, Amsterdam, Netherlands*
[2] *Erasmus MC, Institute of Public Health, Rotterdam, Netherlands*

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

---

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

David Oliviere

St Christopher's Hospice, Education, London, United Kingdom

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

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

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

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

---

50. Palliative care in a multi cultural society

Nathan Cherny

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

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

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

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

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

---

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

Manuela Ciucurel[1], Carmen Teodor[2]

[1] *University of Pitesti, Psychology, Pitesti, Romania*
[2]*St. Andrei Center Pitesti, Children in distress, Pitesti, Romania*

Aim of study
The aim of this study is to identify the job stress implied in palliative care for children and his relation with job satisfaction of professionals.
Method
We realized a corelational study on professionals group of 30 women, who are working in palliative care units for children. For job satisfaction evaluation we used an “SP Questionnaire” with 4 factors: remuneration and promotion, leadership and relationships.
Results
Death and dying represent a major source of job stress among professionals because the patients are children and the professionals has formed a close relationship with them. Other stress sources are: several deaths of children occurring in a short time, resource limitations, difficulties in relationships with other professionals, a lack of understanding of roles, difficulties in building a culture of palliative care despite. Concerning the job satisfaction, the professionals have a significantly lower level of job satisfaction (62%) or a medium level (38%) which are correlated with a higher level of job stress.
Conclusions
The professionals must benefit from more effective training in communication skills, including helping patients through controlling symptoms and having good relationships with patients, relatives and other professionals.

---

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

Maria Wasner, Britta Dierks, Gian Borasio

Interdisciplinary Center for Palliative Medicine, Munich University Hospital, Munich, Germany

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

---

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

Jon Håvard Loge

Ullevål University Hospital, Department of Cancer Research & molecular Medicine, Faculty of Medicine, Oslo, Norway, Norway

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

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

---

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

Irene Higginson

King’s College London, London, United Kingdom

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

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

References

1. Fisch MJ. Depression/anxiety. In: Bruera E, Higginson IJ, Ripamonti C, von Gunten C (Eds). Textbook of Palliative Medicine. London: Edward Arnold (Publishers) Ltd. 2006, pp675-687 2. National Institutes of Health State-of-the-Science Panel. National Institutes of Health State-of-the-Science conference statement: symptom management in cancer: pain, depression, and fatigue, July 15-17 2002. Journal of the National Cancer Institute Monographs 2004;**32**:9-16
3. Ly KL, Chidgey J, Addington-Hall J, Hotopf M. Depression in palliative care: a systematic review. Part 2. Treatment. Palliative Medicine. 2002;**16**:279-284
4. Bains J, Birks JS, Dening TD. Antidepressants for treating depression in dementia. The Cochrane Database of Systematic Reviews. 2007, Issue 1

---

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

Tariq Saleem[1], Nigel Leigh[2], Irene Higginson[3]

[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*
[3]*King’s College London, Department of Palliative care, Policy and Rehabilitation, London, United Kingdom*

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

---

57. Successful fundraising for palliative care

David Burland, Neelam Makhijani

Help the Hospices, National Centre, London, United Kingdom

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

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

There will be an opportunity to question a leading fundraising consultant,on what gaps often exist in proposals.
Aim - To generate creative thinking and new perspectives regarding fundraising proposals, both large and small
Learning Objectives By the end of the workshop, participants will be able to address the common problems that proposals have and funders ask; using a proven logical format for presenting an informal proposal and produce an appropriate balance between emotional and rational arguments in a proposal

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

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

Dilara Khoshknabi[1], Mellar Davis[1], Vlodek Siemionow[2], Declan Walsh[1], Vinoth Ranganathan[3], Guang Yue[2]

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

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

Alexander De Graeff[1], Saskia Teunissen[1], Wendy Wesker[1], Hanneke De Haes[2], Emile Voest[1]

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

60. Dyspnea in palliative care a multidimensional experience

Ingela Henoch[1], Bengt Bergman[2], 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-tumour treatment was finished, 105 patients with lung cancer completed questionnaires concerning aspects of dyspnea i.e. intensity, frequency, discomfort, qualities, including three dimensions of dyspnea; activity-related dyspnea; other symptoms and coping capacity. Performance status was also obtained.
Results: Above 50% of the patients perceived dyspnea. Only 3% perceived dyspnea intensity above 70 on VAS scale, but 23% perceived dyspnea discomfort above 70 on VAS. Correlations between intensity and frequency were 0.68; between frequency and dyspnea qualities 0.30; between intensity, qualities and activity-related dyspnea ranging from 0.48 to 0.56. Different aspects of dyspnea correlated with other symptoms, performance status and negatively with coping capacity. Dyspnea qualities and activity-related dyspnea were related to psychological distress; and intensity and activity-related dyspnea to performance status. Lower coping capacity and higher levels of anxiety explained 22% (R2) of variation in total dyspnea quality.
Conclusions: Dyspnea is a multidimensional experience, with relations between different aspects of dyspnea and physical and emotional measures, which indicate that there are both sensory and affective components in the dyspnea experience which needs to be acknowledged by healthcare professionals in palliative care.

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

Carol Tishelman[1, 2], Eva Doukkali[1, 2], Kristina Bertilsson[2], Mirjam Sprangers[3]

[1] *Karolinska Institutet, Department of neurobiology, care sciences and society, Stockholm, Sweden*
[2] *Stockholms Sjukhem Foundation, Research and development, Stockholm, Sweden*
[3] *Academic Medical Center, University of Amsterdam, Department of Medical Psychology, Amsterdam, Netherlands*

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

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

Sarah Wells

Marie Curie Hospice, Solihull, Solihull, United Kingdom

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

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

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

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

Joanne Droney[1], Sophy Gretton[1], Joy Ross[2], Ken Welch[2], Julia Riley[1]

[1] *Royal Marsden Hospital, Palliative Medicine, London, United Kingdom*
[2] *Imperial College London, Genetics, London, United Kingdom*

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

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

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

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

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

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

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

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

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

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

Gillian Chowns

University of Southampton, Social Work Department, Southampton, United Kingdom

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

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

---

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

Susanne De Kort[1], Dick Willems[2]

[1] *Academic Medical Center, University of Amsterdam, General Practice, Amsterdam, Netherlands*
[2] *Academic Medical Center, University of Amsterdam, General Practice, Amsterdam, Netherlands*

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

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

---

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

Ralf Jox, Sigrid Haarmann-Doetkotte, Maria Wasner, Gian Domenico Borasio

University of Munich, Interdisciplinary Center for Palliative Medicine, Munich, Germany

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

---

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

Sophie Pautex[1], Monia Ghedira[1], Valentina Toni[1], Huguette Guisado[1], Laurence Deramé[1], François Herrmann[3], Gilbert Zulian[2]

[1] *EMASP, CESCO, Rehabilitation and Geriatrics, Collonge-Bellerive, Switzerland*
[2] *CESCO, Rehabilitation and Geriatrics, Collonge-Bellerive, Switzerland*
[3] *Hôpital des 3 Chne, Rehabilitation and Geriatrics, Thonex, Switzerland*

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

---

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

Dick Willems

Academic Medical Center, University of Amsterdam, Department of Family Medicine, Amsterdam, Netherlands

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

---

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

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

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

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

---

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

Philip Larkin

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

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

---

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

Mark Boughey

Territory Palliative Care, Royal Darwin Hospital, Darwin, Australia

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

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

---

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

Barbara Gomes, Marjolein Gysels, Irene Higginson

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

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

---

74. The Battle for Palliative Care during Wartime

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

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

---

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

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

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

---

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

David Clark

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

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

---

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

Sabine Pleschberger[1]

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

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

---

78. Opioids - how to rotate

Per Sjögren[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 dosing a more liberal use has resulted in clinical reports of very high opioid doses causing new forms of side effects, the so-called opioid induced neurotoxicity. Oral morphine is widely used and remains the opioid of choice for its familiarity, availability and costs. For that reason most opioid rotation studies go from morphine to alternative opioids. In these cases clinicians should be skilled in using alternative opioids. According to available data, opioid rotation will result in clinical improvement at least in more than 50% of patients with chronic pain presenting a poor response to one opioid. Despite the favourable effects reported with opioid rotation, data are are mainly based on open studies, most of them retrospective or small case series. Unfortunately, in the setting of uncontrolled pain in the presence of side effects it is difficult if not impossible to conduct randomized controlled studies. Opioid rotation is becoming a popular approach, although data on the use of this practice are poor and difficult to determine. Having these circumstances in mind we will also address the pharmacology of opioids, which is mandatory to understand and practice opioid rotation.
Reference: Mercadante S and Bruera E. Opioid switching: A systematic and critical review. Cancer Treat Rev 2006; 32: 304-315.

---

79. Emergencies in Palliative Care

Friedemann Nauck[1], Stefan John[2], Eberhardt Klaschik[3]

[1] *University Hospital Goettingen, Department of Palliative Medicine, Goettingen, Germany*
[2] *University Hospital Goettingen, Department of Palliative Medicine, Göttingen, Germany*
[3] *University of Bonn, Department of Peadiatric Oncology, Bonn, 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 obstructions, massive haemorrhage, and other syndromes due to advanced malignancy.
Results: We surveyed and assessed the quality of physician-delivered care in inpatient hospices in the state of North Rhine Westphalia. About 9% of the physicians felt to have deficits in dealing with ES. 58 of the surveyed physicians (45%) reported to be annually involved in 1-3 ES; 6% in more than 10. 37% of the ES were related to malignant disease, 26% to side effects of drug treatment and 11% were unrelated to the underlying advanced disease. 86% of the physicians reported to have clear standards for ES in their hospices.
Conclusion: The term "emergency" applies to acute and fearsome, possibly life-threatening situations. However, there is no international consensus on a definition of ES in palliative care. Some principles, however, for the management of ES are widely accepted and include respect for the patient's wishes and early documentation of wishes for probable ES. In many cancer patients, these can be anticipated, and patients, carers and professionals can plan ahead to minimise distress. Clinical scenarios will be addressed in this session.

---

80. The role of religion in palliative care

Michael Wright

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

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