

Oral abstracts

Saturday 9 June

CONNECTING DIVERSITY

10th Congress of the
European Association for Palliative Care

qualitative data.

Results: The majority of the children benefited from the project. All parents and children rated the project as helpful.

Conclusion: Although these are preliminary results, quantitative and qualitative data indicate beneficial effects of the intervention for healthy siblings. As such the project will be implemented as continually offered support.

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

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

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

Alison Rodriguez, Nigel King

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Aim: This paper reports a study that highlights the mental health implications of the lived experiences of parents of children with life-limiting conditions

Background: As medical technology has improved; there has been a marked increase in the numbers of children with life-limiting conditions being managed in the community. Few studies have evaluated the life worlds of the parents of these children; however there have been studies that have reported feelings of isolation and depression amongst mothers.

Method: Semi structured interviews were conducted with ten parents of children with life-limiting conditions and analysed using a phenomenological method.

Findings: The essential meaning of the phenomenon: "the lived experience of parenting a child with a life limiting condition", is understood as a fulltime emotional struggle involving six continuous constituents: inner drive, feeling responsible, psychological affects, threatened self image, social withdrawal, and fear of reaching the bottom line.

Conclusions: Very little attention is focused upon the wider issues that affect parents dealing with caring for a child with a life-limiting condition, not implementing sufficient services on a medical, psychological and social count for children with life-limiting conditions and their families may eventually lead to increased spending through adult mental health services having to pick up the pieces.

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

Matthias Schell¹, Maité Castaing¹, Didier Frappaz¹, Thierry Philip¹, Yves Devaux²

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

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

Methods: We sent an anonymous questionnaires to 33 parents of children deceased of cancer.

Results: 20 parents responded. 10 parents whose child

died at home had no regret for their decision. All 10 benefited from a formal meeting set up by our hospital-team with the family physician and local home care providers and at least one visit at the child's home. 10 parents requested hospitalisation prior to their child's death. Two parents felt sorrow regarding rehospitalisation. Interestingly, for none of them we met their family physician or local home care providers and we didn't organize any visit at the child's home. Local home care providers who met with our hospital-based palliative care team had a more favourable parental view regarding their competence, quality of care, availability, as well as to show humanity. End of life symptoms with the highest impact on parents were their child's fatigue and pain. Parents cited helplessness, despair and loneliness as the most frequent feelings encountered while taking care of their child.

Conclusion: To our knowledge, this is the most important study conducted in France on parental feedback after hospice care of their child. The degree of commitment from the primary hospital-based team seems to be critical in paediatric hospice care.

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

Tamara Vesel

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

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

151. Quality of life - a valuable concept?

Raymond Voltz

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

152. Nutrition - Meet the expert - morning session

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

Practice aids: Practical assessment instruments (including secondary causes, psychosocial distress) and intervention packages can assist teams to face these everyday challenges, and "to respectfully dance between nihilism and overactivity".

153. Constipation - European guidelines.

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

ST CHRISTOPHER HOSPICE, London, United Kingdom

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

154. Adult Education

Ruthmarijke Smeding^{1,2}, John Ellershaw²

¹ PallEd, Würzburg, Germany

² Marie Curie Palliative Care Institute Liverpool, Liverpool, United Kingdom

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

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

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

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

David Oliviere¹, Sheila Payne²

¹ St Christopher's Hospice, Education and Training, London, United Kingdom

² Lancaster University, International Observatory on End of Life Care, Lancaster, United Kingdom

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

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

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

156. Meet the Expert - Volunteers

Anne Merriman¹, Barbara Monroe²

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² St Christopher's Hospice, Cancer department, London, United Kingdom

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

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

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

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

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159. Managing the Patient with Pain and Delirium

Eduardo Bruera

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

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

Pam Firth

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

Much has been written about the difficulties of treating and managing the effects of delirium in advanced cancer and it is described as a common problem in the terminal stage of the disease. The effect of the range of symptoms of severe confusion in a loved one is particularly disturbing and frightening for the family. Family members require sensitive and skilled responses from the multi professional team. **Discussion** The author will consider the reactions and difficulties delirium in patients cause for the family and the staff treating them. The needs of family members to feel

close and recognised as an important person in the life of the terminally ill patient can be frustrated if the patient fails to recognise them and the family and patient have no opportunity to have satisfactory communication. There is anecdotal evidence from family and carers that they need to be prepared when patients are sedated as an attempt to manage the symptoms. Furthermore the patient and family may have failed to make arrangements if the patient becomes incompetent to make decisions which add to the distress. Staff too may feel that they have let the family down. The pressure for all concerned can be stressful. Good support, clinical supervision, discussion amongst team members and sensitive communication with the family can all help.

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

Marianne Hjerstad^{1,2}

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² Norwegian University of Science and Technology Trondheim, Faculty of Medicine, Trondheim, Norway

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

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

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

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

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

162. Definition and principles of palliative sedation therapy

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² Western Memorial Regional Hospital, Palliative Care Department, Corner Brook, Canada

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

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

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

designated surrogate decision maker and/or family. The whole process should be carefully documented.

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

163. Palliative sedation: Pharmacology - evidence and practice

Staffan Lundström

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

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

164. Ethical Considerations

Lars Materstvedt

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

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

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

Philip Larkin, Martine De Vlieger, Françoise Porchet, Corry Van Tol, Avril Jackson, Marielene Filbet

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

The EAPC guidelines on palliative nursing education were published by the EAPC in 2004. This presentation will provide an overview of the key recommendations of the project in relation to the acquisition of knowledge, skills and attitudes for best nursing practice. The presentation will largely focus on a strategic development arising from the nurse guidelines, namely a new EAPC taskforce looking at clinical practice opportunities across Europe. The basis for the STAGE project will be described in terms of increased opportunity for sharing knowledge and skills across Europe and setting nursing practice within a broader multidisciplinary paradigm. Proposals for the

dissemination of the STAGE project will be described and timelines and evaluation strategies presented.

166. Palliative care education and accreditation

David Clark

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

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

167. Suggestions in the communication with cancer patients

Éva Bányai

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

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

Elisabeth Andritsch, Silke Zloklikovits, Verena Ladinek, Hellmut Samonigg

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

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

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

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

169. Communication skills - a core competence in Palliative care

Luzia Travado

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

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

170. A LOVE AFFAIR AS PALLIATIVUM?

Hans-Christof Müller-Busch¹, Matthias Richard Kraska²

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² Witten/Herdecke University, Medical, Witten, Germany

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

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

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

the term into medicine.

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

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

Petra Plunger, Claudia Wenzel

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

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

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

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

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

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

Charlotte Wilson¹, Dai Roberts¹, Ann Cares², Andrew Long⁴, Chris Todd², Peter Mackereth³, Jackie Stringer³, Sam Parkin⁵, Ann Carter¹, Alison Christine McNulty Delgado²

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

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

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

Hans Wildiers¹, Chris D'haenekind², Paul Clement¹, Marc Desmet³, Peter Demeulenaere⁴, Rita Vannuffelen¹, Erna Van Droogenbroeck⁵, Karin Schotte⁶, Filip Geurs⁷, Johan Menten¹

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

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

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

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

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

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

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

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Background: Understanding a work group's culture can facilitate the change process. In this study the relations on organization level were subject to investigation.

Methods: Health care personnel (N=25) at the Palliative Medicine Unit (PMU) answered a questionnaire. The respondent groups consisted of physicians, nurses, physiotherapists and others. Systematizing Person-Group Relations method was used for gathering data and their analysis. The respondents were asked about different statements according to the tree different conditions: *today*, *future* and *desired*. The respondent's statements in the condition *today* and *future* were nearly equal while their statements in the *desired* condition had largest difference.

Results: This study found that the passivity of the respondents can be a severe barrier to changes in a PMU. The difference between the *today* and *desired* condition shows that the respondents are not satisfied with the current situation.

Conclusion: The passive attitude found in this study can also be characterized as a passive resistance that has led to a resignation in their belief in their own influence on the future. This resignation may also have been influenced by the work situation of the respondents with close relation to patients with short expected time to live. Implications are discussed.

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

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Aim

The EAPC guidelines for treatment of cancer pain recommend a double dose (DD) IR morphine at bedtime instead of 4-hourly single doses nightly (SD). A previous open controlled study reported more side-effects after DD than after SD (Todd et al. *Palliat.Med.* 2002). To increase the bulk of evidence a similar, but double-blind study was conducted.

Methods

This was a randomized, double-blind crossover study comparison of DD and SD of IR-morphine during night. The primary outcome this was average pain intensity during night (11-point NRS scale), secondary outcomes were morning pain, number of rescue medications and adverse effects (nausea, xerostomia, tiredness, sleep quality and number of awaking episodes) and patient preference.

Results

Nineteen patients completed the study. A lower average pain during night for DD versus was close to statistical significance (mean 0.8 and 1.4, respectively, p=0.058). The mean (95% CI) for the difference between the two groups was 0.50 (-0.02; 1.0). A similar trend was observed for strongest night pain (p=0.069) and sleep quality (p=0.077). Only two patients required rescue morphine. Four patients had no treatment preference; nine and six favoured DD and SD, respectively.

Conclusion

The observations of Todd et al were not confirmed. Although apparently DD performed slightly better than SD, the two procedures are clinically equivalent, allowing for individual choice of SD or DD among patients

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

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PURPOSE

This population-based study examined the proportion of hospital deaths in six European countries (Belgium, The Netherlands, Sweden, Scotland, England, Wales), and associated factors.

METHODS

Data of all deaths in 2003 of the studied countries (2002 in Sweden) were gathered via official death certificate data, linkage with other population data files, and linkage with regional healthcare statistics, and were integrated into one common database (N=891,780) for analyses.

RESULTS

Of all deaths, 33.9% in The Netherlands to 62.8% in Wales occurred in hospital. Associations of hospital death with other factors, in particular age and type of terminal illness, differed per country. Older age was less in Sweden, Scotland, England, and Wales, than in Flanders and in The Netherlands associated with dying outside hospital. Cancer was especially in The Netherlands, and England, but not in Sweden associated with dying outside hospital. Especially availability of care home beds partly explained country differences in hospital death rate, but relatively large differences maintained.

CONCLUSION

Country differences in proportion of patients dying in hospital are only in part accounted for by differences in health care provision, and were in particular large for certain patient populations, suggesting country-specific end-of-life practices in these populations. Our findings can contribute to a rational policy aimed at reducing hospital death rates for specific patient populations.

177. Description of a new integrated palliative care model

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Background: Palliative care needs to develop and evaluate new models for implementation of care. The integrated palliative care model, which includes formal cooperation between a special Palliative Medicine Unit (PMU), St. Olavs University Hospital and a Palliative Care Unit (PCU), Havstein nursing home, was established in Trondheim, Norway in 1998.

Objective: To describe the integrated palliative care model, the characteristics of its development and to compare patients between the sites.

Methods and material: Patients who were admitted to and died in the PCU (n=85) and in the PMU (n=188) 1 January 2002 to 31 December 2003 were consecutively included.

Results: Patients who died in the PCU were significant older (76 vs. 67 years, p<0.001). The majority of the entire cohort had gastrointestinal cancer, 45% PCU, and 35% PMU. There were significant differences between units, assessed during the last week of patients life, in use of indwelling bladder catheter (31% PCU, 60% PMU), oxygen treatment (24% PCU, 50% PMU), intravenous treatment (46%PCU, 76% PMU) (p<0.001) and central venous catheter (2% PCU, 12%PMU) (p=0.07). PCU had a median survival of 30 days (95% CI 15.95-44.05) versus to 11 days (95% CI 9.01-12.99) in the PMU (p<0.001)

Conclusion: The study is the first description of an integrated palliative care model in Trondheim, Norway. There were significant differences, with regard to medical interventions, which may be explained by patient selection and/or medical preferences guided by site.

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

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Aims: estimating the distribution of places of care for Italian cancer patients in their last three months of life, the proportion who received palliative care (PC) at home and in hospital, and the determinants of referral. **Methods:** this is a mortality follow-back survey of 2,000 cancer deaths identified with a 2-stage probability sample, representative of the whole country.

Information on patients experience was gathered, after the patient's death, from the non-professional caregiver with a semi-structured interview. Multivariate logistic analyses were conducted to identify the determinants of PC referral.

Results: valid interviews were obtained for 67% of the caregivers (n=1271). Most Italian cancer patients were cared at home (91%) or in hospital (63%), but with wide differences within the country. A PC support was provided for 14% patients at home (2% in the South and 18% in the North) and for 20% hospitalized patients (16% in the South and 25% in the North). Significant determinants of referral were: a long interval between diagnosis and death (P=0.01) and the caregivers high educational level (P=0.01) for cancer patients at home; the low patients age (P<0.01) and the caregivers high educational level (P=0.01) for cancer patients in hospital.

Conclusions: in Italy the provision of PC services are unequally distributed across the country and their access is strongly associated with socio demographic characteristics of the patients and their caregivers.

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

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

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

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Aim

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

Methods

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

Results

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

Conclusions

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

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

David Oliviere

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Europe is increasingly diverse in the communities and patient population it serves. This presentation aims to identify a number of challenges that exist in understanding the nature of "cultural pain" (Oliviere, 2004) and facets of culture and ethnicity at the interface with palliative care services, policies and practice. Areas that will be specifically presented will include how advanced illness, death and bereavement impacts on

human cultural experience and vice versa; how the absence of safe cultural practice or cultural insensitivity can leave patient need unmet; and identify areas of commonality and difference in delivering culturally appropriate palliative care. Managing diversity in its connection with other core aspects will be a constant theme.

Method: This paper will draw on the authors review of key literature on culture, the findings of a series of conferences at the Education Centre, St Christophers Hospice, based on diversity and access, and his own training of health professionals in best practice. It includes the changing perceptions and ethical complexities in determining the nature of cultural pain. **Result and Conclusion:** The paper will make suggestions for practice in what health professionals can do to meet cultural needs more accurately, cultural competence and guidance in safe cultural practice. Case scenarios will reinforce best practice points.

182. AIDS challenges for palliative care in Uganda

Anne Merriman

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

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

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

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

Ovidiu Popa Velea

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

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

184. AIDS and Palliative Care in France: new challenges

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Epidemiology

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

The number of cancers is also increasing due to the immunodysfunction and the prolongation of life in HIV patients (lymphoma; cervical carcinoma; Hodgkin disease)

Training

Three European Conferences on AIDS and PC were organized in France in the 90s at the peak of the epidemic (91;92 and 96) while PC were implanted in AIDS Units.

Moreover, AIDS is one topic of many University Diploma on PC in France.

Organization of Care

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

Research on management of specific symptoms

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

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

185. The Song Rooms

Lucinda Jarrett Jarrett

Rosetta Life, Health and Wellbeing, London, United Kingdom

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

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

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

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

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

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

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

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

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

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

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

188. Distress or just a symptom?

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

189. An integrated care pathway - overview

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

1. Select the area of practice.
2. Build the multidisciplinary work-team.
3. Define the diagnosis.
4. Define the patients.

5. Review practice and literature.
6. Develop the clinical path.
7. Pilot and implement the clinical pathway.
8. On going evaluation.
9. Implementation.

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

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

John Ellershaw

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

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

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

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

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Background: Main difficulties of the implementation of palliative care (PC) into Slovene health care system are lack of common vision, little education on PC, ineffective teamwork, lack of organizational solutions for continuity of care across all settings, and others. Liverpool care pathway (LCP) might be a tool to improve this situation. National steering committee decided to start the pilot project in three clinical settings.

Methods: After contacts with LCP authors, translation, development of educational curriculum, identification of local steering committees, and co-ordinators the implementation of LCP in three hospitals started. Process of this implementation is carefully followed up in order to quickly identify the obstacles and find effective solutions.

Results: Some significant findings are described: the national consensus, which is of paramount importance, was easily achieved; on the local level the implementation was much harder discussed; the authorship over the clinical pathway and meticulous attempts to adapt the LCP to each institution were the most obvious features in our findings. Development of common vision, education and involvement of all the staff is sometimes hard to establish. Some solutions to these problems were found and will be presented.

Conclusions: Through this type of implementation process we learned several weaknesses of co-operation and decision-making in our health care system and found some applicable solutions.

193. PALLIATIVE CARE IN GEORGIA

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

194. My own Palliative Care Service

Furio Zucco

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The Palliative Care Unit (UCP) of the "G. Salvini Hospital Trustee" in Milan (Italy), completely managed with public funds, since 2003 provides: **1. Home palliative care**, in home hospitalisation model; **2006: 463** patients assisted; mean period of assistance: 28 days). **2. 10 beds in-patients hospice** (additional 5 beds in 2007); **2006: 216** patients assisted, mean duration of hospitalization: 15 days). **3) day hospice**; 2006: 452 services; **4) out-patients ward**; 2006: 9722 services. **5) in-hospital consultancy**; 2006: 3125 services. The UCP is part of the Anaesthesia and Intensive Care Department, with an autonomous budget, management and personnel. The 2005 budget was **3.043.673,00** supplied by the Regional Health Service: the service is totally free for patients and their families. The UCP full-time staff: 1 Director (doctor), 11 doctors, 1 head-nurse, 23 nurses, 10 health and social service operators, 1 physiotherapist, 2 administrative

employees. Moreover the Hospital supplies as part-time specialized personnel: a) psychological support, b) social assistant, c) religious support (volunteer). Volunteers, belonging to 2 non-profit organizations, members of the Palliative Care Italian Federation (), work both in the hospice and at home. 80% of the personnel is member of the Italian Society for Palliative Care (). The UCP takes part in the national and regional project of the Hospital Without Pain (OSD). The Director coordinates the local Committee for OSD.

195. The regional palliative care program of Extremadura

Javier Rocafort

Regional Palliative Care Program of Extremadura, Mérida, Spain

More than a single service, the Regional Palliative Care Program (RPCP) of Extremadura (Spain) is a network of services and strategies oriented to guarantee palliative care provision to everyone in need. In 2002, a RPCP was built by the government. It is entirely funded by the public insurance system, and patients have not to pay for any service. The annual cost of the program is around 3 million € (equivalent to 3 € per inhabitant per year).

Structure and funding: Primary care provide basic palliative care, and 8 specialized palliative care teams (PCTs), one per health district, take part in complex situations in hospital or in the community. They are mobile and staffed by doctors, nurses and psychologists. Each team offers comprehensive coverage within their corresponding health district. Moreover, all 41 professionals from the PCTs are involved in 4 working groups (evidence, quality, education and tools). In addition, there is a central office where the regional manager of the program, the regional observatory, the research office (two full time researchers) and the voluntary coordinator are located.

Process and activities: During 2006, in Extremadura (1,086,373 inhabitants), 1,687 terminally ill patients were seen by PCTs. 89% of them had a cancer diagnosis. The average survival time in palliative care program was 37.3 days. In the total year, PCTs did 6372 hospital visits; 2100 outpatient clinics; 4039 home visits; 27340 advice or coordination activities; 450 teaching sessions; and 632 meetings. Four of these teams have some beds available in acute hospitals. Last year, 304 patients were treated there, with a median stay of 8.9 days. Moreover, from 2005, there are 30 beds available in medium-term care centres and 50 beds available in long-term care centres.

Opioid consumption: In the year 2005, 494,654 Defined Daily Doses of opioids were prescribed by the Public Health System in Extremadura (equivalent to 49,63 kg of oral morphine per million inhabitants).

Quality control: Quality indicators were chosen by the quality group and the regional coordinator from the criteria of Spanish Palliative Care Association (SECPAL). Last year, the group identified and measured 28 of these indicators in every PCT.

Conclusion: The RPCP care of Extremadura offers a model that is integrated into the Public Health Care system and is able to offer comprehensive coverage, availability, equity and networking.

196. My own palliative care service

Simkó Csaba

Semmelweis Hospital, Elizabeth Hospice, Miskolc, Hungary

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

197. Competencies in Palliative Care

Jose Pereira

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

complete the tasks required in a specific clinical role and these include combinations of knowledge, attitudes, and skills.

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

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

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

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

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

Steffen Eychmueller

Palliative Care Service, St.Gallen, Switzerland

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

200. TWIST IN THE EVALUATION OF THE TERMINAL PATIENT

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Objective: show if the admission time in a Palliative Care Unit, affects the QoL of the patient, through an easily applicable parameter as the TWIST (Time Without Symptoms of Disease and Toxicity). **Methodology:** from 63 patient, were selected 37 who fulfil the conditions of having died in this unit after a stay of more than 3 weeks, with an average stay of 5.7 weeks. The study was done using, on the one hand, the independent variable is weekly admission period; differentiated in three stages: first week, last week and the period between those weeks averaged out to seven days, and on the other hand, the depended variable is number of days in which the patients had felt discomfort/comfort (TWIST), on those stages (rank 0-7). For doing the statistical analysis, the non parametrical Friedman test. **Results:** percentile was found that us much us 40% of patients, had discomfort during the two first admits days lowering until 13% during hospitalisation period, and raising until 50% before to they died. The Friedman test of the three admission periods, gave us a significant difference between them, with a X² value of 12.6 (p<0.001). Tabular value of 14.23 to check what admission period gave the signification. Only were found significant differences in the period between the first and the last stage period (p < 0.001). **Conclusions:** discomfort feeling in a U.C.P. is high in the first week, lowering during the hospitalitation and with an increasing before they died.

201. The Use of Drugs at the End of Life

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Aim

The project aimed to establish the usual prescribing intentions of healthcare professionals who work in Specialist Palliative Care (SPC) caring for patients in the last days of life.

Method

A questionnaire was distributed to senior medical and nursing staff in SPC across the Mersey and Cheshire Palliative Care Network. They were asked to state the drugs they would use to manage symptoms arising in the last days of life. They were asked to assume the patient was opioid naive and that each symptom arose in isolation.

Results 88 healthcare professionals returned questionnaires. 83% of the healthcare professionals would suggest morphine or diamorphine as the first line opioid in the last days of life subject to local availability. 89% suggest midazolam first line for the management of agitation and 61% suggest levomepromazine second line. 64% of healthcare professionals suggest hyoscine hydrobromide for the management of respiratory tract secretions. Cyclizine is the anti-emetic suggested by 37% and levomepromazine by 35%. Morphine is the most commonly suggested drug for the management of breathlessness.

Conclusion

The project has led to the development of guidelines for the management of symptoms in the last days of life. The guidelines aim to empower the general healthcare professional and provide an integrated approach across the Palliative Care Network.

202. PHYSICIANS PREFERENCE OF THROMBOPROPHYLAXIS IN PALLIATIVE CARE PATIENTS

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

Results:Prophylaxis was continued by almost all

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

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

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Aim This paper is the first to discuss ways of helping people with advanced cancer and their care givers manage eating related conflict.
Method The research was a mixed methods investigation of weight loss and eating difficulties in people with advanced cancer. The study participants included 32 patient-caregiver pairs receiving palliative home care in the South of England in either 2003 or 2005. Methods of data collection included semi-structured interviews that were analysed using both content and thematic approaches. An emergent theme was 'conflict'. **Findings** Conflict over food had arisen between 26 of the patient-caregiver pairs. Some patients had found ways of self-managing the conflict, revealing potential for a supportive intervention. The evidence of self-management was synthesized with the emerging literature on collective coping², generating a new perspective from which to approach the conflict problem. **Conclusions** Further work is needed to understand the process through which some patient-caregiver dyads effectively manage conflict over food. This understanding would provide an evidence base for building a complex intervention for the problem.

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

204. Categorising palliative care development: a global perspective

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

205. Opioid prescribing changing Romanian legislation

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

206. Creativity in Promoting Palliative Care Awareness

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

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

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Aim: To identify the barriers to optimal cancer pain management in Latin American institutions as reported by providers and to compare these findings across nations, practice-settings, and specialties.
Methods: A cross-sectional, convenience sample survey of 777 Latin American advanced-cancer care providers was conducted by MD Anderson's WHO Collaborating Center in Supportive Cancer Care. Surveys were collected through mass mailings, distribution at conferences, collaboration with Latin American institutions/organizations, and the Pan American Health

Organization, and online posting.
Results: Overall, the top 4 barriers were: inadequate staff knowledge of pain management (71%); patients' inability to pay for services/analgesics (54%); inadequate pain assessment (52%); and excessive state/legal regulations of prescribing opiates (47%). Stratified analyses revealed important differences. While 87% of Cubans identified "lack of access to a wide-range of analgesics" as a top barrier, only 49% of Mexicans and 38% of Peruvians did. Respondents from private institutions were more likely to identify "patients' inability to pay for services/analgesics" than others. Anesthesiologists were less likely to identify "inadequate assessment of pain" as an important barrier than other specialties.
Conclusion: Findings from this study will provide critical information needed for developing targeted programs and policies to improve palliative cancer care in Latin America.

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

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

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

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

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

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

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Aim Chronic Obstructive Pulmonary Disease (COPD) is a chronic condition characterised by a progressive loss of lung function and leads to a slow, steady decline with intermittent serious episodes. The aim of our study was to explore the end stage of COPD and to describe problems that patients encounter in their every day life. **Methods** We are conducting a prospective mixed-methods study of 90 end-stage COPD patients, including repeated interviews with a subsample of 20 patients.

Results Physical health changes dramatically from day to day, and even within a single day. Patients experience frequent attacks of breathlessness that are mostly unexpected. Although these patients have lived with their disease for many years, most cannot control or predict these sudden attacks. The unpredictability of the disease has an influence on various elements of every day life. Planning things becomes extremely difficult. Even within one day, patients have difficulties in planning their activities. Most patients are reluctant to show their breathlessness in public and some develop a fear of going outside.

Conclusion Patients with end-stage COPD are suffering from a disease which causes a slow deterioration of their general health. On top of this, patients are confronted with a diversity of symptoms that changes daily, like unpredictable attacks of breathlessness. These changes are important for caregivers in determining the appropriate care for these patients.

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

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Background: Many studies have identified unmet specialist palliative care needs of patients with advanced heart failure. Few have focused on patients receiving specialist multidisciplinary care at a heart failure unit (HFU).

Aim: To determine whether patients with advanced heart failure attending a specialist HFU have unmet specialist palliative care needs.

Methods: A prospective cross-sectional study, using quantitative and qualitative methods, of 50 patients consecutively sampled at a specialist HFU.

Results: Mean age(SD): 74.2 yrs(8.6), 76% male. Mean systolic ejection fraction: 27.7%(8.1). Mean ESAS symptom distress score: 33.1(13.2). HADS: mean anxiety score: 5.4(3.5), mean depression score 6.2(3.4). Mean SEIQoL score: 79.2(14.9). Mean Minnesota Living Living with Heart Failure Questionnaire score: 39.9(18.4). Most patients had good understanding of their diagnosis but many had unanswered questions regarding prognosis.

Conclusions: This cohort of heart failure patients had symptom burden equivalent to cancer patients accessing specialist palliative care services. Many had information needs. Communication barriers were identified. Emotional wellbeing was good and SEIQoL scores were higher than cancer patients accessing specialist palliative care services. Some but not all palliative care needs were met. Specialist palliative care and cardiology services should work in partnership to fully address the needs of heart failure patients.

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

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Aim: This study aims to understand families' perspectives on decision making about a loved one's care in an intensive care unit (ICU) and the emotional burden of those decisions. **Methods:** Semi-structured interviews were completed with 27 family members who participated in a decision making family meeting with the Palliative Care Consult Service (PCCS).

Interviews were taped, transcribed and content analyzed using methods from grounded theory. **Results:** Families described specific communication issues and compassionate gestures important to decision making and relief of emotional burden. Communication issues include: timing of the family meeting; listening to family members' understanding of the illness, prognosis, and patient's perspective; and acknowledgement of the patient's personhood. Compassionate gestures include attentiveness to the patient and family's comfort. **Conclusion:** The family meeting is experienced as one event in a series preceding the death. The family members' emotional response to the decisions made is further influenced by their experience of the dying process. The PCCS appears to help families make decisions by communicating their sensitivity to the family's perspective and concerns. Emotional burden is reduced when there is consistency between the decision making and the care provided during the dying process.

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

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

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

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

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

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

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This study examined the comparative incidence of burnout syndrome, risk behaviors and use of coping strategies of doctors working with incurable patients in several representative Romanian palliative services. 34 doctors, dealing with incurable adults, 32 dealing with incurable children and 36 controls were tested using COPE questionnaire, Maslach Burnout Inventory and an own questionnaire assessing risk behaviors, such as smoking, alcohol consumption and work overload. Doctors working with incurable cases had a much more substantial use of emotion-centered strategies, such as positive reinterpretation, mental and behavioral disengagement, focus on emotions, denial and religious coping ($p < 0.05$). Denial, mental disengagement and religious coping were especially prevalent in doctors dealing with children with incurable diseases, compared to other two groups ($p < 0.05$). Heavy smoking (over 15 cigarettes / day) was significantly higher in doctors dealing with incurable adults. The burnout score was higher in both groups of doctors dealing with incurable patients, compared to the control group. The results of this study show a high inefficiency of Romanian doctors from palliative services in dealing with daily professional stress. This suggest that supplementary actions (including psychotherapeutic assistance and active screening for burnout) are needed, in order to assure a better quality of life and work performance of these doctors.

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

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

216. See page 79

217. See page 81