Abstracts of the 4th Research Forum of the European Association for Palliative Care (EAPC)

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ABSTRACTS

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EAPC ABSTRACTS

Invited Lectures

Abstract number: 1
Presentation type: Invited Lecture
Session: Education – An Introduction to Grantsmanship: The art of preparing grants

How to set up a research group

Stein Kaasa, St. Olav's Hospital, Trondheim, Norway, **Ola Dale**, Department of Circulation and Medical Imaging, Trondheim, Norway

Palliative care is defined as an active, total care of patients. Comprehensive palliative care provides relief from pain and other distressing symptoms, integrates the psychological and spiritual care and offers a support system to help the family. In establishing a research group, one need to decide if one want to focus on one specific area of palliative care, or include several of the elements. The skills, knowledge and resources available 'on site' should guide the research strategy. Furthermore, it might be wise to adopt the palliative care research strategy to the overall strategy of the university and the hospital, and even consider national research strategies. In the period of establishment, one may also look for possible national and/or international collaboration, which may strengthen the team in the planning process of the research, in conducting and analysing research, as well as being a partner when applying for funding.

Abstract number: 2
Presentation type: Invited Lecture
Session: Education – Mixed methods approach

Service Evaluation

Chris Todd, University of Manchester, Manchester, U. Kingdom

Evaluation may be defined as the critical assessment of the degree to which entire services or their component parts fulfill stated goals. Donabedian [1] proposed evaluation in terms of structure, process and outcome of services. Such a model requires use of mixed research methods, to describe the structure and process and permit exploration of causality in outcome assessment. We will consider how to design service evaluations in palliative care and draw upon a number of our studies to exemplify how using a variety of research designs and methods is often necessary to conduct rigorous evaluation. Such designs and methods include randomized trials, quasi-experiments, psychometric assessment, in-depth interviews, behavioural observations, patient self report by patient held record, postal surveys, case reviews and case study. Strengths and weaknesses of the different approaches will be considered in relation to exemplar studies and delegates will work through an example.

Reference

1. Donabedian A. Evaluating the quality of medical care. Milbank Memorial Fund Quarterly 1966; 44: 166–206.

Abstract number: 3
Presentation type: Invited Lecture
Session: Education – Mixed methods approach

Participatory action research – palliative challenges and perspectives

Philip J Larkin, The National University of Ireland, Galway, Ireland

Participatory Action Research (P.A.R.) is defined as an approach which aims to take action and create knowledge or theory about that action (Coghlan & Casey 2000). The use of action research is increasingly visible as a method to work with and research within health services. There is also some evidence of its use in palliative care, particularly in quality measurement, audit and standard setting. Participatory Action Research raises some particular challenges, not least the criticism of its scientific merit as a methodology and navigating the phases of such projects within the confines of clinical strucutures. This Invited Educational Session will discuss the benefits and challenges of P.A.R. using examples from clinical research in both a general and palliative care context. Particular reference will be given to the concept of participation and what that means in terms of research. The potential burdens and specific insights will be discussed from the stance of external evaluator to an unsuccessful action research approach in palliative care setting.

Abstract number: 4
Presentation type: Invited Lecture
Session: Education – Mixed methods approach

Organisational case study methodology

Sheila Payne, University of Sheffield, Sheffield, Great Britain

Aims: To introduce the rationale and purpose of case study methods. To explain the different types of case study design. To describe indications for when this might be a suitable research design. To discuss two examples of research using organisational case study methodology. To highlight the strengths and weaknesses of this methodology When to use this method? Case study methodology has its origins in social anthropology and draws upon the principles of naturalistic inquiry. It has subsequently been developed in qualitative sociology and organisational psychology for the understanding and evaluation of complex systems. It is suitable for 'real world' investigations when it is difficult or impossible to control potentially confounding variables. It is also useful for evaluations when the research is focussed on processes and outcomes in dynamic situations and how these fit within their organisational, social and cultural contexts. How to use this method? Case studies may focus on single entities (organisations or groups) or on multiple cases. A number of sources of quantitative and qualitative data may be collected and analysed within the case and also across cases. Examples will be drawn from two major studies conducted in the UK of palliative care in community hospitals and in hospice based bereavement services. Advantages and Disadvantages Case study methodology offers the advantage of richly detailed nuanced analysis of a limited number of cases which takes account of multiple perspectives and contextual background. The method allows investigation of process and outcome factors. It has the disadvantage of limited generalisability and can not make claims of representativeness.

Abstract number: 5
Presentation type: Invited Lecture
Session: Education – Symptom measurement in advanced cancer: from methodology to clinical use

Quality of care in advanced cancer

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Among the most important elements of high quality cancer care are evidence-based standards of cancer care and delivery of treatment in the right way to a patient. Quality of cancer care could be measured based on two key indicators: survival and quality of life (QoL). The patient's care should focus on his/her QoL, as it is the major outcome of treatment in advanced cancer. Better symptom control can produce significant improvement in QoL. Effective control is possible, if symptoms are assessed with instruments which can adequately evaluate their prevalence and severity. Implementation of symptom assessment in routine cancer practice is the first step towards improving quality of care for advanced cancer patients. Many trials and clinical studies have been performed in different countries, making it critical to develop symptom measures in multiple languages, and to evaluate their equivalence. These measures can also improve the implementation of symptom control guidelines in many countries. Understanding of

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symptom interference with a patient's QoL provides the basis for better cancer outcome measurement. Although at present QoL is recognized as an important outcome in advanced cancer treatment and there is a common need for symptom control in cancer, clinicians rarely provide comprehensive QoL and symptom assessment. Improved education of care providers on symptom measurement and their interference with QoL is essential. In conclusion, patients with advanced cancer need comprehensive individualized care with detailed attention to symptom management. Availability of standardized assessment tools would overcome some of the barriers to adequate symptom assessment. Further international research is needed to study the symptom burden in patients with advanced cancer and to explore practical options to reduce their QoL impairment.

Abstract number: 6
Presentation type: Invited Lecture
Session: Education – Symptom measurement in advanced cancer: from methodology to clinical use

Symptom assessment: principles and tools

Tatyana Ionova, National Pirogov Medical Surgical Center, St. Petersburg, Russia

Cancer patients exhibit multiple symptoms that include pain, dyspnea, fatigue, depression, cognitive impairment and others, caused by disease and by treatment-related symptoms. Better symptom control can produce significant improvement in quality of life. Adequate symptom management is impossible without adequate symptom assessment. It is worthwhile to follow the principles of symptom assessment in order to provide correct measurement. The optimal management of symptoms is dependent on frequent, accurate symptom assessment and communication between patients and health care professionals. Effective control is possible if symptoms are assessed with instruments that can adequately evaluate their prevalence and severity. The instruments to measure symptoms in patients with advanced cancer should be scientifically valid self-report tools which are simple, short, easy to understand, and applicable to both clinicians and researchers. They are to be measures of single and multiple symptoms that approach equivalence across cultures and languages and are used extensively in multinational clinical trials and clinical practice. The tools for assessment pain, fatigue and other cancer-related symptoms will be discussed. To make symptom assessment an integral part of the clinic routine, it is helpful to use tools for the simultaneous assessment of multiple symptoms. The ideal symptom assessment instrument for cancer patients should include the symptoms related to cancer and its treatment that occur frequently and are distressing for patients. The examples of such tools will be given. Further research in symptom assessment and management is needed to optimize patient care in advanced cancer.

Abstract number: 7
Presentation type: Invited Lecture
Session: Education – Symptom measurement in advanced cancer: from methodology to clinical use

Cross-cultural experience in symptom assessment

Friedemann Nauck, Malteser Krankenhaus Bonn, Bonn, Germany

Cancer patients frequently suffer from a myriad of symptoms. The development and application of comprehensive assessment tools is essential to the effective management of these symptoms. There are many different assessment tools designed specifically for palliative care patients, but their cross-cultural validity needs to be determined before they can be applied in different cultures and ethnic settings. Patient-oriented evaluations using questionnaires have become an important aspect of clinical studies in palliative care. Any questionnaire must be translated and culturally adapted in order to be used with different language groups, and reliability and validity of the translated version have to be comparable to the original version so that results from clinical trials in different settings can be compared. In Europe it is usual for outcome measures to be translated into other languages. Translation may be difficult and semantic problems may impede the discussion about definitions and assessment tools for example the symptom of fatigue. The term 'fatigue', for example, is common in English and French, but did not exist in other European languages. Therefore, more research in the issue of cross-cultural validity is of paramount importance. The philosophy of palliative care is universal. Despite differences among individuals and cultural groups, basic needs and preferences are common to all humans. For truly effective palliative care, cultural subtleties and nuances must be considered. Assumptions based on one's own culture may be essential barriers to the development of knowledge and insight into the patient. Keeping an open mind about what is new or different within other cultures can extend and improve quality of palliative care.

Abstract number: 8
Presentation type: Invited Lecture
Session: Education – Symptom measurement in advanced cancer: from methodology to clinical use

Studying symptoms: challenges and new developments

Jon Håvard Loge, Ulleval University Hospital, Oslo, Norway

A physical symptom is a perception, feeling or even belief about the state of our body. Psychological symptoms are less clearly conceptualized. Psychophysical symptoms such as fatigue are not clearly physical or psychological in origin. Symptom comes from the Greek symptoma combining the roots for 'to fall' and 'together'. Symptoms are literally a fall from our usual state of functioning. Some symptoms such as fatigue have a continuous distribution while others like nausea, tend to be categorically distributed. This has implications for assessment. Symptoms were central in medicine during the 19th century but lost status as diseases were described and curative treatment gradually became the focus for interventions. Symptoms are part of everyday life. An average person will experience several instances per year with a symptom level sufficiently severe to be described as illnesses. On most occasions the affected will not seek medical care. The threshold for perceiving a symptom as burdensome enough to seek help varies. For some symptoms such as pain, the mechanisms are fairly well understood. For others such as fatigue, the mechanisms are poorly understood. Fatigue is probably best seen as a final common end-point. A common feature for all symptoms is that they are not direct expressions of specific pathological processes but influenced by personal, demographic and cultural factors. In most studied populations symptoms tend to be clustered; i.e. they co-occur and are correlated. The causal and temporal relationship between clustered symptoms can be bidirectional or explained by a third variable (confounding) such as the cancer itself. Because of the co-occurrence of symptoms, symptom clustering (two/three or more symptoms related to each other) receives increased attention. How the symptoms are related can vary and all may not have the same etiology. Still, limited research has been conducted in palliative care to define which symptoms occur within clusters.

Abstract number: 9
Presentation type: Invited Lecture
Session: Education – Symptom measurement in advanced cancer: from methodology to clinical use

Concept of symptom interference with quality of life: application to clinical practice

Andrei Novik, National Pirogov Medical Surgical Center, Moscow, Russia

For the patient suffering from advanced cancer the symptoms are the focus of concern. Unrelieved symptoms lead to significant distress and impaired quality of life (QoL). Although QoL is recognized as an important outcome in advanced cancer, clinicians rarely use QoL data in their decision making. One of the main reasons for this observation is the lack of practical and accurate instruments for quantification of QoL impairment. Grading of QoL impairment and analysis of symptom burden is worthwhile to provide adequate management of advanced cancer. We have introduced a novel grading system of QoL impairment. This system provides physicians with quantitative assessment of QoL worsening in cancer patients as compared to a population norm (PN). Cancer patients may experience 5 grades of QoL impairment: none, mild (25% decrease from a PN), moderate (25–50% decrease), severe (50–75% decrease) or critical (>75% decrease). The practical application of this system has been tested on a sample of 500 advanced cancer patients. The majority of patients exhibited a critical or severe QoL impairment (at least a 50%QoL decrease as compared to PN). Symptom profiles differed remarkably between the groups of patients with different grades of QoL impairment – QoL impairment was directly correlated with the broadness of the spectrum and the severity of the symptoms. It is quite obvious that a patient with advanced cancer rarely experiences a single symptom. Symptom burden is the result of co-occurrence of a number of symptoms. In conclusion, improving patient's QoL is a key issue in treating patients with advanced cancer. Target treatment is impossible without accurate information about QoL impairment. Identification of the grade of QoL impairment is the starting point in the management of patients with advanced cancer. Understanding of symptom interference with a patient's QoL provides the basis for better cancer outcome measurement.

Abstract number: 10
Presentation type: Invited Lecture
Session: Opening Session

Collaborate to catalyse research

Florian Strasser, Dept. Internal Medicine, Cantonal Hospital, St. Gallen, Switzerland

The 3rd EAPC research forum is driven and shaped by your contributions. We look forward to learn and discuss new data, hypothesis, and methods in an atmosphere of respect and collaboration among the variety of professionals from multiple disciplines, professions, research settings, and nationalities. There is enough space and time for focusing on sessions, meeting people, and establishing fruitful contacts. More than 400 posters will be presented in 2 dedicated poster sessions and 111 oral presentations are delivered in 16 new research data sessions. The poster sessions allow you to both see and show research work, by presenting and visiting half time. On the same floor you can enjoy standing lunch. Poster guided tours by faculty aim to provide focused education. Two poster discussion sessions focus on the best posters, and 6 poster awards will be handed over. The new research data sessions are managed by the chairs to dedicate time to both present and discuss the papers in a productive spirit. Finally, 4 abstracts will be offered as plenary session presentation. Sentinel research developments in palliative care and associated educational aspects will be emphasized in plenary sessions, thematic sessions and workshops. Educational aspects are webbed in the forum. All session speakers and chairs follow rules to acknowledge the educational needs of the variety of participants. Meet-the-expert meetings and opportunities and available rooms for informal meeting bring researchers close to other researchers. Three preconference education sessions tackled issues of research methodology and development of research logistics and networks, clarifying the question: How to perform cutting-edge research? It is important to get to know other researchers, be inspired by discussions and learn about networks and working groups to stimulate collaborative research. Welcome to the wonderful place of Venice.

Abstract number: 11
Presentation type: Invited Lecture
Session: Plenary Thursday 25 May

A 25 years perspective on the development of palliative care research in Europe

Stein Kaasa, St. Olav's Hospital, Trondheim, Norway, **Marianne Jensen Hjermstad**, Department of Oncology, Ulleval University, Oslo, Norway, **Jon Haavard Loge**, Department of Behavioural Sciences in Medicine, Oslo, Norway

Research in palliative care has been debated for decades and several positions have been taken: "It is unethical to perform research in frail patients", it is almost impossible methodologically and practically to perform palliative care research, "it is unethical not to do research in palliative care in order to improve symptom control, research is necessary to perform, in order to gain evidence based knowledge". During the last decades the quantity of research has increased and palliative care journals and textbooks in palliative care have been launched. This makes the research more visible and increases the potential for publication. However, the quality, content and the clinical impact of this increased body of research have not been described in detail. In order for research to have impact and become acknowledged, a close connection to the academic arenas within the universities is a 'must'. Palliative care research that meets the scientific standards of quality, PhD students who are university associated and a close link between clinical and academic medicine are important. This will promote palliative care research in general and translational research in particular, thereby increasing the evidence base in this field. Better opportunities for funding as part of a university infrastructure and continuously updated research agendas for initiated by EAPC will in turn yield a greater potential for new projects.

Abstract number: 12
Presentation type: Invited Lecture
Session: Plenary Thursday 25 May

Patterns and predictors of health services utilization and costs at the end of life in Alberta, Canada

Konrad Fassbender, **Barry Finegan**, **Mary Carson**, **Robin Fainsinger**, University of Alberta, Edmonton, Canada, **Carleen Brenneis**, Capital Health Authority, Edmonton, Canada

Background: Decision and policy makers seek cost savings at end of life in order to enhance program planning and evaluation. Most evidence however combines cost of all dying patients and susequently fails to recognize the relationship between trajectories of functional decline and utilization of health care. In this paper we classified dying Albertans by categories of functional decline and assessed their utilization and costs.
Methods: Two final years of health care utilization and costs for three annual cohorts of permanent residents of Alberta Canada (April 1999 to March 2002). Literature, expert opinion and cluster analysis were used to categorize the deceased according to sudden death, terminal illness, organ failure, frailty and other causes of death. Expenditures were decomposed into constituent prices and quantities. Descriptive analysis was used to identify patterns and predictors. Ratio analysis was used to examine the relative distribution of resources for decedents and survivors by disease trajectory.
Results: 18 000 die per year in Alberta: sudden death (7.1%), terminal illness (29.8%), organ failure (30.5%), frailty (30.2%) and other (2.3%). Inpatient care remains the primary cost driver for all trajectories. Trajectories of costs are significantly different for the four categories of dying Albertans. Females consume more resources both as decedents and survivors. Age, residence and socioeconomic status do not explain absolute levels of resource utilization in the last two years of life yet young, non-poor, males receive relatively more health care services in their last year of life. Decedents consume between 10–40 times as many resources as survivors.
Conclusion: Trajectories of dying are a useful classification for analyzing health care use and costs. Significant and predictable health care services are required by non-cancer patients. Finally, policies must be developed to address potential inequities of resources distributed at end of life.

Abstract number: 13
Presentation type: Invited Lecture
Session: Plenary Thursday 25 May

Can the institutionalisation of cancer pain assessment as a 5th vital sign improve cancer pain control in the acute setting?

Marie Fallon, University of Edinburgh, Edinburgh, Great Britain, **Eleanor Clausen**, **Lorna Mcgoldrick**, **John Walley**, Edinburgh Cancer Centre, Edinburgh, Great Britain, **Lesley Colvin**, Western General Hospital, Edinburgh, Great Britain

Background: Lack of a systematic approach to cancer pain assessment in the acute hospital setting is a challenging problem. The American Pain Society (APS) advocates that pain assessment should be integrated in the acute setting by adopting pain as the '5th Vital Sign'. However, this approach has never been evaluated. We have developed a package designed to achieve institutionalisation of pain assessment, the Edinburgh Pain Assessment Tool (EPAT©).
Aim: To assess if the introduction of EPAT in a Regional Cancer Centre leads to improved cancer pain control.
Methodology: A prospective controlled study of 3 assessment approaches: EPAT, the Brief Pain Inventory (BPI) and usual standard care (i.e. no bedside pain assessment) in a UK Regional Cancer Centre. Wards were randomised to 1 of the 3 assessments. Patients with a pain score of >or =4/10 who were able to complete the pain questionnaires were recruited within 24 hours of admission and re-assessed on day 4. The primary outcome measure was patient pain score reduced to <or =4/10 by day 4. Secondary outcome measures included a clinically significant improvement in worst pain as defined by a reduction in pain score of 2 points on the 0–10 scale and patient satisfaction with pain control.
Analysis: Two tailed t-test examining difference in patient's pain scores between baseline assessment and day 4 of admission.
Results: One hundred and fifty consecutive patients completed the study. On assessment on day 4, pain control, as defined by a pain score of <or =4/10, was achieved by 52% of patients in the usual care group, 67% of those in the BPI group and 90% in the EPAT group (P <0.01). Secondary outcome measures were also clinically significant.
Conclusion: The institutionalisation of cancer pain assessment as a 5th vital sign using EPAT gave better pain control than both the BPI and standard care in our Regional Cancer Centre. An 18-centre cluster randomised controlled trial is planned.

Abstract number: 14
Presentation type: Invited Lecture
Session: Bone metastasis – New aspects

Pathophysiology of bone metastasis

Jean-Philippe Vuillez, CHU de Grenoble, Grenoble Cedex, France

Once tumours metastasize to bone, they are usually incurable and responsible for several devastating effects: severe pain, pathologic fractures, life-threatening hypercalcemia, spinal cord compression and other nerve-compression syndromes. Understanding of physiopathological mechanisms responsible for these symptoms is critical for therapeutic approach, especially pain treatments. Three types of pain occurs in tumour bone involvement: tonic or background pain, which are deep non-specific ache rising in intensity as the disease progresses; incident pain on movement (allodynia); and spontaneous pain which can be severe. Bone metastases could be osteolytic or osteoblastic. However, this classification actually represents two extremes of a continuum characterized by dysregulation of the normal bone remodelling process. Biochemical mediators production is crucial as a part of this process. The bone microenvironment plays a critical role in the formation of osteoclasts through the production of macrophage colony-stimulating factor, receptor activator of nuclear factor kB ligand (RANKL)... Many of these mediators of osteolysis also have been shown to activate nociceptors: prostaglandins A and E, IL-1, IL-6, TNF. Thus there is a link between osteolytic destruction, inflammation and pain. It explains that severe pain could occur independently from fractures and in absence of any bone structure alteration and nervous compression. Also, pain is often disproportionate to tumour size or degree of bone involvement. Inflammatory and osteolytic processes depend on number, localization and organization of tumour cells inside bone and bone marrow tissues. All these parameters are crucial to take into account for a good understanding of treatments mechanisms of action, especially anti-inflammatory drugs (corticosteroid and others), biphosphonates, internal radiotherapy (strontium 89 or radiolabelled biphosphonates), external radiotherapy and chemotherapy or hormonotherapy).

Abstract number: 15
Presentation type: Invited Lecture
Session: Bone metastasis – New aspects

Bisphosphonates: effects and side effects

Carla Ripamonti, Rehabilitation and Palliative Care Unit, Milano, Italy

Bone metastases, the most common cause of cancer-related pain, have been found in 70 to 85% of patients with breast, lung and prostate tumours during the course of their illness. Most patients with bone metastases present a rather slow clinical course characterized by severe pain when at rest and/or during movement, hypercalcemia, skeletal complications such as pathological fractures and spinal cord compression, which impair mobility and daily life activity. The prevention of skeletal related complications and pain control at rest and during movement, therefore, have a significant impact on patients' quality of life. According to the data of literature bisphosphonates such as pamidronate, zoledronic acid and ibandronate have in common the quality to reduce the onset of skeletal complications as well as the need for RT and surgery for fractures in patients with bone metastases due to various cancers. Moreover these agents have all been shown useful in the management of pain. The relative benefit of the three bisphosphonates has not been established in head-to head trials. At present, they are not considered an alternative to analgesic drugs, but ongoing studies should better define their position in this respect. What about the bisphosphoantes? faults? Recently, bisphosphonate-associated osteonecrosis (BON) of the jaws has been described by many Authors and represents a serious clinical and distressing complication in cancer patients with bone metastases. Regarding the management of this oral complication, there are no guidelines based on evidence, and the clinical management is based on expert opinion. The prevention of BON is considered to be the best approach to manage this problem. Certain intravenous bisphosphonates have been associated with risk of renal toxicity, thus care should be taken in selecting the most appropriate agent above all in elderly patients.

Abstract number: 16
Presentation type: Invited Lecture
Session: Bone metastasis – New aspects

Scientific evidence of radionucleotides in palliative care

Pierre Olivier, CHU de Brabois, Vandoeuvre Les Nancy, France

Bone pain palliation with radionuclide therapy is mainly aimed at patients with disseminated skeletal metastases. That technique is based on the use of radiopharmaceuticals that target the nons pecific perimetastatic osteoblastic reaction. Those radiopharmaceutical are labelled with beta-emitters that deliver their energy on a short range of some millimeters. Several bone seeking compunds are commercially available, such as 153 Sm-EDTMP, 186 Re HEDP or 89 Sr that demonstrate quite comparable results in terms of pain control. The first aim of current research is to determine how to best use already available radiopharmaceuticals, that is: when to start such therapy, when to reinject the patient; What characterizes the patient who will mostly benefit for such treatment? What is the place of individual dosimetric approaches for finding a compromise between treatment efficacy and myelotoxicity. On the other hand, the combination with other treatment modalities is very promising. The potential interest to associate radionuclides with external beam radiotherapy had been considered a long time ago and remains an interesting perspective to be further evaluated. The issue of combination with biphosphonates and especially with the very efficient zoledronic acid has been recently adressed and that combination would be more efficient that each of the approach used alone. Finally, several works examined the potential of using radionuclides in combination with chemotherapy. Beyond different combinations, a very promising issue would be the use of radionuclides with high-LET alpha particles like 223 Ra. Those radionuclides are axpected to be more efficient by delivering their energy in a more densely way than beta particles which have in comparison a low radiobiological effectiveness. The use of such more efficient particles lets expect an impact not only on pain but also on the disease itself.

Abstract number: 17
Presentation type: Invited Lecture
Session: Bone metastasis – New aspects

Comprehensive treatment for metastatic bone pain

Peter J Hoskin, Cancer Centre, Middlesex, Great Britain

The first imperative in the management of bone metastases is to exclude major complications, for example spinal cord compression, pathological fracture and hypercalcaemia which require active management. Background pain management with non-steroidal anti-inflammatory drugs and analgesics will be implemented. For patients with hormone sensitive disease such as prostate cancer or breast cancer and those with chemotherapy sensitive disease, for example myeloma or small cell lung cancer then systemic anticancer therapy will be appropriate and can be very successful in previously untreated patients. Localised uncomplicated bone pain is best treated with single doses of 8 to 10 Gy local radiotherapy. This is also effective for bone metastases causing neuropathic pain. More widespread bone pain can be treated with wide field hemibody radiotherapy again in single doses of 6 Gy to the upper hemibody or 8 Gy to the lower hemibody. Treating larger fields does result in mild self limiting toxicity affecting approximately 15% of patients treated after upper hemibody and 10% after lower hemibody. Radioisotopes including strontium, samarium and rhenium, have a major role in the treatment of scattered multi-site bone pain. They are contraindicated in patients with renal failure, impaired bone marrow reserve and patients must be continent of urine. Short range beta emitting radionuclides are given as a single intravenous injection and have minimal radioprotection requirements. Similar response rates to external beam radiotherapy are seen; pain flare is common but toxicity otherwise is usually mild. Bisphosphonates are increasingly used for metastatic bone pain. Their efficacy in direct comparison with radiotherapy remains unproven and a cross study comparison suggests that their response rate may be substantially lower. New drugs for bone metastasis include an antibody to RANKL and analogues of osteoprotegenin.

Abstract number: 18
Presentation type: Invited Lecture
Session: Plenary Friday 26 May

Improving palliative function – results from a prospective randomised controlled trial

David Currow, **Amy Abernethy**, **Roger Hunt**, Flinders University, Adelaide, Australia, **Tania Shelby-James**, Repatriation General Hospital, Adelaide, Australia, **Helena Williams**, Southern Divison of General Practice, Adelaide, Australia

Background: Evidence-based palliative care service delivery models are needed. General practitioner (GP) and patient-centred case conferences organised by the palliative care service may increase multidisciplinary interaction and enhance patient care. Educational outreach visiting in pain management may empower learners and improve care.
Methods: Three interventions were tested against a routine care control in a $2 \times 2 \times 2$ cluster factorial randomised controlled trial:case conferencing, educational visiting for GPs, and patient educational visits (PEV). Subjects included adult patients referred to palliative care services in southern Adelaide with any pain in the preceding 3 months. There were followed longitudinally until death. Main outcomes included performance status (Australian-modified Karnofsky Performance Status (AKPS)) and pain intensity. Longitudinal intention-to-treat analyses using cluster-specific methods were conducted. Sample size estimate was 460 participants.
Results: 461 patients were enrolled from 4/02–6/04. Mean age was 71 yrs, 50% were male, 91% had cancer. Mean and median survival on the trial was 146 and 87 days; median baseline AKPS was 60%. Participants randomised to case conferencing had higher mean performance status scores than those in routine care (average daily AKPS, 57.3% vs 51.7%, $p = 0.0368$). Impact of case conferencing was greatest when baseline AKPS <70 at referral (average daily AKPS, 55.0% vs 46.5%, $p = 0.0143$). Similarly, participants with baseline AKPS <70 at referral who were randomised to PEV had higher performance status than routine care (54.7% vs 46.8%, $p = 0.0206$). There was no additive effect for these 2 interventions. GP education did not improve performance status. Pain was not different between groups.
Conclusion: A service delivery model that included a case conference or patient educational visiting for pain led to improved performance status. Patients with deteriorating performance status derived greatest benefit.

Abstract number: 19
Presentation type: Invited Lecture
Session: Plenary Friday 26 May

A phase 3 double – Blind Placebo – Controlled Trial of Subcutaneous (SC) Methylnaltrexone (MNTX) for Opioid – Induced Constipation (OIC) in Advanced Medical Illness (AMI)

Jay Thomas, San Diego Hospice & Palliative Care, San Diego, U. States, **Arthur Lipman**, University of Utah, Salt Lake City, U. States, **Neal Slatkin**, City of Hope National Medical Center, Duarte, U. States, **George Wilson**, Community Hospice of Northeast Florida, Jacksonville, U. States, **Robert Israel**, Progenics Pharmaceuticals, Inc., Tarrytown, U. States

Background: Opioid-induced constipation is common and distressing, can be unresponsive to laxatives, and significantly complicates symptom management. MNTX, a charged derivative of the opioid antagonist naltrexone, does not cross the blood-brain barrier; thus, it may antagonize peripheral opioid side-effects while sparing centrally-mediated beneficial effects. In a hospice phase II trial, MNTX was active in reversing OIC and was well tolerated.
Aim: This phase III study seeks to confirm the hypothesis that MNTX is safe and effective in treating OIC in pts with AMI.
Methods: This was a multi-center, double-blind, randomized, placebo-controlled study of SC MNTX for OIC in AMI. Pts had a life expectancy of <6 months, no laxation for 48 hours, and stable opioids and laxatives. Pts were randomized to either placebo, MNTX 0.15 mg/kg, or MNTX 0.30 mg/kg. The primary efficacy endpoint was laxation within 4 hours after a single double-blind dose. The secondary endpoints were laxation within 24 hours, adverse events, pain scores, opioid withdrawal symptoms, constipation distress, stool consistency, straining, and general clinical impression of change (pt & clinician).
Results: 154 hospice pts were enrolled at 16 sites. Both MNTX doses (0.15 mg/kg & 0.30 mg/kg) significantly enhanced laxation (62% and 58% versus placebo 13%; $p < 0.0001$). Median time to laxation was MNTX 0.15 mg/kg, 70 minutes and MNTX 0.30 mg/kg, 45 minutes vs. placebo, >24 hours ($p < 0.0001$). All other secondary endpoints were all significantly improved in the MNTX arms vs. placebo. MNTX was well tolerated. The most common adverse events were transient abdominal cramps (30–40%) and flatulence (15–20%). There was no opioid withdrawal or increase in pain.
Conclusions: SC MNTX safely results in laxation within 4 hrs in the majority of AMI pts with OIC and may address a significant unmet medical need in supportive care.

Abstract number: 20
Presentation type: Invited Lecture
Session: Plenary Friday 26 May

Caregiving impact on depressive symptoms for family caregivers of terminally ill caner patients in Taiwan

Siew tzuh (stephanie) Tang, Chang Gung University, Tao-Yuan, Taiwan

Background: Providing end-of-life care for patients imposes great physical-psycho-social, and economic hardship on family caregivers. Investigation into family caregiving burden of terminally ill cancer patients in Asia has been limited.

Purpose: To (1) investigate the objective and subjective caregiving burden for family caregivers (CGs) of terminally ill cancer patients in Taiwan; and (2) identify determinants for negative emotional impact of caregiving.

Methods: Cross-sectional survey. 112 CGs (participation rate: 88.9%) were recruited by a convenience sampling strategy. Objective and subjective caregiving burden was measured by total hours of caregiving per day, care tasks and levels of care and the Caregiver Reaction Assessment (CRA), respectively. Negative emotional impact of caregiving was measured by the CES-D.

Results: Over half of the CGs spent greater than 12 hours daily in caregiving. 60.8%$\sim$76.8% of personal care, homemaking, transportation, and health care of the patients was provided by CGs alone. Caregiving introduced a greatest negative impact on CGs' daily schedule (mean =4.0 on a 1–5 Likert scale), followed by health, finance, family support, and self-worth (mean scores: 1.9–2.7). 75.9% of CGs scored higher than 16 on the CES-D. Multivariate logistic regression analysis indicated spouse CGs had 3.06 times higher odds to be depressive than non-spouse CGs (95% CI: 1.01–9.32). CGs experiencing greater caregiving impact on health were more likely to be depressive (OR =1.26; 95% CI =1.06–1.49 with each unit increase). Female gender, comorbidity of CGs, and greater impact of caregiving on finance and family support led to a greater probability of being depressive at bivatiate level of analyses but were not retained in the final multivariate model.

Conclusion: Taiwanese CGs of terminally ill cancer patients were at high risk of depression. Effective interventions shall target on spouse CGs to reduce the negative impact of caregiving on their health.

Abstract number: 21
Presentation type: Invited Lecture
Session: Palliation with oncological treatment – A joint ESMO-EAPC session

Palliation with oncological treatments: a joint ESMO-EAPC session

Stein Kaasa, St. Olav's Hospital, Trondheim, Norway, **Raphael Catane**, Department of Oncology, Sheba Medical Center, Tel Hashomer, Israel

Most patients in palliative care have a cancer diagnosis, and a substantial number of patients in oncological wards receive treatment with a palliative intention. In research the tradition within oncology has been to focus on cure, survival and/or tumour response. However, during the last decade subjective outcomes, including health related quality of life assessment, are often incorporated in several studies in oncology, both as an endpoint in life prolonging studies and in palliative studies. The oncologist pays today more attention to the comprehensive management of his patient and uses the conventional armamentarium [be it chemotherapy, biological therapy or radiotherapy] specifically as a palliative tool. In contrast, in palliative care research, the main focus has been to alleviate pain by means of analgesics, with not as much involvement of anti-cancer treatment. This paradoxical situation needs amendment and closer ties between oncologists and expert palliative care specialists. Within the new development in oncology, more patients are living longer and they receive anti-tumour treatment for a longer period. The 'new cohorts' of patients may potentially suffer longer with a more complex symptom pattern. All these observations emphasize the need for a close collaboration between oncology and palliative care.

Abstract number: 22
Presentation type: Invited Lecture
Session: Palliation with oncological treatment – A joint ESMO-EAPC session

The Interface of oncology and palliative care in research

Nathan Cherny, Director Cancer Pain and Palliative Medicine, Dept., Jerusalem, Israel

It is a sorry truth that more than 50% of all cancer patients will ultimately die of their disease. For those patients with incurable cancer the aims of oncologic care are to help patients live as much time as possible, as well as possible. The qualitative domain of "living well" is influenced by physical, psychological, social and existential factors. The evidence base of palliative oncology is predicated on research addressing both qualitative and qualitative outcomes. Dying patients are not necessarily in a rush to do so, thus the importance of survival as a relevant outcome even for incurable cancer. The quality of survivorship, particularly when treatments add little to duration of survival, has been an increased focus of research. It is now widely accepted that decision to initiate anti tumor therapies may be made on the basis of clinical benefit even in the absence of compelling objective response data. Shared research and clinical initiatives are helping to address thorny issues such as fatigue, anorexia and ataxia. On the psychosocial and spiritual domain, there has been an increasing convergence of interest in evaluating shared concerns; particularly with regards to communication issues, ending disease modifying treatments and end of life issues. There are some many aspects to this interface that it is now self evident that the most effective research strategies will utilize the shared expertise of oncology, palliative medicine, and Psychooncology, along with the input of other relevant medical and paramedical clinicians in constructive interdisciplinary cooperation.

Abstract number: 23
Presentation type: Invited Lecture
Session: Palliation with oncological treatment – A joint ESMO-EAPC session

New Oncological Treatments Impacting PC: Do we need new endpoints?

Raphael Catane, Sheba Medical Center, Ramat Gan, Israel

A new era has arisen in oncology. The treatment of cancer becomes more targeted, that mean more specific to cancer cells. There is much less noxious effect on non-tumor cells; however we do observe new kind of side effects. Instead of encountering alopecia, mucositis and myelosuppression, the new agents may cause allergic reactions, hypertension, diarrhea, skin rash and cardiotoxicity. The toxic effects of the new targeted agents are generally milder and almost never life-threatening. In this situation chronic administration of the treatment is easy and acceptable. Thus, we do not have to aim at eradicating the tumor but stabilizing it is enough. Examples will be given for patients with GIST who were treated with imatinib with no shrinkage of their tumors, but with excellent stabilization for years. Another example is women with breast cancer receiving Trastuzumab for years with no progression and return to normal life. Hormonal manipulation may also be considered as targeted treatment and here also it is possible to give a non-toxic agent for prolonged periods, with excellent quality of life. We conclude that shrinkage of the tumor (Partial Response [PR] or Complete Response [CR]) are not our goal any more and we can better assess the beneficial effect of a treatment by measures such as quality-of-life, duration of stable situation (measured as Time to Relapse or Time to Progression) instead of measuring tumor size.

Abstract number: 24
Presentation type: Invited Lecture
Session: Palliation with oncological treatment – A joint ESMO-EAPC session

Anti-tumor therapy and symptom control: evidence and research agenda

Dirk Schrijvers, Ziekenhuisnetwerk Antwerpen-Middelheim, Antwerp, Belgium

Anti-tumor treatment by surgery, radiotherapy (RT) and medication (hormones, cytotoxic and cytostatic agents) should be considered for symptom control in palliative care cancer patients. They have an impact on the quality and duration of life of these patients. Several studies have shown a positive effect of anti-cancer treatments compared to best supportive care (BSC) in symptom control. Randomized controlled studies showed a positive effect on quality-of-life or specific symptoms of anti-cancer treatments in esophageal cancer (thermoablation/brachytherapy versus stent), lung cancer (single fraction (fct) RT versus (vs) multiple fractions (fcts); platinum-based chemotherapy (CT), vinorelbine, gemcitabine and taxanes vs BSC), Kaposi sarcoma (oral etoposide vs SBC or RT), colorectal and gastric cancer (5-fluorouracil-based CT vs BSC), pancreatic cancer (gemcitabine vs BSC) and bone metastasis (single fct vs multiple fcts). They should be discussed with the patient and their family. However, their use should be carefully considered taking into account the wish and frailty of the patient, the benefit and side effects of the treatment and the experience of the treating team. Future studies should center on the use of new less toxic anti-cancer treatments, specific treatments for symptoms due to cancer, adequate scales to measure quality-of-life in palliative care cancer patients and criteria for patient selection who may benefit of anti-cancer treatment.

Abstract number: 25
Presentation type: Invited Lecture
Session: Cachexia and its consequences

Cachexia and its consequences

Florian Strasser, **Martina Kern**, Dept. Internal Medicine, Cantonal Hospital, St. Gallen, Switzerland

Among clinical conditions causing nutritional problems in the palliative care context, cachexia is one of the predominant clinical challenges. The aim of this session is to touch on and discuss multidimensional aspects of suffering associated with cachexia of patients and their loved ones, learn about state-of-the-art pathophysiological understanding triggering targeted treatment approaches, and to emphasize clinical significant endpoints of research in the field. The session should foster engagement in research on cachexia and its consequences by tackling significant questions and applying a productive methodology. The session aims to provide the grounds for and stimulate discussion on these main points, catalyzing research projects and collaborations. It is another step towards a research agenda on 'nutritional issues in palliative care' in a combined effort of EAPC researchers.

Abstract number: 26
Presentation type: Invited Lecture
Session: Cachexia and its consequences

Paucity of research in spiritual and existential nutritional issues

Martina Kern, Malteser Krankenhaus, Bonn, Germany, **Monika Müller**, ALPHA, Bonn, Germany

Caring for the dying patient and his family means to deal with the issues and concerns that are important to them. Nutrition and intake of fluid are major issues in palliative care. Caregivers mostly deal with the physical aspects of nutrition/malnutrition and focus on adequate intake of nutrients, particularly when patients suffer from side-effects of treatment or symptoms as a result of their disease, i.e. nausea, vomiting and constipation in terminally ill patients. But there is more to food than the nutritional aspect: eating, accepting, preparing and serving food have emotional and sociological meanings and a highly symbolic value. Patients, families and healthcare professionals need to understand whether or not their own religious, cultural and ethical values in the context of nutrition and fluid intake are counterproductive to the patient's quality of life. This is particularly important in patients at the end stages of a life-threatening illness when it becomes more important to give hydration and feeding for pleasure rather than survival. Professionals, volunteers and families involved in the care of palliative care patients would do well to identify their own, probably underlying goals in nutritional care in order to facilitate an approach of care that is free from emotional distress for the patient.

Abstract number: 27
Presentation type: Invited Lecture
Session: Cachexia and its consequences

Pathophysiology: Does a point-of-no-return exist?

Vickie Baracos, Cross Cancer Institute, University of Alberta, Edmonton, Alberta, Canada

The approach taken to cancer cachexia is strongly colored by the fact that the context is that of life-limiting disease. Thus in earlier disease stages, aggressive treatment approaches and nutritional therapy are contemplated, with a view to maintenance of body composition and function. By contrast, in very late stages of disease progression, treatment of cachexia-anorexia, and even feeding itself, may be abandoned. The identity of the point at which treatment of cachexia becomes futile in a physiological sense is not clearly defined. A terminal stage phenomenon of 'nutritional failure' has been anecdotally described, and this may reflect a systemic failure of downstream pathways of nutrient utilization. There is some evidence that cachexia therapy in the last 8–12 weeks of life can realize important benefits, including attenuation of weight loss or weight gain, functional status and quality of life. The latter results would imply a surprisingly robust anabolic potential and ability to incorporate nutrients into cellular structures as well as to use them as fuels to support physiological functions, near to the end of life.

Abstract number: 28
Presentation type: Invited Lecture
Session: Cachexia and its consequences

Targeted interventions for nutritional challenges in palliative care

Florian Strasser, Dept. Internal Medicine, Cantonal Hospital, St. Gallen, Switzerland

In palliative care (PC) nutritional challenges go beyond calories and body weight: they encompass multidimensional aspects of loss of weight, appetite, and function. Diagnosing nutritional issues is challenged by their high incidence, their complexity affecting both patients and family members, often several overlapping syndromes of fluctuating importance, inconsistent identification of reversible causes and distinction from consequences (i.e., body composition, symptoms, function [physical, social, emotional], psycho-social-spiritual distress). Current screening underestimates distress of family members and causes of secondary anorexia (S-ACS). Novel assessment instruments for eating-related distress (ERD) and S-ACS amend to present symptom checklists or screening tools. An EAPC working group ('nutrition in the PC context') aims to develop a common assessment tool. The agreement on goals of interventions and time needed to (not) reach milestones (i.e., symptom severity, distress, intake [kcal, protein], function) requires clarity in diagnosis (causes, consequences). Challenging is the priorization of nutritional 'competing' with other distressing issues. Ceasing oral intake is a sign of the dying process, prognosis influences decisions, as do patients' preferences, price of interventions, and prevention of suffering. Main interventions for S-ACS target constipation, eating habits, chronic nausea, and severe symptoms. For primary ACS multi-targeted approaches unfold (antiinflammatory drugs, appetite stimulants, anabolics, muscle care, optimized nutritional intake). Research groups test the hypothesis that defined ACS phenotypes guide different types of multi-targeted approaches. Clinical trial design should include prospective, hypothesis-driven, subgroup analysis. Research in ERD of patients and family members begins with collaborative work to define different targets (characteristics of distress) and types of counselling interventions.

Abstract number: 29
Presentation type: Invited Lecture
Session: Cachexia and its consequences

Critical evaluation of priorities and therapeutic outcome measures

Eduardo Bruera, MD Anderson Cancer Center, Houston, TX, U. States

The vast majority of patients with cancer, AIDS, and a significant proportion of patients with congestive heart failure and chronic lung disease develop cachexia before death. This multi dimensional syndrome reduces survival and causes severe physical symptoms such as fatigue, anorexia, and chronic nausea as well as psychosocial distress in patients and their families. In recent years there has been renewed interest in the pathophysiology and potential treatments of cachexia. The idea treatment would result in significant gain in total body lean mass and total body fat as well improvement in the symptoms of cachexia. Such treatment is not available at the present time. While the reversal of cachexia is not possible for the vast majority of patients, significant alleviation of symptoms and a reduction in the rate of progression of this syndrome is quite possible. Causes of secondary cachexia should be routinely investigated and treated to decrease the starvation of the component. Primary cachexia should be treated mainly in patients in whom the physical and psychological symptoms of cachexia are important as compared to other existing symptoms such as pain, dyspnea, or delirium. Recent research has allowed a much better assessment of outcomes such as body composition, oxygen consumption, physical and psychosocial symptoms. The different strategies for future research in the areas of assessment, decision making, and interventions will be discussed.

Abstract number: 30
Presentation type: Invited Lecture
Session: End-of-life care decisions

Definition of end of life decisions and clinical practice

Guido Miccinesi, Department of Clinical Epidemiology, Unit of, Firenze, Italy

The epidemiological and the clinical perspective on decision making near the end of life are different but interrelated. The presentation will focus on the epidemiological perspective, its methodological characteristics, its limits, and the main questions of research that we have, in the next future, to deal with. A review of published epidemiological research on this issue will be presented. Differences and consistency between studies on practices and studies on attitudes will be stressed. Geographical variability in Europe, in different settings of care, will be reported and commented. To look at what happened near the end of life the presentation shows how is important the specific point of view of medical doctors, nurses, caregivers, and dying patients. The presentation also intends to discuss the usefulness of considering the doctor intention in epidemiological studies on end of life decisions. In conclusion the presentation will end by a question: which impact we would like to obtain from this kind of epidemiological research on both clinical practice and public discussion?

Abstract number: 31
Presentation type: Invited Lecture
Session: End-of-life care decisions

End of life decisions in intensive care: cultural differences

Charles Sprung, Hadassah Hebrew University Medical Center, Jerusalem, Israel

Different cultures and countries deal in different ways with the wider availability of life-sustaining therapies. Some have not adopted the Western emphasis on patient autonomy or methods of terminating life support. The Ethicus study prospectively evaluated all consecutive adult patients admitted to ICUs who died or had any limitation of life-saving interventions in the ICU. During the study, 31 417 patients were admitted to ICUs in 37 centers located in 17 countries. Of the 31 417 patients, 4248 patients (13.5% of those admitted to ICUs) comprised the study population. End of life categories were prospectively defined enabling the classification of each patient into one of five mutually exclusive categories: CPR, brain death, withholding, withdrawing and active shortening of the dying process (SDP). Countries were divided into three geographic regions and culture: Northern (Denmark, Finland, Ireland, The Netherlands, Sweden, United Kingdom), Central (Austria, Belgium, Czechia, Germany, Switzerland) and Southern (Greece, Israel, Italy, Portugal, Spain, Turkey). End-of-life practices related to culture and religion. There was greater use of CPR (30%) and less withdrawing (18%) and SDP (0%) in the Southern countries than Central (18%, 34%, 6%) or Northern European countries (10%, 48%, 1%) respectively, $p < 0.001$. The median time from ICU admission until the first limitation was 1.6 days in Northern, 3.3 days in Central and 5.7 days in Southern countries ($p < 0.001$). Withdrawal of life-sustaining treatment occurred more often if the doctor was Protestant, Catholic or had no religious affiliation than if he/she were Greek Orthodox, Jewish or Moslem ($p < 0.001$). There were also differences in CPR use and withholding treatment based on doctor's religion.

Abstract number: 32
Presentation type: Invited Lecture
Session: End-of-life care decisions

End-of-Life care (EOL) decision-making: the view of patients and carers

Steffen Eychmüller, Kantonsspital St. Gallen, St. Gallen, Switzerland

In 2004 and 2005 the needs of patients suffering from far advanced disease and the needs of their professional and lay carers was assessed through focus groups (3–10 participants) in 3 different language regions of Switzerland (German, French, Italian). Some results correspond well with the findings in the literature, some are far more detailed. This presentation will highlight some of the findings that relate to the question of decision making. Common needs of all groups (patients, family members and professionals) can be found in the area of information, cooperation and education. Patients and family members confronted with far advanced disease (mainly cancer) claim – A lack of ''un-biased'' professional information about treatment alternatives if cared by specialists – A lack of psychological skills while counselling/ decision making by physicians, especially from a highly specialized background-A specialist's barrier of asking a second opinion from other professionals – A lack of concrete planning for ''shared decision making'' integrating the patient, his family and the physician/ other professionals (time, setting, preparation) – A lack of integrating the patient's GP if decisions are made in the hospital/ by specialists – Insufficient communication/ transfer of information from one professional to a colleague once a decision has been made. Patients and their families feel insufficiently informed about the availability of concrete support systems in their region. Not to become a burden for the loved ones is a priority and sometimes the call for euthanasia seems to be triggered by the lack of this kind of information. This is also true for a systematic information about the options offered by Palliative Care and basic, self directed symptom management. Most patients show a clearly defined concern about symptoms when death is approaching but again there seems to be no attention from professional side to this problem: discuss theses issues in depth and the options for their management.

Abstract number: 33
Presentation type: Invited Lecture
Session: Translational research: Examples from pain and cachexia research

What is translational research in pain and palliation?

Pal Klepstad, St. Olavs University Hospital, Trondheim, Norway

Research in pain and palliation has traditionally been performed by clinicians performing studies on palliative care patients and by basic researchers studying basic biological mechanisms. Translational research is to combine clinical and basic research. In translational research clinical observations can initiate basic research or, the opposite, that findings in basic research may raise hypotheses to be tested in clinical studies. Important issues in doing translational research is communication between basic and clinical researcher and respect for each other professional abilities. To facilitate translational research it is vital that research institutions support research groups including researchers from different professions and that the research institution organisation makes it natural for reseachers from different professions to meet. The cooperation between professions can be formalized but perhaps even more important is the informal contact between individual researchers.

Abstract number: 34
Presentation type: Invited Lecture
Session: Translational research: Examples from pain and cachexia research

Internalization of opioids – implications for current research

Pal Klepstad, NTNU, Norwegian University of Science, Trondheim, Norway, **Cecilie Baar**, **Tor-Morten Kvam**, **Sonja Andersen**, **Frank Skorpen**, Medical Faculty, NTNU, Trondheim, Norway

Opioids act through binding at opioid receptors located at the cell membrane. The binding of an opioid ligand to the opioid receptor can elicit a biological effect (opioid agonist) or inactivate the receptor (opioid antagonist). After binding of an opioid substance to the opioid receptor the new ligand-receptor complex can be internalized into the cell. After internalization the ligand-receptor complex can be degraded in the cell or recycled as a receptor complex to the cell membrane. This process can be observed by heterologous expression of fluorescence-tagged opioid receptors in mammalian cell systems, exposure to opioids, and monitoring by confocal laser microscopy. Internalization of opioid receptors may differ between different opioid receptor variants and between different opioid ligands. Hence, this process may contribute to variability in opioid efficacy due to interindividual differences in opioid receptor expression patterns. Furthermore, the fate of the receptor complex after internalization into the cell, degradation or recycling, can be hypothesized to influence clinical observations such as the development of tolerance. The presentation will review current knowledge from basic science for internalization of opioids and discuss the possible implications of these findings for the clinical effects of opioids.

Abstract number: 35
Presentation type: Invited Lecture
Session: Translational research: Examples from pain and cachexia research

Cachexia: From mouse to man

Vickie Baracos, University of Alberta, Edmonton, Canada

A review of publications available on health research data bases reveals hundreds of articles on animal models of cancer-associated cachexia. These include a number of human tumors xenografted into immuno-suppressed rodents (ie nude mice), as well as transplantable rodent tumors in syngeneic (inbred) hosts. The group of researchers employing these models have never met to develop a consensus statement on the utility of these models. It must be recognized that cancer is an ensemble of diseases varying in biology, epidemiology and prognosis. There is no single tumor model to represent cancer, since cancer is not a single entity. Therefore, the selection of a model will depend upon the intent of the planned investigations. Broadly speaking, there does seem to be a concordance between many of the animal models and the key features of cancer cachexia seen in humans: anorexia, metabolic alterations, the presence of systemic inflammation, activation of catabolic pathways. When he object of the investigation is the pre-clinical evaluation of cachexia-anorexia therapy, close attention must be paid to the clinically relevant features of the model, including dietary design, tumor burden, and anti-neoplastic therapy.

Abstract number: 36
Presentation type: Invited Lecture
Session: Translational research: Examples from pain and cachexia research

PET-imaging of pain and the opioid receptor system

Frode Willoch, Aker University Hospital, Oslo, Norway

The advent of functional brain imaging has contributed to a major advance in the understanding of the central mechanisms of pain processing. From the multiplicity of activated brain sites observed in different pain states, it has become evident that there may not be a common structure or neuronal master switch for the generation of pain, but rather a distributed parallel network or matrix of cortical and subcortical structures that are subserved with afferent input via distinct anatomical pathways. Pain is a multidimensional experience including sensory-discriminative, affective-motivational and cognitive-evaluative components and different brain areas concert to produce these different sensations. In spite of the increasing knowledge, there is still no specific indicator of what might be the cause of chronic pain. Neuronal plasticity is an essential feature of the nervous system in the transfer of physiological noxious response into a state of a pathological processing. Neuroplastic changes may be derived from measuring changes in the neuronal activity or the neuroreceptor function of the brain structures known to participate in the central pain processing network. For example, many of the neuronal structures, that are involved in the processing of noxious information, express high-level opioid receptor binding. These structures show a region-specific reduction of opioid receptor binding during ongoing pain and normalized binding after pain treatment. Moreover, activation studies with PET revealed that opioids induce analgesia by the differential activation/deactivation of brain structures such as the anterior cingulate, that are centrally involved in the processing of pain. Keeping in mind the differential therapeutic potency of opioids on different pain states, these region-specific patterns of activation/deactivation allow delineation of brain structures that are critically responsible for the generation of particular phenotypes of pain and response to therapy.

Abstract number: 37
Presentation type: Invited Lecture
Session: Prognosis and staging of palliative care patients

The work of the EAPC prognosis group

Maria Nabal, Hospital Universitario Arnau de Vilanova, Lerida, Spain

The Research Network of the European Association for Palliative Care decided to establish a Working Group (WG) with the aim of providing evidence-based recommendations on the use of prognostic factors to determine length of survival in advanced cancer patients (ACP). Group Membership: on the basis of their palliative care clinical experience and in prognostic cancer studies; epidemiologic, statistical, nursing, sociologic and philosophical points of view were available. Target Population studies in which the median survival of the group was 90 days were included. Surgical series were excluded. Key Questions: Six key questions were assigned to different pairs of WG to carry out a literature analyze of the evidence: clinical signs and symptoms, psychosocial characteristics, laboratory parameters, and prognostic scores. Systematic Literature Search: The articles search was performed on Medline and Embase databases. Prognostic strength of each predictor was described considering the hazard ratios and their CIs. Level of Evidence: was based on the type and methodologic quality of the study. Final Recommendations: 1: In ACP physicians should base their decisions idering both quality of life and life expectancy (grade D) 2: Clinical prediction of survival is a valid tool to obtain a general prognostic (grade A), but it is unacurated. Its use is recommended together with other prognostic factors (grade A) 3: Clinicians can use cancer anorexia-cachexia syndrome (grade B), dyspnea (grade B), and cognitive failure or delirium (grade B) as predictors of life expectancy. 4: Clinicians can use leukocytosis (grade B), lymphocytopenia (grade B), and high C-reactive protein (grade B) as predictors of life expectancy. 5: Clinicians can use prognostic scores to make a rapid prediction and identify patients with significantly different life expectancies (grade A). 6: Patients have the right to be informed or not to be informed about their prognosis. (grade D).

Abstract number: 38
Presentation type: Invited Lecture
Session: Prognosis and staging of palliative care patients

Prognosis and "staging" of palliative care patients: what is the research agenda

Paul Glare, Camperdown NSW, Australia

Clinicians can formulate a prognosis in one of two ways: by relying on their subjective judgement (SJ) otherwise known as “clinical acumen” or by using actuarial judgment (AJ)based on statistically-derived key factors to prognosticate [1]. A systematic review has shown that SJ of time to death is usually inaccurate, mostly in the optimistic direction, which is bad if it results in overly aggressive cancer treatment or delays referral to palliative care.[2] Nevertheless, SJ is simple to use and is quite stongly correlated with actual survival, explaining $>50\%$ of the variance in actual survival. AJ. To date, performance status, symptoms (particularly those of the cancer cachexia syndrome), quality of life and simple laboratory markers like leukocytosis and lymphopenia have been identified as survival predictors in patients with advanced cancer, being more important than the factors relevant in newly diagnosed disease, such as tumour size, grade or extent of spread.[3] While AJ ought to provide greater prognostic accuracy than SJ, the factors studied so far account for less of the variance in observed survival than SJ does. A research agenda for prognostication in palliative care might therefore include studies to: v Identify novel prognostic markers to improve the accuracy of AJ. Candidates could include inflammatory markers (e.g. cytokines, CRP), co-morbidities, fighting spirit v Better understand how experienced clinicians formulate prognoses using SJ v Develop and test new AJ prognostic models combining these factors v Develop nomograms and other tools to make AJ easier v Explore the role of prognosis as a “clinical predicition rule”. v Explore prognostic domains other than death, e.g. disease recurrence, disability, discomfort, adverse effects and cost of treatments.

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Abstract number: 39
Presentation type: Invited Lecture
Session: Prognosis and staging of palliative care patients

How useful are prognostic scores in clinical practice?

Marco Maltoni, Hospice, Forlimpopoli, Italy

We evaluated the accuracy of the Palliative Prognostic Score (PaP-Score) in selecting patients with metastatic gastrointestinal or non-small-cell lung cancer to be treated with palliative chemotherapy. The PaP-Score was calculated in 173 patients with advanced, pretreated gastrointestinal or non-small-cell lung cancer before starting a further line of chemotherapy with palliative aim. In all patients symptom distress score was calculated using the ESAS scale and evaluated before every course of chemotherapy. Overall median survival was 161 days, with 136 (78.6%), 126 (72.8%), 111 (64.1%) and 61 (35.2%) patients alive after 1, 2, 3 and 6 months of follow up, respectively. Median survival was 175 days in group A (best survival goup) and 62 days in group B (intermediate survival group), with 117 (78%), 112 (74.6%), 99 (66%), and 59 (39.3%) patients alive in group A, and 19 (82.6%), 12 (52.1%), 9 (39.1%) and 1 (4.3%) patients alive in group B, after 1, 2, 3, and 6 months ($p < 0.0001$). No patient was classified in group C (worst survival group in the training and testing populations of the palliative care setting where the Score was built). A trend towards a worsening of symptom distress was observed in the entire population and in group A. The high number of missed data did not permit an adequate analysis in group B. The PaP-Score seems to discriminate the patients that could benefit by a palliative chemotherapy from those that could better benefit by a supportive and palliative approach. It may represent an useful tool to improve the appropriateness in the choice of palliative chemotherapy and the quality of care in oncology.

Abstract number: 40
Presentation type: Invited Lecture
Session: EAPC Research activities

Computerized symptom assessment in palliative care-current status of the PAT-C project

Marianne Hjermstad, Ulleval University Hospital, Oslo, Norway

Overall objective: To develop a comprehensive computer-based tool for assessment of symptoms and functioning in palliative care, the Palliative Assessment Tool-Computerized (PAT-C). This study represents a further step toward the overall objective aiming to: Collect large data samples on pain, physical and cognitive function for further statistical analyses, test the computerized data handling procedures in different clinical settings, test the user friendliness of computerized symptom assessment.
Methods: The content of the current PAT-C prototype covers cognitive (CF) and physical (PF) function and pain. Extensive literature studies, expert reviews, clinical studies and creation of item banks have been conducted to identify relevant items for the empirical study. Current standing: The present content of the PAT-C tool consists of 4 CF items (year, date, copy design, backward spelling) that showed good ability for estimation of cognitive impairment (92% sensitivity) in two samples ($N = 329$). The pain domains intensity, interference, location treatment, temporal pattern (58 items) from a clinical study ($N = 208$) are now being judged for clinical validity after item response theory analyses. Items on PF are evaluated for palliative relevance by clinical experts. Depression will be screened by a single question: Are you depressed? Software programming is continuously upgraded.
Study design: Data collection (including Karnofsky, ESAS, medical variables) starts March 1st, at 7–10 Norwegian oncology/palliative care units/hospices. Touch sensitive PC tablets with large bold font questions displayed on the screen one at a time will be used.
Conclusions: Modern computer technology may facilitate symptom assessment, but needs better clinical documentation regarding content and user-friendliness. Item response theory can guide the selection of items, but clinical considerations seem necessary for determination of their relevance. These are investigated in the current project.

Abstract number: 41
Presentation type: Invited Lecture
Session: EAPC Research activities

EPOS: Barriers, difficulties and solutions in multi-centre palliative care research

Pal Klepstad, St. Olavs University Hospital, Trondheim, Norway

The European Pharmacogenetic Opioid Study (EPOS) plan to include 3000 patients using opioids for cancer pain. The aim of the study is to observe the reationship between opioid genetics, opioid pharmacology and clinical symptoms. Participating countries are Austria, Denmark, Germany, Iceland, italy, Lithuania, Netherland, Norway, Sweden, Switzerland and United Kingdom. At the time of submitting this abstract (December 2005) about 700 patients are included in the study. Challenges to be met doing multi-centre studies are to chose research instruments validated throughout the participating countries, to comply with different research regulations across countries and to organise data and blood sample collection. Also some ideals for data collections must be carefully weighted against what is actually feasable in a multi-centre study. Another challenge is to define rules to decides how data should be utilized. It is important to ensure that researchers putting a lot of work into the study also get a fair part of access to data analyses and subsequent publications. The presentation will briefly review some of our experiences from planning and running the EPOS study.

Abstract number: 42
Presentation type: Invited Lecture
Session: EAPC Research activities

EPOS – NUF (Nutrition Fatigue): How to utilise multi-centre research for additional projects

Florian Strasser, Dept. Internal Medicine, Cantonal Hospital, St. Gallen, Switzerland

The EPOS study, a multicentre, international project collects clinical data and biological (blood) samples from 3000 pts across europe to develop tailored and molecular targeted opioid therapies. The inclusion criteria tackle patients (pts) with advanced cancer having pain. Research in other main syndromes, such as cachexia and fatigue, follows related strategies in collecting defined clinical and biological data from a considerable number of pts. EPOS-NUF (Nutrition-Fatigue) is a subproject of EPOS aiming at collecting relevant data for the characterisation of anorexia/cachexia and fatigue syndromes (ACS-FS) based on clinical, biological and genetic variables. The potential of making double-use of the same logistics is obvious, however, several issues arise by applying the for EPOS designed criteria of pts accrued and time frame (single, cross-sectional examination). Given the high incidence of both pain and anorexia and fatigue, the patient population seems to be appropriate for the purpose of EPOS-NUF, but a fraction of pts may be lost having ACS-FS without using opioids. The choice of assessment tools for ACS and FS is challenged by the availability of only single language pilot tools for secondary ACS or main FS. The burden of assessments for pts can be considerable, when adding to the questionnaires of EPOS (BPI, EORTC-QLQ-C30, MMSQ) other tools; in addition, many centres involved in EPOS have local additional studies increasing patient burden. The logistics of biological sample storage and database management of subprojects is mainly dependent on the resources and possibilities of the main study; but the collection of urine (relevant for ACS) causes relevant freezer availability issues. Finally, when adding additional questions to the collection of anonymous biological samples, national implications on patient informed consent arise. Presently, several german-speaking centres participate in the EPOS-NUF subproject, other countries are invited to join.

Abstract number: 43
Presentation type: Invited Lecture
Session: EAPC Research activities

Fatigue: Pro's and Con's of expert groups and variable pathways to publication

Lukas Radbruch, University of Aachen, Aachen, Germany

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. As the output of expert groups may depend on the professional and cultural position of the members of the group, more formalized procedures such as consensus group process or Delphi method have been recommended for the construction of guidelines. Review of the available literature according to evidence levels is a main issue in many guideline procedures and is also required by many reviewers and editors of medical journals. However, fatigue (as other areas in palliative care) is not ready yet for evidence-based guidelines. 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. Identifying these problem areas, 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. For this approach, the composition of the expert group should include the full cultural and conceptual scope. One way to ensure this is to utilize an open discussion process, for example with an online discussion forum of the position paper draft on the EAPC website.

Abstract number: 44
Presentation type: Invited Lecture
Session: EAPC Research activities

An EU application based upon the EAPC Research Network

Stein Kaasa, St. Olav's Hospital, Trondheim, Norway, **Franco De Conno**, National Cancer Institute, Milano, Italy

During the last call for the 6th EU Framework-combating major diseases, combating cancer. A specific targeted research project was announced. In the call it was stated that: Research efforts should focus on palliative care in advanced cancer patients suffering from the consequence of the disease. The successful network should address the cancer related symptoms, pain, depression and fatigue. The research plan of the collaborative organised from the Pain and Palliation Research group in Trondheim was based upon questions raised in the clinic, with focus on cancer palliative care patients. This research plan was possible to establish based upon a collaborative with skills in basic pharmacology, genomics and clinical research within the EAPC Research Network. Writing an EU application takes time and effort. One need to coordinate a large number of collaboratives in the writing process, and still keep focused in a clear structure, play and expected achievements in the research plan. Commitments need to be raised by collaboratives in a pan European setting in order to lay the ground for future research.

Abstract number: 45
Presentation type: Invited Lecture
Session: EAPC Research activities

The current work of the EAPC task force on the development of palliative care in Europe

Carlos Centeno, Clínica Universitaria de Navarra, Pamplona, Spain

In 2003 the Board of Directors of the EAPC started a Task Force on the development of Palliative Care in Europe. From the beginning, the EAPC deemed necessary to make a cooperative effort to bring together the experience from other groups and institutions that were already working on spreading the reality of Palliative Care in their own environment. The result was the successive addition to the project of the International Observatory on End of Life Care, The Hospice Information from Help the Hospices and The International Association for Hospice and Palliative Care. Since then, the work team has met 6 times and has added more members until their current constitution. Keeping in mind the general goal of evaluating the degree of development of Palliative care in Europe, four work methods were outlined: a literature review, a review of all the Directories of Palliative Care, and two different international studies, one qualitative and the other quantitative, to be carried out through specific surveys. Un update of the currents works will be done. At the moment we have received answer from more than 80% of the 52 countries and we are in process to write country reports of each one. We planning spread this information on a web base and publishing an Atlas of PC in Europe.

Abstract number: 46
Presentation type: Invited Lecture
Session: Long term consequences of opioid therapy in cancer

Long-term consequences of opioid therapy in cancer

Per Sjøgren, Rigshospitalet, Copenhagen, Denmark

Apart from conventional side effects long-term opioid treatment may also have other consequences that should be considered in palliative care. Physical dependence is defined by the appearance of withdrawal symptoms, when the opioid dose is reduced or abruptly discontinued and may occur within few days of continuous use. Pharmacologically, tolerance may develop with the repeated use of opioids and is characterized by the necessity of increased doses in order to maintain the drug effects. A distinction could be made between associative (learned) tolerance and non-associative (adaptive) tolerance. Associative tolerance involves environmental and psychological factors, whereas non-associative tolerance is an adaptive process at the cellular level due to down regulation and/or desensitisation of the opioid receptors. The development of opioid-induced pain sensitivity is closely linked to the development of pharmacological tolerance. The two components of apparent opioid tolerance may involve opposing cellular mechanisms: a desensitisation process (pharmacological tolerance) and a sensitisation process (opioid induced pain sensitivity). Addiction in the context of opioid therapy for pain constitutes a constellation of maladaptive behaviours including loss of control over use, preoccupation with opioid use despite adequate pain relief and continued use of the drugs despite apparent obvious adverse consequences due to their use. Finally, new knowledge concerning detrimental influence of long-term administration of opioids on the immune and reproductive systems is emerging. Some of these consequences will be addressed in this session.

Abstract number: 47
Presentation type: Invited Lecture
Session: Long term consequences of opioid therapy in cancer

Opioid tolerance and hypersensitivity: a mask with two faces

Jürgen Sandkühler, Center of Brain Research, Vienna, Austria

Opioids are still the gold-standard to treat acute and chronic forms of severe pain. The indications for opioid therapy are continuously widened. As a result, some previously unrecognised effects of opioids have now attracted the attention of pain therapists and scientists (1, 2). During the last years, it has become increasingly clear that opioids can induce abnormal pain sensitivity via ‘central sensitization’, i.e. amplify pre-existing pain or cause pain by themselves. Selective desensitization of inhibitory opioid receptors during continuous opioid application or a shift in the proportions of Gs versus Gi/Go-coupled receptors may lead to prevalence of stimulatory opioid effects and promote opioid-induced central sensitization The mechanisms and signal transduction pathways that mediate opioid-induced hyperalgesia include activation of NMDA receptors and protein kinase C (PKC), activation of facilitatory supraspinal loops, up-regulation of spinal dynorphin and apoptosis of spinal dorsal horn neurons (3–5). These mechanisms are very similar to those of both opioid tolerance and neuropathic pain, which has important implications for the understanding and treatment options of these states. It has been proposed that apparent behavioural tolerance to the antinociceptive effects of opioids may in fact be the result of opioid-induced hyperalgesia. This has considerable therapeutic consequences: while a true pharmacodynamic tolerance can be addressed by increasing opioid doses, this will worsen the opioid-induced hyperalgesia that, in turn, requires dose reduction.

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Abstract number: 48
Presentation type: Invited Lecture
Session: Long term consequences of opioid therapy in cancer

High dose opioid therapy are we still treating pain?

Sebastiano Mercadante, La Maddalena Cancer Center, University of, Palermo, Italy

Clinical reports suggest that opioids, intended to abolish pain, can unexpectedly produce abnormally heightened pain sensations. It is possible to hypothesize an iatrogenic syndrome characterized initially by a declining analgesia, requiring further opioid escalation to mantain the previous level of analgesia – a worsening of pain and whole ‘body hyperalgesia (panalgesia) often associated with cognitive disturbances, delirium, agitation ranging to screaming in agony, grand mal seizures and multifocal myoclonus. Alternately, patients on opioid therapy, who present long periods of breakthrough nociception due to an inadequate dosage, may require an aggressive treatment with increasing opioid doses. After an initially favourable response, they could develop an hyperexcitated state worsened by further dose increments. The therapeutic difficulties paradoxically stay in accepting the widespread concept of morphine as a pure agonist, with a linear dose-response curve expressed as the more pain, the more drug. This may corresponds to a therapeutic paradox where the consequence (increasing pain), is treated favoring its cause (opioid escalation). Experimental and clinical studies have pointed out the possible autonomous hyperalgesic effect of high doses of opioids. In escalating opioid doses rapidly a recognition of the development of hyperalgesia should be suspected, as higher doses of opioids may stimulate rather than inhibiting the central nervous system, with different mechanisms, well recognized in experimental studies. Alternative procedures should be taken into consideration to break this vicious circle before pain conditions worsen irreversibly.

Abstract number: 49
Presentation type: Invited Lecture
Session: Long term consequences of opioid therapy in cancer

Pain epidemiology in cancer patients treated with opioids: new analytical approaches

Mogens Groenvold, Bispebjerg Hospital, Copenhagen NV, Denmark

This paper discusses methodological questions related to assessment of pain in longitudinal studies of consecutive, opioid-treated patients in palliative care, for example when routine palliative care is evaluated. A simple, widely used model is to measure pain intensity in all patients at the first contact, T0, and again at one or more later contacts, e.g. after one week, T1. This method assumes that one aims at reducing pain in all patients. However, if in some patients it is agreed that pain treatment is already optimized, then a simple comparison of pain in all patients at T0 and T1 is diluted by the patients for whom a reduction is not intended. The alternative would be to restrict the population to those for whom pain reduction is a goal. We present results from a study comparing the outcome of pain in 167 patients. The overall reduction in ESAS pain score was 9 points at one week (0–100 scale). In the 120 patients reporting pain as one of their five most important symptoms, pain change was? 13. In 47 patients not viewing pain as one of the most important symptoms (in whom pain treatment reduction was probably not sought), pain increased by 4 points. These data support the hypothesis that it may be more meaningful to evaluate the outcome of pain in clinically meaningful subgroups than in an entire cohort of patients. Pain outcome measures: Pain intensity is the most widely used outcome measure but alternative variables are also used. Osoba et al. developed the ‘Subjective Significance Questionnaire’ (SSQ) to quantify the patient’s subjective perception of the magnitude of changes. Cross-tabulation of SSQ ratings against changes in mean pain intensity scores may be used to interpret changes in mean scores. Results from a longitudinal study using four different measures of pain intensity as well as evaluation of pain according to the SSQ will be presented.

Abstract number: 50
Presentation type: Invited Lecture
Session: Bridging the gap between palliative Care Research in Developed and Developing countries – A joint IAHPC–EAPC session

The gap between research in developing and developed countries in Asia

Cynthia Goh, National Cancer Centre, Singapore, Singapore

Palliative Care services in Asia developed largely in the 1980’s and early 1990’s in the emerging economies of East Asia-Hong Kong, Japan, Korea, Singapore and Taiwan. But in many of the developing countries of South

East Asia, service development is only just beginning, and there is little time and effort to spare to spend on research. The development of research in palliative care tends to follow the establishment of services at a point when charitably funded services begin to achieve acceptance into the healthcare system with concomitant funding from government or insurance schemes. Sometimes, studies are instigated to justify the services for funding. For example, in Korea, the government funded a large project in 2003 to define the types of palliative care services the country needed. This gave a great impetus to palliative care research. Many of the countries in East Asia are non-English speaking, and what research there is tends to be published in the non-English local literature. The Asia Pacific Hospice Palliative Care Network is trying to improve this situation in a project where members select the most important papers in their local language and translate the abstracts into English for publication in a special series in the Journal Progress in Palliative Care.

Abstract number: 51
Presentation type: Invited Lecture
Session: Bridging the gap between palliative Care Research in Developed and Developing countries – A joint IAHPC -EAPC session

Bridging the gap between palliative care research in Developed and Developing Countries – setting a Global strategy

Suresh Kumar, Medical College, Calicut, India

Most people in need of palliative care live in the Developing world. But most of the palliative care services are concentrated in the developed world. In addition to the lack of access to much needed care to the majority of people, this situation also has so many other consequences. The most important among them probably is in the area of research. Almost all the research in palliative care now happen in the developed world. These research programs, understandably, concentrate on issues relevant to the developed world. A huge area of issues vital to the development and practice of palliative care in most regions of the world remain untouched. Lack of even the basic health care services, development and delivery of services becoming a priority for the few existing initiatives in palliative care in the “third world”, lack of resources or expertise to guide etc are some of the hurdles in the way of palliative care research in the Developing world. The situation can only be changed through meaningful partnership in research between initiatives in the developing and developed world. Such collaborations need to take the ‘third world realities’ into consideration. This is a complex challenge, but needs to be addressed. Some of the early initiatives in this direction are discussed.

Abstract number: 52
Presentation type: Invited Lecture
Session: Bridging the gap between palliative Care Research in Developed and Developing countries – A joint IAHPC-EAPC session

Barriers in research in Eastern Europe and how to overcome them

Daniela Mosoiu, Study Centre for Palliative Care, Brasov, Romania

Daniela Mosoiu MD. Palliative care is in the early stage of development in most ex communist European countries with few exceptions (Poland, Hungary). Tasks for those developing and promoting palliative care services in their countries include: delivering of services, up-dating and improving their own performance, setting standards, finding resources both human and financial, developing educational programs and working with authorities at local and national level. All these activities leave very little time for staff working in palliative care to perform research. Research needs to be carried out in the field and papers need to be presented at conferences in order to give palliative care the same status as other medical disciplines and to increase its credibility. Other barriers to research are related to lack of experience in research methodologies, difficulties in accessing up to date information due to prohibitive prices of journals or full text articles on the internet and limited financial resources. Research is not necessarily seen as an integral part of medical practice. Research in palliative care has to address different aspects that are often not related to drug efficiency and require other research modalities than the randomized controlled trials for example qualitative research methods. These barriers can be over come by training programs, increased access to information, multi-centre studies, and links with universities.

Abstract number: 53
Presentation type: Invited Lecture
Session: Bridging the gap between palliative Care Research in Developed and Developing countries – A joint IAHPC-EAPC session

Palliative care (PC) research in Latin America (LA). Results of a survey in the region

Roberto Wenk, Buenos Aires, Argentina, **Liliana DeLima**, Asociación Latinoamericana de Cuidado Paliativo, **Jorge Eisenchlas**, Pallium Latino-América

Objective: PC practice must be based on knowledge and evidence, and must be evaluated and reviewed: research is important for this process. PC research improves the care of patients with advanced incurable diseases facilitating evidence-based practice. Research in developing countries and regions of the world is limited. PC research in LA is scarce due to insufficient knowledge, limited funding and lack of infrastructure. A single barrier is the most influential: in 80% of the countries PC is not recognized as a discipline and it is not included in the health systems. Two consequences, lack of resources and failures in education, jeopardize PC research: limit training opportunities, limit funds for salaries, limit availability of trained researchers, limit the knowledge on how to select research topics and conduct fruitful research, etc. ALCP must assist PC programs and individuals to start or optimize research to produce results with impact on clinical practice and policy. The objective of this study is to obtain current information in LA countries about the level, amount and type of PC research available in the Region.
Method: The survey includes 16 questions, in Spanish and Portuguese, about demographic characteristics of responders; training, methodology and funding, and amount and type of research they conduct. It will be posted in the ALCP website during March 1 to April 1, 2006 (4 invitations to participate will be e-mailed to 1,650 subscribers), and will be distributed and hand collected among the participants to the Third Latin-American PC Congress during March 22–26, 2006.
Results and Conclusions: The survey is being implemented and no results are yet available. Its results and conclusions are expected to provide the rationale to support PC research through: • Increasing research awareness in the region. Providing assistance to develop research protocols with sufficient participants to generate valid data. • Generating collaboration between regional and developed international researchers. • Optimizing the access to specific resources for researchers. • Generating grants and training opportunities to selected health professionals. • Supporting the Columna de investigación in the ACLP electronic newsletter. • Conducting surveys to obtain information about successes and failures.

Abstract number: 54
Presentation type: Invited Lecture
Session: Studies that never landed or never got off the ground

Accrual and Attrition

Eduardo Bruera, MD Anderson Cancer Center, Houston, TX, U. States

One of the main challenges in palliative care research is how to identify patients and how to keep them in the studies. Most of the time fatal flaws exist from before activation. This presentation will discuss difficulties with accrual and attrition based on practical examples. Eligibility criteria made recruitment extremely difficult for studies on the management of dyspnea, delirium, and hydration. The excessive length of the study and/or the need for frequent hospital visits resulted in excessive attrition in studies of cachexia and pain. This presentation will discuss modifications in the protocol that were able to rescue some of these trials. Most palliative care research nurse's time is spent trying to identify candidates for studies. This is quite different from conventional research nurse positions and both funding and logistic planning should be conducted accordingly. Some important conclusions from these studies include: 1) clinicians and research nurses should be part of the writing of the protocol in order to identify obstacles to accrual and attrition; 2) pilot studies are very important in identifying problems; 3) researchers and clinicians over estimate the number of eligible patients and likely acceptance to participate in a study and underestimate the likelihood of complications such as infections, delirium, or missed appointments.

Abstract number: 55
Presentation type: Invited Lecture
Session: Studies that never landed or never got off the ground

Resilience and research: experiences of applying for project funds

Sheila Payne, University of Sheffield, Sheffield, Great Britain

Aims: To discuss two examples of research that was difficult to get funded – To identify the principles which help promote success when applying for research funds – To consider the role of resilience, persistence and determination in securing research funds. Two examples of challenging project A study of children's bereavement services – in collaboration with my colleague Liz Rolls, a total of eight applications of various types were submitted before this project was funded. A study of Chinese people's knowledge about cancer and palliative care services – in collaboration with my colleagues this study was funded after three previous attempts. The history of these two grant applications and the challenge to get funding will be described. Principles in applying for research project funds A number of key learning points will be shared and discussed including: The importance of a good research question – Getting the methods "'right' and explaining them well with a convincing rationale for their use – Do a literature review – Do a pilot or feasibility study – Building a research team with all the necessary skills and expertise – Establishing access to the sample – Forming collaborations with relevant stakeholders – Understanding the political and policy context – Ensuring the proposal fits with the remit of the funding body – Costing the study realistically – Responding promptly to new opportunities – Revise in response to feedback Resilience, persistence and determination in securing research funds. The main message will be to advocate resilience, persistence and determination in securing research funds-never give up''.

Abstract number: 56
Presentation type: Invited Lecture
Session: Studies that never landed or never got off the ground

Factors contributing to studies failing

Jurg Bernhard, Inselspital, Bern, Switzerland

There is no 'perfect' clinical study but a trade off between competing factors of inventive questions, sound methods and feasibility. For example, from a clinical point of view we are interested in the patient's overall experience of symptoms over the time of the relevant intervention rather than in widely spaced single point estimates. A comprehensive assessment ('best practice') may not be feasible in a palliative setting. If the investigators have achieved a reasonable compromise among these factors, and the proposal has been accepted, the highest hurdles are yet to come. The basic elements necessary to make a proposal successful may also be the preconditions of its failure. Inventive questions can only be addressed in a supportive environment, with a dedicated group of investigators willing to take the extra steps to collaborate. This environment can be difficult to create, even in academic institutions. It is essential to prepare investigators regarding the importance of the research question. Questions of palliative interventions are particularly vulnerable in times of clinical studies funded by pharmaceutical companies: Proposals are approved but internal resources are used for the lucrative company studies. Lip service by the persons in charge and educational advertising are not sufficient. A clearly defined allocation of resources is imperative. The study staff may best be motivated by a combined top down and bottom up management strategy. Proposals are implemented with the tacit understanding of investigators' pertinacity and long-term commitment. These features are challenged in rapidly changing environments, particularly in multi-center or multi-cultural trials. In conclusion, the factors contributing to studies failing are not solely related to the proposal but also to the research environment and the investigators. Failure is inherent in research. It is an ethical responsibility to pass on such experiences, especially to young investigators.

Abstract number: 57
Presentation type: Invited Lecture
Session: Plenary Saturday 27 May

A framework for developing randomised controlled trials for complex interventions in palliative care: The UK MRC model

Chris Todd, University of Manchester, Manchester, UK

Randomised controlled trials (RCTs) are the 'gold standard' design for clinical sciences. However, few RCTs have been conducted in palliative care (differentiated from palliative medicine), and even fewer have been conducted successfully. Complex interventions are a hallmark of palliative care. They are such things as The Liverpool Dying Pathway or Gold Standards Framework, or introducing a respite nurse, or making end of life decisions following a guideline, or changing the skill mix of nurses in the hospice, or arranging for a counsellor to talk to relatives of all patients on admission to the hospice. Complex intervention comprise a series of components, which may act independently or may be interdependent in their action. Complex interventions may be aimed at improving individual patient care, (e.g. a 'talk therapy' for depression) or a modification to how a service is organised (e.g introducing a hospice at home service), targeted at health care professionals to change their behaviour (e.g. Gold Standards Framework). Some complex interventions are at a public health or population level (e.g. publicity campaign about how to cope as a carer) but such interventions are uncommon in palliative care. When evaluating complex interventions we are usually trying to identify if the intervention is effective and/or to identify what components are actively making a difference. We may well use pragmatic RCT designs. The UK Medical Research Council has proposed a framework1 for designing trials of complex interventions which comprises 5 phases. (1) Pre-cinical or theoretical (2) Phase I or modeling (3) Phase II or exploratory trial (4) Phase III or definitive (5) Phase IV or long term surveillance. The purpose of each phase is described and each phase described in more detail. Of considerable importance in this scheme is the mix of methods (qualitative and quantitative) used in developing and testing the complex intervention. Such a scheme has a lot to offer palliative care research and we are currently designing studies in the UK using this approach in a number of areas of palliative care research.

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Oral Presentation

Abstract number: 58
Presentation type: Oral Presentation
Session: Policy & Politics

Choice or chance? How does patient choice operate in community palliative care services?

Catherine Walshe, **Ann Caress**, **Carolyn Chew-graham**, **Chris Todd**, The University of Manchester, Manchester, Great Britain

Background: Patient choice is central to palliative care policy. Patients are reported to desire respectful, individualised treatment and making informed

choices. Little is currently known about how patient choice operates within community palliative care services.
Aim: This research explored palliative care referrals within three UK primary care organisations.
Method and sample: Qualitative case study, purposively selecting three sites in North West England with different patterns of palliative care provision. Multiple sources of evidence included 58 patients and palliative care provider interviews, observation of referral meetings and documentary analysis.
Analysis: Data were coded, charted, mapped and interpreted, developing a thematic framework and theoretical propositions. Framework analysis techniques facilitated pattern matching within and across cases.
Results: Cross-case analysis yielded two main themes: Knowing about services. The onus was often placed on patients to contact and use services. However there were significant barriers: knowing what services were available, and understanding what services do. Community services were 'invisible' with no systematic way of informing patients or professionals about them. Choosing to use services. The stigma and fear surrounding palliative care concerned professionals and patients, causing services to be declined or deferred inappropriately. Once referred, professionals gave patients choice in visit frequency, but this was underused as patients were concerned about 'bothering' professionals. A strategy intended to empower patients thus appeared to restrict access.
Discussion: Professionals espoused the rhetoric of choice, but did not make informed choice a reality for patients. Information must be available in a structured way, which also takes account of both patients' and professionals' attitudes to care.

Abstract number: 59
Presentation type: Oral Presentation
Session: Policy & Politics

Factors associated with understanding palliative care: results from a survey of oncology out-patients

Jonathan Koffman, King' College London, London, Great Britain, **Angela Dias**, **Bharti Raval**, **Geraldine Burke**, **Charles Daniels**, St. Luke's Hospice, London, Great Britain

Introduction: Up-take of palliative care and related services has been shown to be influenced not only by supply, but also an understanding of what services are (1).
Research aim: To determine what factors are associated with an understanding of palliative care and related services.
Sampling frame: Oncology out-patients treated at two district general hospitals in north west London, an area with a high representation of black and minority ethnic (BME) communities.
Methodology: Face-to-face interviews with oncology out-patients.
Method of analysis: Associations were evaluated using univariate and logistic regression analyses.
Results: Out of 329 eligible cancer patients, 252 (77%) agreed to be interviewed between December 2004 and April 2005. Overall, 69% (n = 174) patients were female and the mean age of all patients was 63.3 years (range 32–95 years). A total of 82 (34%) patients self-assigned themselves as being from BME groups. Few patients interviewed (21%, n = 53) understood the term 'palliative care'. The role of Macmillan cancer nurses was better understood (66.7%, n = 164). After adjusting for confounding variables using logistic regression, not understanding the term 'palliative care' was significantly associated with BME patients (OR = 0.40, CI = 0.18–0.85, P = 0.018) and being male (OR = 2.36, CI = 1.07–5.20, P = 0.032). Not understanding the role of Macmillan cancer nurses was significantly associated with BME patients (OR = 0.49, CI = 0.26–0.89, P = 0.020), being male (OR = 2.09, CI = 1.13–3.86, P = 0.018), and not living with a spouse or partner (OR = 0.07, CI = 0.008–0.69, P = 0.023).
Conclusions: Understanding palliative care and related services was fragmented for many patients interviewed. However, it was worse among male patients, those from BME groups, and those living alone. Innovative strategies are required to mediate demand for palliative care among these population groups.

Reference

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Abstract number: 60
Presentation type: Oral Presentation
Session: Policy & Politics

Doctors' perceptions of palliative care and triggers and barriers to referral: a qualitative investigation

Claire Johnson, The Cancer Council NSW & Univeristy of Wallsend, Australia, **Afaf Girgis**, **Chris Paul**, The Cancer Council NSW/University of Newcastle, Newcastle, Australia

Introduction: Palliative care (PC) is often perceived as care for those who are within a few months of death. Therefore, people with advanced cancer who might benefit from earlier referral may not have their needs adequately met by late referral and many do not access PC services at all.
Aims: To obtain a deeper understanding of doctors' perceptions of PC and perceived triggers and barriers to referral to specialist palliative care services (SPCSs)in Australia.
Methods: Telephone interviews with 40 medical referrers to SPCSs, and five focus groups with PC providers.
Sample: A stratified, convenience sampling strategy was adopted. Both telephone and focus group interviews included participants from across Australia as well as from urban, regional and rural environments.
Analysis: Thematic analysis of data was conducted using both inductive and deductive reasoning. Broad categories were identified, grouped into related themes and compared with current literature.
Results: Results suggest that PC is perceived to provide comfort or symptom management for those nearing death. Referral was described as a reaction to patient symptoms. A broad holistic approach to the care of patients and the need for introduction early in the disease trajectory was not a dominant theme. There was limited identification of non-physical characteristics as causes for referral; and reports of anticipatory, proactive referral were rare. Reasons for non-referral related to the absence of symptoms, the doctors' ability to manage and how PC was perceived.
Conclusion: Education of medical practitioners is needed to impart the key principles of PC that are important for optimal care and appropriate referral of patients and families, particularly where psychological, emotional, cultural and spiritual concerns are evident. An objective needs-based approach to referral is needed to maximise the palliative care benefits for patients and their families.

Abstract number: 61
Presentation type: Oral Presentation
Session: Policy & Politics

The role of the general practitioner in end-of-life care: a qualitative study of patient views

Eva Michiels, Vrije Universiteit Brussel, Brussels, Belgium, **Reginald Deschepper**, **Luc Deliens**, Free University Brussels, Brussels, Belgium, **Freddy Mortier**, **Robert Vander stichele**, University of Ghent, Ghent, Belgium

Background: Different caregivers are involved in care for the dying in different stages of the dying process. General practitioners (GPs) are involved in all stages. Continuity and coordination of care are considered core features of general practice. However, little is known about how patients value their GPs' role in continuity of care at the end of life.
Objective: To evaluate patients' perceptions on the role of their GPs in continuity of care at the end of life.
Methods: Qualitative study design: in depth-interviews with 17 terminally ill patients with a metastatic solid cancer. All interviews were transcribed. Analysis based on grounded theory.
Results: Ten men and 7 women, all informed about diagnosis and prognosis and aged 30–90, were interviewed. In 11 cases we conducted a 2nd semi-structured interview after 3 months (2 with patient and next of kin, 4 with patient only, 5 with bereaved next of kin). Two dimensions of continuity were

identified as important for patients at the end of life. Important aspects of 'Relational Continuity' were follow-up in time, keeping in touch after referral to another care setting, contact with the family after death, feeling responsible for the patient, giving tailor-made information, and trust in relatives' GP. Important aspects of 'Informational Continuity' were exchange of information between the GP, specialists and care facilities and 'holistic' knowledge. Patients identified some 'Barriers' to the delivery of continuous care: lack of time, initiative, and knowledge, financial restrictions, waiting times, and holidays.

Discussion: Present-day developments of general practice, like increase of part-time work and out of hours services, are considered a threat to continuity. As this study suggests that patients attribute a pivotal role to the GP for specific aspects of continuity at the end of life, it is important to find a balance between these apparently conflicting facts.

Abstract number: 62
Presentation type: Oral Presentation
Session: Policy & Politics

Mapping palliative care development in Africa

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Aim: To assess the current state of hospice and palliative care provision in Africa, mapping the existence of services country by country and exploring the perspectives and experiences of those involved, with a view to stimulating new development.

Methods and analysis: Multi-method review involving a synthesis of evidence from published and grey documentary literature; ethnographic field visits to 7 countries; qualitative interviews with 94 individuals from 14 countries; collation of existing public health data. 47 African countries in total were studied. Participants were hospice and palliative care activists in Africa, including clinicians, managers, volunteers, policy makers and staff of donor organisations.

Results: The 47 countries of Africa could be grouped into four categories: no identified hospice or palliative care activity (21); capacity building activity is underway to promote hospice and palliative care delivery (11); localised provision of hospice and palliative care is in place, often supported by external donors (11); hospice and palliative care services are achieving some measure of integration with mainstream service providers and gaining wider policy recognition (4). Major difficulties relate to: opioid availability; workforce development; achieving sustainable critical mass; absorption capacity in relation to major external funding initiatives; coping with the scale of the HIV/AIDS related suffering.

Conclusions: Models exist in Uganda, Kenya, South Africa and Zimbabwe for the development of affordable, sustainable community-based hospice and palliative care services. The newly formed African Palliative Care Association has huge potential to promote innovation. Overall, interest in the development of hospice and palliative care in Africa has never been greater.

Abstract number: 63
Presentation type: Oral Presentation
Session: Policy & Politics

Ongoing national multi-center epidemiological study on prevalence and treatment of cancer-related symptoms in Russia

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At present in Russia no systematic national data on the prevalence and severity of cancer related symptoms in advanced cancer patients are available. To have a better understanding of the current status of symptom management the national multi-center epidemiological study among patients with advanced cancer was started in 2005. Specific aims of this study are to describe the prevalence of pain, fatigue, and other cancer-related symptoms among cancer patients being treated in institutions across Russia and to assess current symptom treatment and response to it across institutions. The expected sample size is 500 patients with advanced cancer from 10 cancer centers across Russia. Symptom status was assessed using M.D. Anderson Symptom Inventory at two time points and their treatment was monitored. The analysis of data from 181 patients (male/female 66/115; mean age 53 (SD 10.8) included in the study from all participating centers is presented. As a result, the most severe symptoms were fatigue (5.2), pain (5.2) and sleep disturbance (4.2) with the prevalence of 81.2%, 68.5% and 66.7%, respectively. Out of the total sample, 52 patients (28.7%) had only mild symptoms and 127 patients (70%) reported at least one symptom as moderate-to-severe. Among them there were 54 patients (30%) who had 5 or more moderate-to-severe symptoms and 8 patients (4.4%) who had 10 or more such symptoms. Fatigue was treated only in 40 (22%) patients; the decrease in fatigue level was achieved by 14 (35%) patients. Inadequate pain management was provided for 59% of patients. In conclusion, the results of this symptom outcome study will provide the first-line data on symptom control in Russia and will establish the framework for identifying the populations who experience poor symptom assessment and management. The results may also help policy-makers determine the factors that perpetuate poor symptom management, and to develop policies that will facilitate efforts for improved symptom treatment.

Abstract number: 64
Presentation type: Oral Presentation
Session: Policy & Politics

Antagonism or synergy between palliative care and euthanasia?

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Background: The European Association for Palliative Care (EAPC) posited that "euthanasia should not be part of the responsibility of PC" because legalisation of euthanasia could 1) cause slippery slope effects, and 2) impede the development of PC. Research question: Is the latter concern supported by the Belgian experience?

Method: Review of the historical, epidemiological and regulatory data.

Results: Among European countries Belgium, the second country to, after intense public debate, in 2002 legalise euthanasia, was second only to the UK in the development of PC. The highest per capita participation in EAPC conferences between 1999 and 2005 was by far from Belgium. Between 1980 and 2002 the drives for PC and euthanasia coincided, and both had wide public support. Many caregivers were pioneers and advocates of both. The eventual euthanasia bill adopted in 2002 coincided with a palliative care bill funding nation-wide implementation of PC. Physicians trained in PC practice euthanasia no less than their untrained colleagues. The catholic health-care institutions developed guidelines for the application of the law in the framework of their commitment to PC. Guidelines by medical and PC professional organisations endorsed the concept of 'integral palliative care', including euthanasia. Between 1998 and 2001, i.e. during the run-up to the legalisation of euthanasia, the incidence of administration of drugs with the intent to shorten life (physician-assisted dying) decreased and the incidence of symptom alleviation by (potentially life-shortening) treatment increased. This suggests that the tenets of mainstream PC influenced the practice of euthanasia and other life-shortening end-of-life decisions.

Discussion: Historical, epidemiological, public funding and regulatory data suggest that the drive for the legalisation of euthanasia reinforced the development of PC. Conversely, a well-developed PC network made the legalisation of euthanasia acceptable.

Abstract number: 65
Presentation type: Oral Presentation
Session: Policy & Politics

Complementary therapies for cancer patients: Availability, use and referral to complementary therapy services

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Background: In the last twenty years demand for complementary therapies (CTs) in supportive and palliative care for cancer patients has increased. Yet there has been little research about CT availability, use and referral patterns in cancer.
Aims: To explore CT availability, use and referral to two community based and one in-patient CT service for cancer patients.
Methods: CT availability was ascertained from each service. A two-part (pre & post therapy) postal questionnaire collecting data on referral patterns, use of CTs and demographics was sent to patients referred to each service over one year (N =280). A postal questionnaire was also sent to 1257 healthcare professionals (HCPs) to determine referral patterns to CT services.
Results: 101 patients returned both pre & post questionnaires (mean age = 54 years; female =82) and 292 HCPs (mean age =41.6 years; female =241) returned completed questionnaires. One community based service offered 5 CTs, the other 11, and the in-patient service 9. The top 3 therapies used by patients were aromatherapy massage (40.6%), reiki (38.6%), and reflexology (29.7%). 5 of the available CTs were not used. The top 3 therapies HCPs would/have referred to were aromatherapy massage (80.3%), aromatherapy (78.6%), and reflexology (76.9%). Self referral was more common to the community based services than to the in-patient service (43.2% vs. 24.3%). 81 patients (61.4%) were referred by a professional (only 3 by a physician). Reasons given by HCPs for non referral included lack of evidence for CTs, time and awareness & knowledge of CT services.
Conclusions: Few of the many CTs available were used often, and popularity of those used differed from what HCPs have/would refer to. Non-referral by HCPs, and matching patient to therapy remain problematic and may be remedied by research that improves the evidence base and development of referral policies for CTs. There is a need to inform HCPs of patients' motivations for choosing CT.

Abstract number: 66
Presentation type: Oral Presentation
Session: Non Cancer

Evaluation of a novel palliative care service for patients severely affected by multiple sclerosis

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Aim: to evaluate a new clinical service for people severely affected by multiple sclerosis (PwMS) in southeast London.
Methods: PwMS were referred to the new service by health and social care providers. Those patients consenting to participate in the evaluation were randomised to be seen by the service as soon as possible (fast track, FT) or after three months (standard intervention, SI). All study PwMS underwent baseline interviews (I1). All were then interviewed after 4–6 weeks (I2), 12–16 (I3) weeks and 24–26 weeks. SI patients undertook an additional interview 16–18 weeks post baseline, after they had received the clinical service. The outcome measures used with patients were the UNDS, AMTS, MSIS, POS, POS-MS-S1, health and social services questionnaire.
Analysis: the questionnaire data was entered into SPSS and analysed using descriptive statistics.
Results: 69 PwMS were referred to the service; 52 were randomised to the evaluation study, 26 to the FT and 26 to the SI group. Three patients in the SI group died during the study. The demographics of the two groups were equally matched (mean age 53; 17 females & 9 males in the FT group, 19 females and 7 males in SI; year of diagnosis 1987; total UNDS score 29 in the FT group and 30 in the SI group; no difference in type of MS.) Preliminary analysis has shown no differences between the groups at I1 and I3 for the MSIS, POS and POS-MS-S1 outcome data. We will be exploring whether some patients benefit from the service and some not by analysing any changes over time.
Conclusion: This model of specialist palliative care may not offer added value in the management of PwMS. The difference in survival between the two groups warrants further investigation.

Abstract number: 67
Presentation type: Oral Presentation
Session: Non Cancer

Supportive and Palliative Care needs of people with neurodegenerative conditions: findings from a national survey

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This is the first national Australian study to assess the effectiveness of supportive and palliative care services for people with Motor Neurone Disease (MND), Multiple Sclerosis (MS), Parkinson's Disease (PD) and Huntington's Disease (HD). The study comprised two phases: Phase 1 was a qualitative study involving interviews with 130 patients, caregivers and service providers. Phase 2 consisted of a national survey with a total of 503 patients and 373 caregivers responding to a mailed out questionnaire from three Australian states. Four support services rated high in importance by both caregivers and patients: Information about disease, equipment for daily living, reliable and ongoing dependable support workers and financial assistance for care. Caregivers were least satisfied with psychosocial care, availability of respite, family conferences held to discuss condition and information given about managing pain. It was acknowledged that caring at home depended on the caregiver's ability to cope physically and mentally with this role. A considerable amount of distress was inflicted on patients and their caregivers by the perceived lack of empathy, interest and communication skills of specialists, lack of knowledge about the conditions by hospital staff and delays in getting the diagnosis. Differences between the four groups will be highlighted. The analysis indicated that as dependency increased and more support was needed, both patients and caregivers were exhibiting higher distress symptoms and a poorer quality of life. Those who received more tailored services and more palliative care services were the most satisfied. Yet when faced with the expansion of palliative care in non-malignant disease, the palliative care movement seems cautious, perhaps even daunted about providing care to a wider range of patients than those with cancer''.

Abstract number: 68
Presentation type: Oral Presentation
Session: Non Cancer

The last three days of life of a random sample of people who died in the South of England following a stroke: views of bereaved relatives

Julia Addington-Hall, **Amanda Young**, **Angie Rogers**, University of Southampton, Southampton, Great Britain, **Tariq Saleem**, Kings College London, London, Great Britain

Background: There is increased recognition of the relevance of palliative care to people who die from circulatory and neurological conditions. Cerebrovascular disease (stroke) remains the third leading cause of death but very little is known about dying following stroke.
Aim: To investigate the experiences in the last 3 days of life of people who died from stroke, and their families, from the perspective of bereaved relatives.
Methods: A Stroke specific version of the VOICES questionnaire for bereaved relatives was developed and piloted. Informants were asked about the use of and satisfaction with services and quality of care in the last 3 days of life. The Office of National Statistics drew a random sample of 495 people who had registered a stroke death in Southern England, and sent them a questionnaire and one reminder 3 to 9 months after the death. Data from returned questionnaires were analysed using SPSS.
Results: 183 questionnaires were returned, a 37% response rate. 61% of the deceased were women; 64% were aged 80 or over at death. 53% of informants were the deceased's adult child. 61% of the deceased were in hospital during

their last 3 days of life, 24% in nursing or residential homes and 14% were at home. 28% were reported to be unconscious all the time and 24% some of the time. 31% of informants said that there was not enough help to meet personal needs and 30% not enough help with nursing care. 65% felt the deceased was always treated with respect and dignity. 60% had pain, for 66% of whom it was relieved partially, if at all. 13% of informants had some bereavement support, 22% of the remainder would have liked some.
Conclusion: People who die from stroke may experience inadequate nursing and personal care, and poor pain control. Further research is needed to explore effective ways of promoting better end of life care, including family support before and after bereavement, in the settings in which stroke patients die.

Abstract number: 69
Presentation type: Oral Presentation
Session: Non Cancer

A mixed methods approach to generate an evidence-based chronic heart failure palliative care service

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Background: Despite being a leading cause of death with high prevalence of distressing symptoms, relatively few chronic heart failure (CHF) referrals are made to specialist palliative care.
Aim: To develop an evidence-based palliative care service for CHF patients through original data integration.
Methods: The mixed methods protocol utilised concurrently: A) literature review on need and effectiveness B) 1 day census of hospital inpatients with CHF and palliative care needs C) Qualitative interviews with hospital cardiologists D) Qualitative interviews with hospital palliative care doctors & nurses E) Semi-structured telephone interviews with CHF/palliative practitioners nationwide F) Qualitative interviews with NYHA Stage III/IV patients G) Qualitative interviews with family carers.
Results: A) Only 1 service evaluation was identified. B) Of 981 occupied beds, 28 pts had CHF diagnosis, of which 18 pts had palliative care needs. C) Cardiologists ($n = 6$) were reluctant to disclose poor prognosis & had a strong curative focus with palliative care only relevant for the actively dying. D) Palliative care staff ($n = 6$) felt their skills for managing CHF pts were comparatively weaker due to low exposure. E) Services ($n = 20$) stressed need for joint pt care and mutual education. F) Patients ($n = 20$) reported poor understanding of their illness & prognosis but a desire for honest communication. G) Family carers ($n = 12$) reported little communication and planning for future exacerbations and preferred modalities of care.
Discussion: Service development recommendations are 1. Effective referral criteria for CHF patients, with adequate allocation of resources for the potential caseload increase. 2. Emphasis on improved communication and enhancement of basic palliative care skills within cardiology. 3. Improved co-management between cardiology and palliative care to better manage pain and symptoms during chronic stages. 4. Improved patient and family participation in care planning.

Abstract number: 70
Presentation type: Oral Presentation
Session: Non Cancer

Preparation for dying and views about the 'good death' in heart failure: a qualitative study with older patients and bereaved carers

Merryn Gott, **Sarah Barnes**, **Sheila Payne**, University of Sheffield, Sheffield, Great Britain, **David Seamark**, University of Exeter, Exeter, Great Britain, **Neil Small**, University of Bradford, Bradford, Great Britain

Aim: To explore attitudes to dying and views of a good death amongst older people with heart failure and their informal carers.
Methods: Participants were recruited from a larger study exploring palliative care needs amongst older people with heart failure recruited from primary care in the UK. This presentation draws upon interviews conducted with 40 people aged >60 years with heart failure (NYHA III–IV) and 10 interviews conducted with the bereaved carers of people with heart failure (3 months after the death). Interviews were transcribed verbatim and analysed thematically with the assistance of NUDIST.
Findings: Acceptance of death varied with some patient participants 'not ready' to die and others 'just waiting' to die. Some participants expressed concerns about the process of dying, particularly about being in pain, suffering, being breathless, dying alone, being a burden and having to go into residential care; however, they had few opportunities to discuss these. Both patients and bereaved carers confirmed that whilst funeral arrangements and financial matters were discussed prior to death, issues relating to the preferred manner of dying were rarely considered. Where participants did express views about their own death, sudden, but 'peaceful' deaths at home were preferred. This understanding of a 'good death' was confirmed by bereaved carers. Co-morbidities shaped the experience of dying, with bereaved carers of people who had a cancer diagnosis welcoming specialist palliative care services both prior to, and following, the death.
Conclusions: These findings confirm that older people with heart failure have concerns about dying; however, they rarely discuss these, or their wishes for the end of life. Primary care professionals are well placed to facilitate advance care planning, although are likely to require training to enable them to do so.

Abstract number: 71
Presentation type: Oral Presentation
Session: Non Cancer

Changing practice through action research: Palliative Care and Intensive Care

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Background: One of the challenges facing palliative care is to transfer best practice of care for the dying from a hospice to other care settings, and to non-cancer patients. It was noted that patients on the Intensive Care Unit (ICU) have a high mortality rate and many patients with advanced illnesses spend some time ICU during their final hospital admission. Research indicated that organisational and cultural barriers exist to improving the care given to dying patients on the ICU.
Aim: The aim of this study was to produce a revised version of the Liverpool Care Pathway for the Dying Patient (LCP), specifically for use on the ICU. The objectives of the study were: To examine current practice on the ICU in caring for dying patients – To evaluate the opinions of the staff on the value of the LCP – To evaluate changes in documentation of care given at end-of-life, following introduction of the revised LCP.
Method and Results: An action research methodology was utilised, in order for ICU staff to take an active role in the study, thus leading to a better chance of sustainable change. The methods used included: Focus group interviews with ICU staff, with thematic analysis of results – Field notes – Analysis of documentation pre and post-study A working group, made up of members of the ICU and hospital palliative care teams used the focus groups' findings to amend the LCP. After further consultation, the new LCP was launched on ICU with an accompanying teaching programme, run by the palliative care team. Completed LCPs were analysed after the project and compared with a base review of documentation carried out previously. The results included the following changes in documentation: 70% increase in patients stopping non-essential medications 100% of dying patients no longer undergoing blood tests, versus 25% pre-study Conclusion This demonstrates how a change in practice can be brought about by collaboration through action research.

Abstract number: 72
Presentation type: Oral Presentation
Session: Non Cancer

The Implementation and evaluation of the Liverpool Care Pathway (LCP) in one area of Scotland

Linda Kerr, Ayr Hospital, Ayr, Great Britain

Background: Inspired by the work undertaken by Ellershaw and colleagues (1997) the palliative care nurse specialist led the adaptation and implementation of the LCP within all medical wards within 2 district general hospitals.
Method: Implementation plan based on the 10 step programme developed by Liverpool was used-pilot areas identified; baseline review of clinical records; adaptation of pathway for Scottish health care system; development of an education programme; implementaion of LCP; evaluate programme. The project manager was notified each time a patient was identified in order to provide additional staff support at this time. A resource folder was also developed for each ward using the pathway. Data was collected, recorded on access database and analysed within a week of the patient's death.
Results: A total of 226 nurses attended the ward-based education programme and 60 patients have benefitted from using the LCP during the 12 month project. Following results are on 38 completed pathways. Mean age 74 with 42% male and 58% female. Only 12 patients were known to the hospital palliative care team and 17/38 had non-malignant disease enabling us to influence practice via use of the tool. Mean number of hours on pathway was 79. Discontinuation of innapropriate interventions were achieved in 80%thus promoting cost-effective care; pre-emptive prescribing according to the guidelines was achieved in 96% thus ensuring evidence-based care; documentary evidence available showing this group of patients are comfortable and families are supported at end of life.
Conclusion: The LCP has empowered staff to deliver high quality care to dying patients and their families irrespective of diagnosis and within busy acute wards. It has proved a useful mechanism for improving the quality of the documentation in this area of care with significant improvement in the results compared against the baseline. Furher implementation across the whole Health Board area is now planned.

Abstract number: 73
Presentation type: Oral Presentation
Session: Non Cancer

Decision making for incompetent patients

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UK guidelines stress the importance of consulting with patients' relatives when making decisions for incompetent patients. Little has been published on the effects of such discussion neither on patient care nor about their impact on patients' relatives or health care professionals. Methods Semi structured telephone interviews with specialist palliative care health professionals who had cared for a patient with vCJD within the previous two years. Interviews analysed using a framework approach. Results 22 palliative care professionals were interviewed about the care of 21 patients. Patients had a mean age of 29 years (16–66). On referral all patients were cognitively impaired, four were able to speak and seven were bed bound. Twenty patients were cared for at home by their family. Interviewees reported that being unable to communicate with patients, having little or no prior knowledge of the patient made it difficult to make decisions about treatments and this might have made them more reliant on the views of the patient's family. Interviewees reported a number of instances in which they and their patient's family have differed over the treatment of "symptoms", including drooling and jerking. Families were reported to have felt a great weight of responsibility and sometimes guilt when involved in making decisions about hydration and feeding. Families were frustrated when they were involved in discussions about treatments but did not have their wishes acted upon. Conclusion In caring for incompetent patients palliative care professionals will be involved in discussions and decision making with patients' relatives. Our study highlights difficulties that may arise from such discussion including, conflict between health care professionals and relatives and feelings of responsibility and guilt on the part of relatives. Relatives may also be frustrated by their lack of power in the decision making process.

Abstract number: 74
Presentation type: Oral Presentation
Session: Epidemiology

Electronic medical record: content and levels of interpersonal communication in terminal illness

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Premise: Communication is an instrument used to establish a doctor-patient relationship and a therapeutic course. The level, content and modes of communication depend on the patient's health and on the health care personnel (HCP) involved.
Aim: To define a model of data acquisition using an EMR (Electronic Medical Record) application that is coherent with the level, content and modes of communication used with terminally ill cancer patients.
Methods and patients: We used an EMR specifically designed for use in a home palliative care setting. 6 doctors, 5 nurses involved in verifying data acquisition specifically for end of life care. Communication was defined and stratified on 3 levels: patient-HCP; patient-caregiver; caregiver-HCP. The topics taken into consideration were: symptoms, prognosis, expectations, discomfort, anxiety, death. We analyzed a sample population dying in 2005.
Results 196 patients (121 male/75 female) dying in the first six months of 2005 were analyzed. The average survival time was 28 days (range 2–146 days). In 76% patient-HCP discussions involved symptoms, while in 27% prognosis was the main topic. These same two issues were discussed only 29% between the patient and caregiver, but were the topic of discussion in 85% between caregiver and HCP. The death, which deeply influences relationships between the patient, caregiver and HCP, was the topic of caregiver-HCP discussion in 54%, patient-HCP in 10% and patient-caregiver in 14%.
Conclusions: An EMR provides a means of logically monitoring home health care particularly if data is indexed. The communication used between all persons involved in home health care is difficult to analyze both for its complexity and scope. Nonetheless we thought it necessary to analyze the main issues discussed and to verify the effectiveness of communication so as to promote adequate counseling. All items and 2005 data will be analyzed so as to verify a model of data acquisition in a home palliative care setting.

Abstract number: 75
Presentation type: Oral Presentation
Session: Epidemiology

Are there typical trajectories of social, psychological and spiritual needs in patients with lung cancer and severe heart failure?

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Background and aims: Typical trajectories of physical decline have recently been described for people with end stage disease. Do social, psychological and spiritual levels of distress also follow characteristic patterns? We aimed to describe and compare the psychological, social and spiritual end of life needs of patients with cancer and heart failure and how these varied over time.
Methods: We synthesised data from two recent qualitative, longitudinal studies investigating the experiences and needs of people with advanced illnesses. The studies yielded 108 interviews with patients with advanced lung cancer ($n = 24$) or heart failure ($n = 24$) and 57 interviews with their informal carers. Interviews were transcribed with field notes. We thematically analysed the serial interviews as case studies longitudinally, and then cross-sectionally according to the stage of physical illness.
Results: Typical social, psychological and spiritual end of life trajectories can be discerned. In lung cancer, the social trajectory mirrors the steady physical decline, while psychological and spiritual well-being together dip at four key transitions: diagnosis, discharge home, recurrence and terminal stage. In advanced heart failure, social and psychological decline both tend to follow the physical decline, while spiritual distress fluctuates but tends to increase.

Conclusions: Distinctive trajectories of social, psychological and spiritual decline exist in these two conditions, and may well exist in a range of chronic disorders leading to death. An undue emphasis on assessing physical distress can be detrimental to health, defined in its broadest sense, in the face of death. Awareness of these trajectories may help clinicians explain to patients about the likely course of events, anticipate times of likely heightened social, psychological and existential distress, and think creatively about ways of minimising distress in their quest to help patients achieve a death with dignity.

Abstract number: 76
Presentation type: Oral Presentation
Session: Epidemiology

Patterns of analgesic use in hospitalised cancer patients

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Introduction: Despite better knowledge and clinical experience regarding pain treatment, many patients still do not receive adequate pain relief. Unfortunately clinical guidelines are not followed and the established treatment modalities not fully utilised. A survey was performed in order to assess cancer pain and its treatment offered in pubic Norwegian hospitals.
Methods: The survey was performed as a single day prevalence study in all somatic hospitals in Norway. Administrative data (including use of analgesic drugs) was registered for all patients while pain scores (using BPI) were performed in included patients.
Results: Data from 1337 patients from 57 hospitals was analysed. 872 were included in the final evaluation and 453 patients confirmed experience of cancer pain. 28% (n = 374) of the cancer patients used no analgesics, 4% (n = 57) only used co-analgesics like steroids, antidepressants, or antiepileptics for analgesic purposes, while the rest used traditional analgesics related to steps on the WHO ladder. 1/3 (n = 48) of the included patients using weak opioids (n = 140), corresponding to step 2, also used strong opioids belonging to the step 3 on the WHO ladder. No difference related to age was found in the use of opioids or NSAIDs. The overall use of co-analgesics like antidepressants and antiepileptics were low. 30% (n = 54) of patients with mean pain score > 5 (VAS 1–10) did not use opioids, and 7% (n = 12) of these patients did not receive any analgesics at all. Patients reported having break-through-pain (BTP) received significantly more analgesics and co-analgesics.
Discussion: We postulate that opioids, as well as co-analgesics, are underused in general and that patients with complex and advanced disease suffer more than necessary. Care workers' lack of basic knowledge of palliative care, insufficient focus on the patients' pain experience, and inadequate systematic symptom assessment are reasons for suboptimal treatment offered.

Abstract number: 77
Presentation type: Oral Presentation
Session: Epidemiology

Experiencing pleural mesothelioma: palliative care needs of mesothelioma patients and their families

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Aim: To determine the experience of mesothelioma from the perspectives of patients, their families and health professionals.
Sample frame and method: Community-based case study in 3 sites in Northern England with a history of asbestos-related industries using four methods: 1. Review of GP, hospital and hospice medical records of 80 deceased pleural mesothelioma patients. 2. Semi-structured interviews with 15 mesothelioma patients, m = 13, f = 2, 13 spouses present. 3. Six focus groups with bereaved relatives. 4. Interviews with 10 health professionals.
Analysis: Records review data were entered onto SPSS software and reported as descriptive statistics. Interview and focus group data were subjected to thematic analysis aided by software package, Atlas-ti.
Results: Interviews with patients and carers reveal a heavy disease burden, unmet physical and psychosocial needs, but also stoical determination to cope. Bereaved relatives recall severe caregiver burden and report ongoing distress exacerbated by coronial procedures and civil compensation claims. Interviews with health professionals demonstrate concerns and distress around the lack of effective treatments and standardised care and the disease burden suffered by patients. Records review revealed that 47 patients with pleural effusions required 163 pleural aspirations in the last year of life. Statistically significant differences were found between the sites including recording of psychosocial problems, use of opiates, success rates for pleurodesis, but no significant difference was found regarding survival (median 294 days).
Conclusion: This mixed method study reveals that the experience of mesothelioma includes a heavy disease burden for patients. Ongoing distress for relatives and difficulties for health professionals are exacerbated by lack of effective treatment or standardised supportive care. The particular difficulties of this group of patients and relatives are compounded by legal frameworks and issues of blame.

Abstract number: 78
Presentation type: Oral Presentation
Session: Epidemiology

HOPE 2004-cluster analysis of symptoms and problems

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HOPE (Hospice and Palliative Care Evaluation) is an ongoing quality assurance project in Germany. In the evaluation phase 2004 69 palliative care units participated in the evaluation and documented 1665 patients with a standardized documentation system. The documentation form included a checklist with 8 physical and 4 psychological symptoms, 2 nursing problems and 3 social problems. This checklist had been developed and evaluated in previous evaluation phases of HOPE. Checklist data at the time of admission were analysed in a two-step cluster analysis. Using Schwarz's Bayesian Criterion and ratio of distance measure an optimal solution with 3 clusters was identified. Patients in cluster 1 scored less symptom and problem intensity in all areas (less ill = LI), patients in cluster 2 scored highest on nausea, vomiting, constipation and appetite loss (gastrointestinal = GI) and cluster 3 emphasized organisational problems, excessive burdening of relatives as well as the physical symptoms dyspnea and disorientation (Dyspnea = DY). Female patients were more frequent in the GI cluster (LI 47%, GI 64%, DY 49%). Patients in the DY cluster more often were treated less than seven days (LI: 27% of patients, GI 28%, DY 36%). Patients in GI and DY clusters were more likely to have reduced performance status (LI: 55% of patients with ECOG 3/4, GI 84%, DY 89%) and to be treated until death (LI: 30% of patients, GI 51%, DY 54%). Cluster analysis identified three groups of patients treated on palliative care units in Germany. This may be used to develop and allocate resources according to patients needs.

Abstract number: 79
Presentation type: Oral Presentation
Session: Epidemiology

Hospice utilization in Taiwan by cancer patients who died between 2000 and 2002

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Background: To facilitate utilization of hospice services, Taiwan uses the National Health Insurance (NHI) as a major policy instrument.
Objectives: To evaluate the effect of this policy on hospice utilization by cancer patients during their final year of life, this study examines changes in the rate of hospice utilization, the length of stay (LOS), duration of patient survival (DOS) after enrollment, and the rate of late referral to hospice care from 2000 to 2002. Research Design: Retrospective cohort design by linking individual patient-level data from the National Register of Deaths Database and the NHI claims database.
Results: Among the 101 498 cancer patients who died between year 2000 ∼ 2002, the rate of hospice utilization during their final year of life grew substantially from 5.5% to 13.7%. However, Taiwanese cancer patients used hospice services for very short stays (median LOS ranged from 13.0 to 15.0 days) and were enrolled in hospice care close to death (median DOS ranged from 16.0 to 24.0 days). One-third to one-fourth of cancer decedents died within seven days or less after enrollment in hospice care. With the exception of significant increases in the mean DOS for inpatient hospice care, the mean LOS for both types of hospice care, the DOS for hospice home care, and the proportion of late referral to hospice care did not vary much over time.

Abstract number: 80
Presentation type: Oral Presentation
Session: Epidemiology

Forgoing artificial administration of hydration or nutrition in six European countries

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Background: Forgoing artificial hydration or nutrition (AHN), especially in incompetent patients who are terminally ill, has been subject of medical and ethical discussions. Opinions vary on whether stopping such fundamental care is ever justifiable. Information about the frequency and background characteristics of making decisions to forgo AHN is generally limited to specific clinical settings.
Objective: Comparing the practice of forgoing AHN in six European countries: Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland.
Methods: In each country, random samples of deaths were drawn from death registries. The reporting physician received a written questionnaire about the medical decisions that had preceded the patient's death. All deaths occurred between June 2001 and February 2002 and the total number of deaths studied was 20 480. Data were weighted for stratification and non-response to make the results representative for all deaths.
Results: A decision to forgo AHN, whether or not combined with other end-of-life decisions, varied from 3% of all deaths studied in Italy to 11% in the Netherlands. In all countries, AHN was more frequently withheld than withdrawn. A decision to forgo AHN often concerned patients aged 80 years or older, incompetent patients, and patients with a disease of the nervous system (including dementia). In all countries, patients for whom AHN was forgone did not more often receive drugs to alleviate pain and symptoms than other patients. A decision to forgo AHN was discussed with competent patients in 59% to 100% of the cases. For incompetent patients, relatives were involved in the decision-making in 62% to 90% of the cases. Nursing staff was more often involved in the decision-making than physicians.
Conclusions: Decisions to forgo AHN are made in all six countries studied. A large number of patients were incompetent and relatives were involved in the decision-making in about three quarters of these cases.

Abstract number: 81
Presentation type: Oral Presentation
Session: Epidemiology

Quality of life after radical cystectomy and orthotopic bladder substitution in Sweden and in Egypt – a prospective study

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Objective: To compare patient populations with assumed cultural differences to see if such differences translate into differences in answers to quality of life (QL)-instruments.
Patients and Methods: 29 Swedish and 32 Egyptian men who had undergone radical cystectomy due to locally advanced bladder cancer were included in the study. Two types of questionnaires were used in the prospective assessment of QL; FACT-G with the bladder cancer specific module FACT-Bl (Functional Assessment of Cancer Therapy-Bladder Cancer) and HADS (Hospital Anxiety and Depression Scale) and one for assessment of view of life.
Results: Higher FACT-G scores, e.i. better QL, were obtained in the Swedish patients compared to the Egyptian patients, both preoperatively and 3 mo postoperatively (except for physical well-being), but not after 12 mo (except for functional- and emotional well-being). Differences were also seen in the urogenital assessments provided by FACT-Bl module. The HADS revealed more depression among the Egyptian patient pre- as well as 3 and 12 mo postoperatively. Also anxiety was more common preoperatively and after 3 mo in the Egyptian patients, but not after one year. In 9 out of 15 questions concerning view of life the answers differed between the Swedish and the Egyptian men, both concerning their central values, (medical, moral, religious, private and global) and their belief-related values. Concordance between the two groups was seen to the statement "a difficult experience of life creates a greater will to live and often deepens understanding".
Conclusion: Patients with different cultural backgrounds respond differently to questions in QL-instruments. This should be recognized when analyzing results from comparative QL studies after medical or surgical treatment of malignant diseases. A detailed description of patients included in such studies is necessary or, better, instruments developed which eliminate the problem of cultural bias.

Abstract number: 82
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Assessment of pain in elderly patients with severe dementia: self-assessment or observational pain scales?

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Introduction: Pain assessment remains a clinical challenge in seriously demented elderly as there is limited data about the performance of pain assessment tools in this population.
Method: To address this issue we performed a prospective clinical study conducted in the Geneva University Departments of Geriatrics and of Psychiatry. All patients with DSMIV criteria for dementia, with a MMSE $<$ 11 and a dementia rating scale $= 3$ were eligible. Three unidimensional self-assessment tools: the verbal, horizontal visual and faces pain scales were administered in randomized order. An observational pain rating scale was independently completed by the nursing team.
Results: 61% percent of the 129 patients (mean age 83.7, 69%W) understood at least one scale. Comprehension rates were significantly better for the verbal rating and faces pain scales. There was moderate to substantial agreement between the two assessments of comprehension (intra rater kappa 0.60–0.83; inter rater kappa 0.59–0.65). The reliability of the three self assessment scales was substantial ($0.60 < ICC < 0.8$) to almost perfect ($ICC > 0.8$). Correlation between the three self assessment scales was moderate to strong (Spearman's coefficient from 0.45 to 0.94; $p < 0.001$). Observational rating correlated only moderately with self assessment. Among patients reporting pain, the observational rating scale under-estimated severity compared to all 3 self assessment scales.

Conclusions: Clinicians should not apply observational scales routinely in severely demented patients as many of these are capable of reliably reporting their own pain.

Abstract number: 83
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Living Now with Future Dying: integrating end-of-life care into a care home for older people

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Aim: The end-of-life needs of older people in care homes are receiving increased attention in the United Kingdom. An action research study is being undertaken to develop end-of-life care in two care homes for older people in order to explore how residents, relatives and staff can be involved in the process of change. In this paper, the views about end-of-life issues held by residents, relatives and staff in one care home for older people are presented.
Method: Data collection in the first care home entailed participant observation, interviews with residents, relatives and staff ($n = 10$) and a review of policies. Data from staff education sessions and seven meetings of a staff working group were also collected. Data analysis entailed a content analysis of the interview transcripts and meeting notes.
Results: A tension is seen in the place of end-of- life care in the care home context. 'Living now' describes the emphasis that residents and relatives placed upon life in the care home. Residents alluded to their own mortality in everyday conversations, and some residents were able to engage in more formal discussions about existential and practical matters. Relatives, too, acknowledged the future death of their family member, and wished to be involved in discussions about end-of-life decisions. However, their immediate concern was the quality of life in the care home. Staff were aware of the 'future dying' that residents would face, but were not always able to fully address this issue because of personal unease with death and dying. Staff who were uncomfortable talking about or caring for dying residents were limited in the end-of-life care they could provide.
Conclusions: There is a need to hold living and dying in balance in care homes for older people in order to develop appropriate of end-of-life care in this setting.

Abstract number: 84
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

End of life care: Experiences and attitudes of white indigenous and Chinese older people in the UK

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This paper reports two linked studies of white indigenous (n 77) and Chinese older adults (n 92). The research questions are: What preferences do older adults from white English and Chinese communities in the UK report in relation to end of life care? – What implications for service delivery can be identified?
Sample: Study 1 involved 77 older people from three socio-economically contrasting areas of Sheffield, UK. Study 2 involved 92 older adults from the Chinese communities in Sheffield and Manchester.
Study design: Both studies involved participatory qualitative research and liaised closely with community groups. Each study was conducted in two phases over 24 months. Phase 1: focus groups with participants drawn from community groups. Phase 2: interviews using 'vignettes' to prompt discussion.
Analysis: Data were audio taped and transcribed verbatim, and analysed as freestanding data sets. Focus group analysis informed the development of vignettes for interviews.
Findings: The use of modalities of end of life care: Most Chinese participants relied on a mixture of Chinese traditional and western medicine. Food was an important aspect of care for both groups, but with special significance for Chinese elders. White elders had clear understandings of hospice; few Chinese people understood this. Chinese elders perceived language barriers and culturally inappropriate environments in all settings of care.
Informal care at the end of life: Both Chinese and white older adults had concerns about the abilities of their family members to undertake end of life care, and their availability.
Preferred place of death: Older white people saw home as the preferred place of care and death but recognised practical problems in relation to this. The majority of Chinese participants expressed a preference for hospital for both pragmatic reasons and to ensure that the spirit of the dead person is located safely.

Abstract number: 85
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Involvement of nurses in medical end-of-life decisions

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Objective: To investigate how often nurses are consulted by physicians in taking end-of-life decisions with a possible or certain life-shortening effect (ELDs), how often nurses participate in administering lethal drugs to patients, and what factors are related to this involvement of nurses.
Methods: Data were collected in Flanders (Belgium) in 2001 within a nationwide cross-sectional retrospective death certificate study. Anonymous questionnaires about the medical end-of-life decision making were mailed to the certifying physicians. Data were corrected for disproportional stratification of the sample and for non-response bias in patient characteristics.
Results: Response rate was 59% ($N = 2950$). Physicians consulted at least one nurse in 57.1% of all ELDs. This occurred more often when the patient died in a nursing home (76.4%) or hospital (64.4%), than at home (38.9%). In all settings, discussion with nurses was positively associated with discussion with the patient's family, and in hospitals also with the patient. In hospitals and nursing homes, physicians were more likely to discuss the decision with nurses when it concerned lower educated patients. Of all cases where the physician reported the use of life-ending drugs, nurses administered these drugs in 66.7% in hospitals and nursing homes, and in 29.4% at the patient's home.
Discussion: Physicians' consultation of nurses before end-of-life decision making is substantial but can be improved considerably. Nurses' involvement in administering lethal drugs, although illegal in Belgium, is high. Lower education of patients as a predicting factor for physicians to involve nurses raises serious questions about the physicians' ability to communicate with all patients, but also about the existence of social inequalities in end-of-life care issues. Although additional research is needed to study these findings in more depth, guidelines to assign responsibilities and to optimize communication in ELDs seem appropriate.

Abstract number: 86
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Judgment of decision-making process by family regarding starting or forgoing artificial nutrition and hydration in nursing home patients with severe dementia

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Aim: The purpose of this study is to investigate how relatives of nursing home patients with dementia, for whom the decision whether to start or forgo artificial nutrition and hydration (ANH) was made, assess the decision-making process. Furthermore we evaluated the information given by the nursing home staff to the relatives and the care provided by them to the patient.

Methods: The study was an observational study based on written questionnaires. Relatives of 99 nursing home patients with dementia filled in a questionnaire at the time of the decision-making and 6 weeks after the decision was made or 6 weeks after the patient had died.

Results: Almost all relatives assessed the 4 aspects of the decision-making process (number of consults, content of the consults, carefulness of the decision-making and their own part in the decision-making process) at both times as ''good'' or ''satisfactory''. Furthermore it appeared that they judged the carefulness of the decision-making process significantly more often as ''good'' when they also assessed the other three aspects as ''good''. Especially their own influence on the decision-making process appeared to play a part in this matter. Information about the possible consequences of starting ANH as well as about the condition of the patient were experienced as sufficient by almost all relatives. This was also the case for the care offered to the patient.

Conclusion: In general almost all relatives reported satisfaction with the decision and with the carefulness of the decision-making process. This satisfaction did not differ between the moment of the decision and afterwards. For this it did not make any difference whether the patient had or had not died.

Abstract number: 87
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Terminal sedation: last medical resort in dying patients

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Object: Terminal sedation is defined as the induction of a pharmacological induced coma in immanently dying patients suffering from refractory symptoms. However, moral and conceptual confusion exists about terminal sedation and it's relation to euthanasia. The purpose of this study is to clarify this confusion in view of national policy in terminal sedation.

Methods: A questionnaire was sent to GP's, medical and nursing staff of hospitals, nursing homes, and hospices, involving questions about the aim of terminal sedation (n =1471). Additionally, a selected group of health care providers were interviewed by semi-structured interviews (n =50).

Results: The response rate of the questionnaires was 36%. The following results were obtained: 2% (95% CI; 1–4%) of the respondents agreed that there is no difference between terminal sedation and euthanasia, while 79% (95% CI; 76–83%) of them agreed that the aim of terminal sedation is not the death of the patient. Furthermore, 68% (95% CI; 64–72%) agreed that terminal sedation is part of the therapy for symptom control. The interviews showed that terminal sedation is an effective method to relieve physical suffering in the dying phase. Most respondents therefore agree that a medical necessity for euthanasia is inconceivable, but many still accept euthanasia for existential reasons.

Conclusions and discussion: Terminal sedation and euthansia are equally effective in relieving suffering for patients. Although, most of the respondents agree that terminal sedation is not aimed at death, but on symptom control. Therefore, terminal sedation should be the first option for dying patients as it concerns medical arguments. The pivotal argument for voluntary euthanasia as 'being a last resort', is challenged by terminal sedation. Further social debate is needed whether the preferences of the patient alone can serve as a sufficient justification to perform euthanasia.

Abstract number: 88
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Terminal sedation and medication use: Dutch regional guidelines of limited influence

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Object: Terminal sedation is defined as the induction of a pharmacological induced coma in immanently dying patients suffering from refractory symptoms. However, there is much confusion about the practice of terminal sedation. This abstract concentrates on medication use for terminal sedation.

Methods: A questionnaire was send to GP's, hospital physician's and nursing home physician's asking for the specific mediations used in terminal sedation (n =1471). The reported use of medication was compared to the prescription schemes of two Dutch regional guidelines. One from region of Nijmegen and one from region of Utrecht. Both guidelines are directed at intended terminal sedation and reject the use of morphine as independent sedative medicine.

Results: 36% of the contacted health care providers responded, 21% reported their last case (n =314). The respondents reported the use of the following medications (%): Benzodiazepines (18%), morphine (23%), neuroleptica (3%), benzodiazepine/morphine (33%), benzodiazepine/neuroleptica (5%), morphine/neuroleptica (6%), benzodiazepine/morphine/neuroleptica (11%). Compared to the regional guidelines, 23% (95% CI; 18%–28%) of the respondents acted according to the Nijmegen guideline, 42% (95% CI; 37%–47%) of the respondents acted according to the Utrecht guideline.

Conclusions: These results indicate that the guidelines have limited influence in medical practice. This can have two possible reasons. First, the guidelines are too restrictive. Since the guidelines are only concerned with intended sedation, sedations that appear as a side effect of normal symptom management in the terminal phase are not defined as terminal sedation. Second, the respondents lack specific knowledge about the correct application of the guidelines. Physician skills about the correct use of medication for refractory symptoms and terminal sedation should be improved and guidelines should be more inclusive.

Abstract number: 89
Presentation type: Oral Presentation
Session: Terminal Care & Elderly

Constraints of the Ordinary: caring for dying patients in a hospice in Scotland

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The phenomenon ''being with'' that relates to what the patient is experiencing when close to death is an important aspect underlying specialist palliative care. The aim of this observational study was to generate adequate description of how nurses and nursing care assistants do ''being with'' in day-to-day nursing practice within a hospice setting. Observational data was collected over an 8-month period in an inpatient hospice in Scotland in 2002. Drawing on the philosophy of Charles Taylor, I reflect and interpret the way that nurses and nursing care assistants constructed their care for dying patients. I came to understand that the nurses and the nursing care assistants perception of ''being with'' was in relation to providing 'comfort' rather than facilitating the opportunity of facing death. The consequence of this was that the patients where 'comforted' but they were not encouraged to face death in the way that Saunders suggests. Through revisiting Saunders's theory in the light of my data, it became clear that there is a tension between the 'theory' and the 'practice' of ''being with'' in relation to its practical outworking. In conclusion I compare the phenomenon of death as discussed by Saunders with that of Heidegger. By discussing my data in light of Heidegger's theory and how human beings can face death, provides an understanding of how the nurses and nursing care assistants in this hospice cared for dying patients. They constructed ''being with'' in terms of providing comfort in order to manage their own feelings around death and dying. The research offers some important insights around the tension between the hospice ideology of a 'good death' as provided by Saunders, and how in reality the day-to-day care of dying patients in this hospice was being managed. The results of my research have serious implications and may herald the watering down of an important ideology if specialist palliative care is to remain significant.

Abstract number: 90
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Low-intesity phsycial exercise (LIPE) in palliative care day therapy patients: a pilot study

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Physical exercise has been used as a non-pharmacological therapeutic intervention in cancer, COLD, CHF and the elderly and has demonstrated improvements in fatigue, pain, mood states and general QOL. There is however, limited research on physical exercise in the palliative stage of cancer. Aims of the study were: 1. To determine the feasibility of using LIPE in the palliative stage; 2. Explore the effect of LIPE on fatigue, mood and QOL; 3. Provide data to determine sample size for a future multi-centre study. Methods: A pre- and post-intervetnion sudy was conducted, with an intervetnion group undertaking LIPE 5–7 times per week for 3 weeks using a video provided for home use. Intervention was a 12 minute seated low-intensity exercise programme (ROM) designed by chartered physiotherapist. Sample criteria were that the individual was in the palliative stage of their illness, had a rating on the Karnofsky Performance Scale of 60, had an estimated life expectancy of at least 6 weeks and were able to stand up and sit down independently. In total 14 subjects were enrolled in the intervention group and 13 in the control group. Data: Using standard instruments, fatigue, mood, quality of life were measured at the beginning and end of the 3 week study period. A diary was also filled in twice daily. This presentation will report the findings of the pilot using Rinck's (et al, 1997) framework of methodological concerns in effectivness research in palliative care. The acceptability of the programme to patients in the palliative stage of their illness was also assessed and will be reported. The intervention of LIPE was feasible, well tolerated and safe in this population. The outcomes were able to be measured with the additional support of a dedicated research assistant. In the intervention group, the accrual rate of eligible subjects was 50%, the attrition rate was 30%.

Abstract number: 91
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Using a Cybex dynamometer to measure quadriceps endurance in patients with lung cancer

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Introduction: Cachexia is common and difficult to treat. New approaches are required and need to be assessed. Muscle endurance may be an appropriate outcome to use but its measurement needs to be acceptable and repeatable. This study has examined the use of a Cybex dynamometer to measure endurance of the quadriceps muscles.
Methods: 16 patients with non-small cell lung cancer and an ECOG of 0 or 1, underwent the test on three separate days, 48 h apart and one month later. The first test was for familiarisation. In each test, the patient had their dominant leg attached to the Cybex and extended and flexed the leg at the knee for 25 repetitions. Acceptability was assessed by questionnaire. Aspects of endurance assessed were the total work done (in joules, J) in 25 repetitions (TW25) and in the first and last 5 repetitions (WF5 and WL5 respectively). Between-day repeatability was expressed as the standard deviation of the difference between tests (SDdiff) and the intra-class correlation coefficient (ICCC; values >0.8 indicate good repeatability).
Results: Of 16 patients recruited, full data was available for 13. Two patients withdrew due to clinical deterioration and for one data was lost because of technical reasons. All subjects found the test acceptable. The outcome measures were highly repeatable with SDdiff and ICCC values of 288J and 0.92 for TW25, 90J and 0.88 for WF5 and 45J and 0.92 for WL5.
Conclusion: The Cybex dynamometer is an acceptable and repeatable method of measuring quadriceps muscle endurance and we plan to further examine its use as an outcome measure in cachexia trials.

Abstract number: 92
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Cancer related fatigue: central or peripheral

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Purpose: Cancer related fatigue (CRF) occurs in more than 70% of cancer patients and is a major factor determining quality of life. The pathophysiology and site of origin of CRF remains unknown. CRF may originate from the central and/or from the peripheral neuromuscular system. The purpose of this study was to determine effects of motor activity-induced fatigue on subjective and objective fatigue rating, motor performance, and physiological measurements involving central and peripheral neuromuscular locations in advanced cancer patients.
Methods: Patients with advanced solid tumors and age, gender, and Body Mass Index (BMI) and matched healthy controls participated. They all completed a Brief Fatigue Inventory (BFI). Cancer patients were not on antidepressants, had Hgb $>10\%$ and were at least 4 weeks from the last chemotherapy or radiation treatment. BFI scores, motor performance, central drive, neuromuscular junction propagation (NMJP) function, electromyography (EMG) signal and force generating capability (FGC) of muscle were evaluated before and after a fatigue task that required the participants to sustain a muscle contraction to exhaustion.
Results: Compared to the healthy controls, CRF patients exhibited greater BFI scores, reduced motor performance, impaired NMJP function and greater muscle reserve as measured by involuntary stimulated muscle force (twitch force) at the onset of fatigue. CRF had fewer effects on central drive, EMG and FGC than on NMJP.
Conclusions: Patients with CRF feel significantly more fatigued (neuropsychological fatigue), which limits their motor performance. The fatigue symptom in CRF is determined at least in part by impairment in the NMJP function. Within a given duration of motor performance, CRF has an effect on central drive, EMG and FGC of the muscle in CRF. Motor performance related CRF involves dysfunction in both the central nervous system and neuromuscular junction.

Abstract number: 93
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

The use of parenteral/enteral nutrition in Swedish palliative care

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Background: The use of enteral or parenteral nutrition in palliative care is controversial and the evidence-base is still weak.
Aim: The aim was to study the use of enteral (EN) and parenteral nutrition (PN) in Swedish palliative care.
Materials and Methods: A questionnaire with 24 specified items was sent in the spring of 2005 to all members of the palliative research network in Sweden-PANIS-which at that time comprised 42 units with over 2000 patients enrolled. A web based survey generator was used to collect data. All judgements of treatment effect were performed by the nurse and/or physician responsible for the patient.
Results: 34 units participated and data from 1531 patients, mainly in advanced home care, were collected. Mean age was 68 years, 54% were

female and 90% had a cancer diagnosis. A total of 127 (8%) patients had received PN during the week before assessment. 104 (82%) patients had a cancer diagnosis and the main indications for treatment in these patients were weight loss and/or anorexia. Bowel obstruction was an indication in 19 patients. 75% of the cancer patients had an estimated life expectancy of more than a month and 86% of these patients were judged as having positive effect of the treatment, as compared to 48% of those with an estimated life expectancy of less than a month. Almost 90% of the patients with PN had an oral intake and more than 50% could digest solid food. A total of 51 (3%) patients received EN, 29 (57%) of them had a cancer diagnosis and 86% had dysphagia as the main indication for treatment.

Discussion: The research method used in the network has been validated and data on this will be presented. This study shows that PN is not uncommon in Swedish palliative care. It is mainly used as a complement to ordinary food in contrast to general guidelines which states that it should be restricted to patients in whom the GI-tract can not be used for nutrition. Studies investigating the impact on quality of life are needed.

Abstract number: 94
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Views about the use of traditional Chinese medicine in the UK

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Aims: This paper reports on the perceived role of traditional Chinese medicine in end of life care by the Chinese older people resident in two northern cities in the UK. It draws on the findings from a study exploring and understanding the views of older Chinese people about cancer, palliative care and end of life care.

Sample: A total of 92 Chinese older people (aged: 50–89) from Sheffield and Manchester were interviewed.

Design and method: A qualitative research study with 46 people participated in 7 focus group discussions. A further 46 people participated in semi-structured interviews. The discussions and interviews were conducted in Cantonese, Hakka, Mandarin and English.

Analysis: Data were transcribed and translated into English for analysis using the principles of grounded theory. With the aid of NVivo software, an agreed framework of thematic categories was developed and applied to all the focus group data. This early stage of analysis informed subsequent data collection and all emergent issues were pursued throughout the research.

Results: Western medicine was regarded as suitable and desirable for serious diseases such as cancer. Chinese medicine was used to counteract side effects of chemotherapy and other forms of western treatments; provide comfort, invigorate the body, improve energy level and give hope; treat the person in illness rather than the mere symptoms. Most respondents would use a combination of Western and Chinese medicine as cancer and palliative treatment.

Conclusion: Providing comfort and support, giving hope, promoting quality of life and treating the person as an individual are some of the key concepts of palliative care. Our studied group believe traditional Chinese medical model does incorporate these concepts. Health professionals should be aware that an integrated approach to palliative care using a combination of western and other health models might be of value.

Abstract number: 95
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Do women experience higher levels of fatigue than men at the end of life? A longitudinal study shows a gender difference in fatigue severity in a home palliative population.

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Advances in fatigue research are limited in part by the lack of a consistent, clinically and biologically meaningful definition of this symptom complex. Our conceptual understanding of fatigue will be greatly influenced if gender differences exist in how men and women experience or report fatigue. Despite data from primary care to palliative settings suggesting that women may report fatigue differently than men, few studies have evaluated gender differences in fatigue at the end of life. Fewer still have described gender differences in the course of fatigue over the trajectory of disease. This longitudinal study used the Brief Fatigue Inventory (BFI), the McGill Quality of Life Questionnaire (MQOL), and performance status measures at approximate 2-week intervals in a home palliative population. 102 patients were enrolled. Results show that fatigue scores are significantly higher in women than men at entry (week 0, $p = <0.001$) in both univariate and multivariate analysis. This difference is also significant longitudinally in a repeated measures analysis. Quality of life scores, although moderately correlated with fatigue scores, do not differ by gender. Whereas, depression is significantly higher in women and related to fatigue scores at week 0 and over time. However, depression does not explain the difference in fatigue scores by gender. This study shows a significant gender effect on fatigue scores that is not explained by baseline differences in performance status, depression, quality of life or socio-demographic variables. Further disease-specific studies are needed to elucidate the role of the underlying diagnosis and the treatment associated with it on the fatigue reported by men and women. However, this study raises questions regarding gender differences in the underlying biologic mechanisms and social gender role functioning. If this finding is substantiated, it will significantly impact the assessment and management of fatigue.

Abstract number: 96
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Nutrition, inflammatory markers and quality of life in palliative care patients

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Purpose: Most patients with advanced cancer develop symptoms of anorexia and cachexia, but the biological mechanisms and psychosocial correlates are not fully elucidated. This study aims to use a standardised assessment to evaluate associations between nutrition, psychosocial parameters, cytokines and survival in a convenience sample of 100 patients with advanced cancer referred to a hospital palliative medicine team.

Methods: Patients provided clinical and demographic data, and on one occasion underwent nutritional assessment [BMI, Patient Generated Subjective Global Assessment (PGSGA), grip strength, serum albumin], psychosocial assessment [Hospital Anxiety and Depression Scale (HADS); Social Support Questionnaire; McGill Quality of Life instrument (MQOL)] and gave blood for inflammatory markers [C-reactive protein CRP, vitamin B12 and pro-inflammatory cytokines]. Survival was measured in days, truncated at 180.

Results: As of 1st August 2005, 79 patients had been recruited, median age 65 years, median performance status ECOG 2. Lung cancer was commonest primary. Median BMI is 23, 22% being <20. Median albumin level was 35 g/L. Median PG-SGA score 14, 89% malnourished/at risk of malnutrition. Median global QOL score and subjective wellbeing score both 5. Median CRP was 41 mg/L (range 1–562), >10 mg/L in 79% and >100 mg/L in 27%. Cytokines analysis shows some IL-6 and IL-8 positives and many positive for VEGF. All other cytokines are negative. 40 (50%) participants are known to have died, 40% of them within a month of recruitment.

Conclusion: Malnutrition is very common in the advanced cancer population, frequently associated with an inflammatory state and impaired quality of life. It is feasible to formally assess these variables in the healthier subset of the palliative care population. Prospective studies are needed to determine causal relationships amongst the various factors and any impact of therapeutic interventions at this late stage of disease.

Abstract number: 97
Presentation type: Oral Presentation
Session: Nutrition & Fatigue

Ghrelin for patients with anorexia/cachexia related to advanced cancer: a randomised, placebo-controlled, double-blind, cross-over Phase I/II Study

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Background: New treatments for anorexia/cachexia in the palliative care context are needed. Ghrelin is a natural hormone with stimulatory effects on appetite, gastrointestinal motility and growth hormone, and likely amelioration of proinflammatory cytokines.
Aim: to assess safety, tolerability, and preliminary efficacy of i.v. ghrelin in pts with advanced, incurable cancer.
Methods: Inclusion criteria: loss of appetite (> =3 VAS), weight loss (2%/2 or 5%/6 mts), chemotherapy (wkly or continuous) ongoing for > =8 wks or stopped (> =4 wks). Ghrelin (Merck Biosciences, Switzerland; dose first 10 pts of 10 pmol/kg BW/min, pts 11–21: 40) or normal saline were given in randomized order wkly for two wks (Tx days 1, 4, 8, 11) iv over 60 min before lunch. Baseline (BL) and end-of-study (EOS) visits were 1 wk before and after treatment. Toxicity and safety were assessed clinical (CTC-Toxicity Criteria, safety labs) and by tumour measurement. On Tx VAS of appetite, hunger, anxiety, early satiety, nausea, fatigue and nutritional intake were measured repeatedly. At BL, Tx, and EOS quality of life (EORTC-QlQ-C30), eating-related symptoms (adapted FAACT, NCCTG-instrument), weight, and autonomic function were assessed. Hormones regulating food intake were monitored.
Results: 21 pts were randomised, 2 pts dropped out before day 11 (sepsis, bowel obstruction). Drug-related adverse events (placebo or ghrelin) included increased bowel activity in many patients, sweating, and sporadic nausea/vomiting, dyspnea, chest pain, diarrhea and constipation. The development of tumour was as expected in the population. The trial is closed as accrual is now completed, final results are expected beginning 2006.
Conclusion: Ghrelin as given here is well tolerated and safe in pts with far advanced cancer. Data analysis will reveal whether ghrelin has a potential to palliate eating-related suffering in the palliative care context. Supported by Oncosuisse and Gastrotech, Denmark.

Abstract number: 98
Presentation type: Oral Presentation
Session: Methodology

The Swedish national registry of palliative care

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Sweden is a country with a tradition of national quality registries. In October 2004 a workgroup was formed to make a national registry regarding palliative care. In Sweden approximately 10% of deaths occur with a palliative service directly involved. The workgroup decided then to try to cover all deaths. The overall goal is to achieve good palliative care for everyone no matter who the caregiver is. Having made that decision the group focused on the last week before death, death itself and the remaining family. A questionnaire containing questions like “Was the patient informed that he was soon to die?”, “The degree of symptom control last week in life”, “How long before death did the patient loose his ability to express his opinion?” was made. This is to be filled in by the caregivers (nurse or dr) at each death. Another questionnaire concerning the unit itself asks about, beds, staff, routines etc and is filled in once a year. The questionnaires works over a secure connection on the internet. A pilot study was performed in the period May 2005–August 2005. 124 units from hospitals, hospices, community nursing homes, advanced homecare teams etc all over the country filled in 282 patient questionnaires. That is about 1% of all deaths that occurred during that period. The pilot study showed that both the questions and the internet technique works with all kinds of caregivers. The report shows both differences and similarities between the different types of caregivers. This study has been observed by the National Board of Health and Welfare. The Board and the Registry will collaborate the coming 12 months. The main goals are spreading the registry all over the country, analyze the data to find measures of good palliative care and to make an inventory of palliative services. Data are already available on different aggregation levels and will in the end be open to the public as well. In May 2006 there will be data representative for all of Sweden.

Abstract number: 99
Presentation type: Oral Presentation
Session: Methodology

Cross-cultural adaptation (CCA) of the palliative outcome scale (POS) into Spanish/Argentina

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Background: Although hardly followed in a strict way, CCA remains essentialas a previous step to validate any outcome measure developed in foreign languages and cultures, being crucial before proceeding to the psychometric validation phase. To perform this process it is necessary to take account not only of linguistics but of cultural adaptation to achieve conceptual equivalence, whose lack precludes the possibility of adaptation.
Objective:To develop a CCA of the POS into the Argentine culture and language (Spanish).
Population and Methods: A classical method of CCA was enhanced by seeking a set of equivalences based on the universalist assumption that relevant domains vary across cultures. Conceptual equivalence was tested by reviewing the literature and interviewing experts patients before starting the adaptation process itself. It was followed by 2 forward, 2 back translations and synthesis of all of them, later reviewed by an experts’ committee. Finally pretesting in a purposeful sample of 65 palliative care patients and 20 health-related professionals was done.
Results: The multiple sources searched showed the POS presented adequate conceptual equivalence for our population. Forward and backward translations made necessary to introduce changes related to grammatical aspects, cultural differneces in word usage and concept experience in most of the items. No blatant inconsistencies between original and backtranslated versions were found. Committee approach and close contact with the POS author lead to introduce further changes in the tool. Field testing through structured and in-deep interviews with 65 patients was crucial to develop the final version. The stages followed through the CCA process ensured the achievement of semantic, item, operational and functional equivalence.
Conclusions: Through a strict methodology we developed a culturally validated translation of the POS ready to be validated before its use in the PC context.

Abstract number: 100
Presentation type: Oral Presentation
Session: Methodology

Failure of a research protocol

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Background: Many research protocols in palliative medicine will never be brought to the end or their results, for a number of reasons, will never be published.
Aim: Sharing the experience of a failed research protocol and identifying the main reasons of failure in order to avoid them in future research activities.
Method: In a pilot study 5 out of 9 patients draw benefit from the topical application of morphine gel on painful skin ulcers. Encouraged by these results a placebo controlled RCT was started, with the aim to include 24 patients over 18 months. For a low patient accrual (1 patient in 12 months) the study was stopped after 1 year. The main reasons of this low accrual were identified and analyzed.
Results: The main reasons of the study failure were: 1. Lack of specific allocation of resources for the research. 2. Uncertainty about the allocation of the responsibilities for the study. 3. Underestimation of logistical problems (study period too long, study too complicated). 4. Unset of an ethical dilemma among caregivers caused by the use of placebo. 5. Difficulty of caregivers to match interest in caring with interest in research. These problems and pitfalls will be shared and discussed with the audience.

Abstract number: 101
Presentation type: Oral Presentation
Session: Methodology

"I will do it if it will help others": motivations and distress among patients taking part in qualitative studies on palliative care

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Background: Palliative care patients are perceived as a vulnerable population and are often shielded from research by health care professionals and ethical concerns.
Aim: To investigate the process of recruiting and interviewing palliative care patients and carers for qualitative and mixed-methods studies and to understand what causes distress and what is helpful.
Sample: Patients were recruited for 2 studies through Nurse Specialists. Currently 31 patients and 6 carers have been interviewed.
Methods: A descriptive qualitative study. The interviews ended with questions to patients and carers about their motivation to participate, their thoughts on the studies and whether this had been a distressing or helpful event and why.
Analysis: The recruitment process was recorded, as was the number of patients or carers accepting or declining. The circumstances in which the interviews took place were described. The patients' reflections on the process of participating in these studies were labelled and themes were identified.
Results: Only 20% of patients declined an interview although attrition due to illness and death was higher amongst cancer patients. Motivation to participate in the studies were 1) altruistic, patients wanted to contribute to the improvement of future care for others, 2) to register gratitude and concerns about care. The interviews were considered helpful, especially thinking about the future. Helpful comments were received on the process and instruments for one of the studies. Consent forms were sometimes read with apprehension and being unable to sign was experienced as upsetting.
Conclusions: Palliative care patients and carers were capable of deciding whether to participate in interviews and negotiating the circumstances in which they wanted this to happen. The informal nature of the interview allows for an empathic relationship between the researcher and palliative care patient and carer which is appreciated and experienced as beneficial.

Abstract number: 102
Presentation type: Oral Presentation
Session: Methodology

Response shift in palliative treatment of small cell lung cancer patients

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Objective: To demonstrate the usefulness of SEIQOL-DW to measure adaptation in the palliative treatment of small cell lung cancer (SCLC) patients. Adaptation in order to maintain optimal levels of QoL is essential. Response shift (RS) represents aspects of adaptation that are related to QoL. RS in this study is defined as changes in content and importance of individually nominated life areas. This paper provides information by which the measurement of RS with the Schedule for the Evaluation of Individual QoL (SEIQoL-DW) can be improved.
Methods: A qualitative exploratory longitudinal multiple case study. SCLC patients were recruited from five outpatients' clinics for lung diseases in the Netherlands. Interviews were conducted at equivalent points in treatment, starting within 14 days after diagnosis. The SEIQoL-DW is a semi-structured interview method. Patients 1. may nominate five important life areas ('cues'), 2. rate the cues, and 3. determine the relative importance of the cues. At different points in time, patients might nominate different cues and might change their weighting of identical cues.
Results: 21 patients were interviewed 4 times (9 men, 12 women, age 38–73). QoL scores remained stable or improved in most patients, despite deteriorating health. RS's during treatment were observed in all but three patients. RS could be assessed reliably using the standard SEIQoL-DW form in 11 patients. But in the remaining 10 patients transcripts of the interviews were needed to accurately determine the content of RS's. Especially changes in the description (i.e.meaning) of cues showed what 'really matters' to patients and their impact on QOL.
Conclusion: The SEIQoL-DW is a useful tool for the assessment of RS in SCLC patients and revealed useful information about the specific content of each patient's adaptation process. The standard SEIQoL-DW protocol needs to be supplemented by transcripts or audio tapes of the interviews in order to reliably assess RS.

Abstract number: 103
Presentation type: Oral Presentation
Session: Methodology

The evidence base of palliative medicine: a critical appraisal of systematic Reviews

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A systematic review was undertaken of published systematic reviews of effectiveness research in palliative medicine to assess the quality of these sources of evidence.
Inclusions: Reviews of effectiveness of treatments normally instituted or delivered by palliative physicians to patients with advanced incurable disease quality was assessed using a tool designed by the Scottish Intercollegiate Guidelines Network Exclusions Evaluations of psychosocial interventions or assessments of services; treatments which would not normally be instituted or delivered by a palliative physician. Identification of relevant studies: Systematic reviews were identified using a detailed search strategy from a number of electronic databases: Embase (1988–2005); Medline (1966–2005) Cinahl (1982–2005), Cancerlit (1962–2005) The Cochrane Database of Systematic Reviews 2005 Issue 4. Hand searches of a number of palliative care journals were also undertaken (Palliative Medicine, Journal of Pain and Symptom Management, Progress in Palliative Care, Journal of Palliative Care, Journal of Palliative Medicine). No restriction was placed on the language of the original article. Results Of 606 articles assessed, 26 systematic reviews were eligible for inclusion. Clinical findings 13/26 were unable to give any conclusions or recommendations for practice because of the paucity of evidence from primary studies. Methodological Quality The quality of the majority of reviews was good or very good with a low or very low risk of bias. There was no difference in the quality of reviews between those published in palliative care journals and those published elsewhere. The quality of systematic reviews was not related to the year of publication, the number centres or the number of authors. In general, the limited number of primary studies and the small number of subjects in those studies limited the usefulness of systematic reviews.

Abstract number: 104
Presentation type: Oral Presentation
Session: Methodology

Improving ascertainment, recruitment, and enrollment in prospective outpatient research: successful strategies from a two-year longitudinal study

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Background: Palliative care research depends on an ability to identify, recruit, enroll, and retain patients and families as they traverse the end of life. The literature is replete with studies that have fallen short of enrollment goals, resulting in inadequate power to test hypotheses or draw conclusions. Community-based prospective studies provide population heterogeneity and generalizability, yet present a particular challenge for ascertainment and retention. For example, a recent NCI funded study of patients with advanced cancer or AIDS, interviewed monthly, showed non-mortality attrition rates of 39% and 73%, respectively.
Objectives: Outline the successful recruitment methods and results of a new longitudinal study of patients and caregivers.
Design: A two year longitudinal study of 240 patients with Stage IV cancer (breast, prostate, colorectal, lung), advanced CHF, or advanced COPD, and their caregivers, interviewed monthly, in-home and by phone.
Results: 41% of eligible patients enrolled in this study, and 75% of their caregivers enrolled. We experienced only 7.8% non-mortality attrition. Representative and successful ascertainment was associated with: coordinated use of clinical criteria and medical record review rather than provider prognostication, personal physician recruitment letters, refined letter content, “opt-out” recruiting, brochures and small monetary incentives, interactive phone scripts, use of matched-ethnicity interviewers, patient and caregiver rapport, and interviewer support, including grief and bereavement. Enrolled caregivers appeared to move from the role of gatekeeper to active participant, thus increasing patient enrollment.
Conclusions: Recruitment to prospective longitudinal studies at the end of life is difficult, but possible. The lessons learned from this study are applicable to future investigators conducting prospective research.

Abstract number: 105
Presentation type: Oral Presentation
Session: Pain & Translation Research

Different profiles of opioid-induced analgesia and antihyperalgesia in a human pain model

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Aim of the study: Opioids are well recognized as unsurpassed analgesics for relieving severe pain. However, clinical pain states are often associated with neuronal plasticity leading to a pain hypersensititivity. Treating pain may not be limited to the use of antinociceptive agents even if they are very potent like opioids, but an anti-hypersensitivity strategy per se should also be considered. Interestingly, different mechanisms were proposed for opioid-induced analgesia and antihyperalgesia which might result in different pharmacodynamics. To address this issue, the time courses of analgesic and antihyperalgesic effects of the pure μ-receptor agonists fentanyl and alfentanil as well as the partial μ-receptor agonist and k-receptor antagonist buprenorphine were assessed in an experimental human pain model.
Methods: 43 volunteers were enrolled in three randomized, double-blind, and placebo controlled cross-over studies. The magnitude of pain and the area of secondary hyperalgesia following transcutaneous stimulation were repetitively assessed before and up to 150 minutes after intravenous administration of 1) fentanyl 1.5 μg/kg, 2) alfentanil 30 μg/kg or 3) buprenorphine 1.5 μg/kg. The sessions were separated by two week wash-out periods.
Results: In contrast to pure μ-agonists, buprenorphine induced antihyperalgesic effects with a significant longer half-time as compared to its analgesic effects, leading to an antihyperalgesia/analgesia ratio of 2.6. This longer lasting antihyperalgesia contrasts the delayed increase of hyperalgesia observed following the pure μ-receptor agonists fentanyl and alfentanil that result in antihyperalgesia/analgesia ratio of 0.6 and 0.3, respectively.
Conclusion: In contrast to pure μ-receptor agonists, buprenorphine exerts a lasting antihyperalgesic effect in our model. It will be of major clinical interest whether this difference will translate into improved treatment of pain states dominated by central sensitization.

Abstract number: 106
Presentation type: Oral Presentation
Session: Pain & Translation Research

Conversion factor for morphine when changing from oral to parenteral administration

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Aim: To find out if the conversion factor from oral to parenteral morphine is different in the palliative patient with continuous infusion compared to earlier recommendations based on intermittent injection, and if there is any difference between intravenous and subcutaneous infusion.
Method: Eleven consecutive incurably ill cancer patients with well controlled pain (NRS <4) and oral medium long acting morphine were included. Each patient received a parenteral morphine dose that was equal to half the oral dose/24 hours. All patients got both subcutaneous and intravenous morphine infusions in a random sequence. Each way of administration was used at least for 3 days. Blood samples during oral medication were taken 5–6 hours after dosage, measuring S-morphine, S-morphine-6-glucuronide, S-morphine-3-glucuronide. After each change of administration route new samples were taken 48–84 hours after the change.
Analysis: The 5-hour oral concentration was divided by the intravenous concentration and the subcutaneous concentration forming quotas.
Results: Eleven patients with lung, prostate, intestinal, gynecological and breast cancer were included. Median oral morphine dose = 40 mg/24 h (range 10–200). Median age was 71 years (58–80), five males and six females. Median oral morphine/s.c. morphine = 0.91 (interquartilrange = 0.39), s.c. morphine/i.v. morphine = 1.0 (IQR = 0.29). Median oral M3G/s.c. M3G = 2.47 (IQR = 0.57) and oral M6G/s.c. M6G = 2.48 (IQR = 1.2) No significant differences were found concerning pain, nausea, obstipation, or tiredness.
Conclusion: The conversion factor from oral to subcutaneous administration of morphine is approximately 2 as assumed, but with some individual variations. The morphine concentrations are identical with subcutaneous or intravenous administration. The concentrations of metabolites are 2.5 times higher with oral administration compared with parenteral administration.

Abstract number: 107
Presentation type: Oral Presentation
Session: Pain & Translation Research

Morphine pharmacokinetics and pharmacodynamics after P-glycorpotein inhibition by itraconazole

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P-glycoprotein is an efflux protein expressed both in the gut wall and the brain capillary endothelium. In animal studies, inhibition of P-glycoprotein has been shown to markedly enhance the antinociceptive effects of morphine. The aim of this study was to determine whether the potent P-glycoprotein inhibitor itraconazole affects morphine pharmacodynamics and its absorption in the intestine.
Methods: The study was a randomized, double-blind crossover comparison of the effects of itraconazole and placebo on the pharmacodynamics and pharmacokinetics of a single dose of immediate-release oral morphine.

Twelve healthy volunteers completed the study. Computer-generated randomization was used. The subjects received 200 mg oral itraconazole or placebo premedication for four days. One hour after the last dose of premedication the subjects were administered 0.3 mg/kg oral morphine. Plasma concentrations of morphine, M3G, M6G, and itraconazole were measured from before to 48 hours after morphine administration. Subjective symptoms VAS and the Specific Drug Effect Questionnaire were used to evaluate drug effects. Psychomotor function was evaluated using three different tests. Adverse experiences were recorded and managed as needed. HPLC-mass spectrometry was used for plasma drug concentration analysis. Pharmacokinetics were characterized by AUC. Two-way ANOVA was used for statistical analysis.
Results: Plasma morphine concentrations increased 20–30% after intraconazole premedication. There was a statistically significant difference in subjective pharmacodynamic evaluations, the VAS scores being higher after intraconazole pretreatment. Psychomotor performance was not significantly different between the two study phases.
Conclusions: P-glycoprotein inhibition by itraconazole significantly enhanced the pharmacodynamic effects of a single dose of morphine and increased the plasma morphine concentrations in healthy volunteers.

Abstract number: 108
Presentation type: Oral Presentation
Session: Pain & Translation Research

Economics of morphine equivalent daily doses (MEDD)

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Background: Individual responses to opioids are affected by inter-patient variability in clearance and opioid receptor profiles. Since starting the Palliative Care Service at MD Anderson Cancer Center in 1999, there has been an increased usage of methadone within the institution. This study was designed to assess the effect of increased methadone usage on the overall cost of opioid utilization.
Methods: We evaluated the inpatient usage patterns for methadone (oral, SQ, and IV), transdermal fentanyl (TDF), and sustained release oxycodone (SRO) and morphine (SRM). Using the pharmacy database, for the month of October in each year from 1999–2004, the following data was collected: total milligrams used per day by product, conversion to morphine equivalent daily dose (MEDD) used by product, average wholesale price (AWP), number of unique patients by product, total days of product use, and total number of inpatient days (INPD). A total of 12 625 unique drug doses were included in the final database.
Results: The number of unique patients receiving opioids increased for all study drugs. The usage of methadone in MEDD increased 400% from 1999 to 2004. Using AWP per patient day treated, TDF was $9.43, SRO was $3.63, methadone was $2.38, and SRM was $1.24. In total usage, methadone provided the largest MEDD (mg/day) coverage, up to 9 times the amount of TDF. Since 2000, methadone has contributed more MEDD as a percentage than the other 3 agents combined, while the methadone MEDD cost contribution has never been more than 10%. The mean for the cost of 1 mg of MEDD per patient day was $0.02 for methadone, $0.02 for SRO, $0.11 for SRM, and $0.216 for TDF.
Conclusions: Usage of methadone has increased. The MEDD contribution of methadone surpasses other long acting opioids in our inpatient population. The non-annualized total cost per MEDD mg for all products combined has remained stable at $0.05, but cost per patient treated increased by $0.77 per (INPD). Our analysis continues.

Abstract number: 109
Presentation type: Oral Presentation
Session: Pain & Translation Research

Morphine and metabolite levels predict response to morphine

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Research Aim: Historically 'response' to morphine has been characterised by analgesic efficacy alone. Studies have not demonstrated significant correlations between pain scores and morphine or metabolite levels. However, our group has shown that many patients who do not respond to morphine are switched to alternative strong opioids due to debilitating side-effects (SE). This study therefore explored associations between morphine and metabolite levels and total response to morphine, including SE profiles. Prospective two centre study: 228 cancer patients initially treated with morphine. Responders had good clinical benefit from morphine for at least one month. Non-responders had poor pain control and/or severe dose limiting SE. Patients completed pain and SE scores; plasma morphine and metabolites were measured by HPLC.
Results: Although, in line with previous findings we found no significant difference in 24 h morphine dose, non-responders had significantly lower plasma morphine and M3G levels with a trend towards lower M6G levels ($p = 0.009$, $p = 0.03$, $p = 0.07$ respectively). Similar significance was seen for morphine, M3G and M6G ($p = 0.003$, $p = 0.005$, $p = 0.01$). Thus responders had more active drug (morphine + M6G) for a given dose of morphine. No association was found between pain scores and morphine or metabolite levels. However, we demonstrated a significant association between morphine and metabolite levels and the presence and severity of SE. Confusion or hallucinations (none, mild, moderate or severe) correlated with the Morphine: M6G ratio ($p = 0.01$) and myoclonus was associated with plasma morphine, M3G and M6G levels ($p = 0.009$, $p = 0.007$, $p = 0.009$ respectively).
Conclusion: In agreement with other studies, morphine and metabolite levels do not correlate with pain scores. However, they do correlate with morphine-induced SE and are therefore important in furthering our understanding of 'response' to morphine.

Abstract number: 110
Presentation type: Oral Presentation
Session: Pain & Translation Research

Breakthrough pain measurement with numerical and verbal rating scales

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Background: At present no data are available on the best one-dimensional method for measuring breakthrough pain (BKP) intensity in cancer patients and different scales are used. Aim of the study In this study, a 0–10 points numeric rating scale (NRS) and a verbal rating scale (VRS) describing six pain levels, were compared in terms of bivariate score distribution, capability in discriminating between baseline pain and BKP intensity and test–retest reliability.
Methods: A multi-centre cross-sectional study on prevalence of BKP was carried out on cancer patients using a new questionnaire for BKP evaluation. The first version of the questionnaire used both NRS and VRS to evaluate baseline and BKP intensity and for validation purposes it was administered twice by two different interviewers in a subgroup of patients. Each scale discriminating ability was evaluated through two indicators: % of patients with BKP lower than baseline pain (wrong evaluations) and % of patients with BKP equal to baseline pain (lack of discrimination). Reliability of the two scales was assessed through Cohen's Kappa between test and retest evaluations. Only data on patients reporting BKP ($N = 158$) were analysed in this study.
Results: NRS and VRS scores were strongly and positively correlated both for baseline pain ($r = 0.83$) and for BKP r($= 0.86$); high variability in NRS scores was observed for intermediate VRS scores (scores ranged from 3 to 8 for patients scoring "moderate pain"). The % of wrong evaluations was

limited for both scales (1% and 3% respectively for VRS and NRS) while the % of lack of discrimination was higher for the VRS (24% vs 11% of NRS). Reliability of the scales was also different: K = 0.77 (baseline pain) and = 0.53 (BKP) for VRS versus K = 0.80 (baseline pain) and = 0.86 (BKP) for NRS.

Conclusions: Given the better performance of NRS with respect to VRS (higher discriminative power and reliability) the use of NRS should be preferred to VRS for BKP intensity evaluation.

Abstract number: 111
Presentation type: Oral Presentation
Session: Pain & Translation Research

Effects of ibandronate in a model of inflammatory pain: comparison with zoledronic acid

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Bone cancer pain is the most common source of pain in patients with malignant disease. Despite the availability of a variety of therapies, complete pain relief often is not achieved. In the last few years bisphosphonates have become important in the management of pain in patients with bone metastases. The main effect of these drugs is to reduce bone resorption by inhibiting osteoclast function. However, this biological action does not fully explain their analgesic efficacy. In particular, the rapid appearance of pain relief after the administration suggests a possible dissociation between the analgesic and the metabolic effects of these compounds. To investigate the mechanisms through which bisphosphonates may decrease pain we studied the effects of two drugs largely used for the treatment of patients with bone pain in a standard preclinical model of inflammatory pain. We evaluated the effects of ibandronate and zoledronic acid on inflammatory oedema, cutaneous hyperalgesia, and on tissue levels of two pro-inflammatory mediators: PGE-2 and Substance P. Both drugs were able to reduce the inflammatory oedema. The anti-hyperalgesic effect of ibandronate was more evident than that of zoledronic acid. In particular, the onset of the anti-hyperalgesic action of ibandronate was more rapid than with zoledronic acid. Neither ibandronate nor zoledronic acid modified the levels of PGE-2. Both drugs decreased the levels of SP in the inflamed tissue. However, 7 days after the induction of the inflammation this reduction was statistically significant only in animals treated with ibandronate. These preliminary data may contribute to explain the fast analgesic effect of ibandronate in patients with cancer pain. With regard to the mechanisms involved in the analgesic action, these results suggest that our attention should be focussed on the neuronal more than on the cellular component of the inflammatory pain pathway.

Abstract number: 112
Presentation type: Oral Presentation
Session: Ethics

Trends in acceptance of euthanasia among the general public in 12 European countries (1981–1999)

Joachim Cohen, Vrije, Universiteit Brussels – Faculty of medicine, Brussels, Belgium, **Isabelle Marcoux**, Centre for Research and Intervention on Suicide, Montreal, Canada, **Johan Bilsen**, **Luc Deliens**, End of Life Care Research Group, VUB – Faculty, Brussels, Belgium, **Gerrit Van der wal**, Dfepartment of Public and Occupational Health and, Amsterdam, Netherlands

Background: Within the context of an increasing debate on the rights of terminally ill patients we wanted to examine whether and how the acceptance of euthanasia among the general public in western Europe has changed in the last decades and to look for possible explanations.

Methods: We analysed data from representative samples of 12 western European populations, collected in the context of the European Values Surveys, in 1981 (N = 14 281), 1990 (N = 17 234) and 1999–2000 (N = 15 784). The main outcome measure of our study was the (change in) acceptance of euthanasia (rated on a scale from 1 to 10). A multivariate ordinal regression was performed to examine the change in acceptance of euthanasia, controlling for possibly influencing factors.

Results: A significant increase in acceptance of euthanasia was found in all countries except (West) Germany. While the average increase in euthanasia acceptance was 22%, the increase was particularly obvious in Belgium, Italy, Spain and Sweden. The secularisation of society, the rising permissiveness and (to a lesser extent) the rise in numbers of people with higher levels of education were important societal factors associated with growing acceptance of euthanasia. Nonetheless, the multivariate analysis revealed that the general increase remained significant after controlling for these factors (OR = 1.38; 95% CI = 1.33–1.44).

Conclusions: A systematic increase of euthanasia acceptance among the general public took place over the last two decades in almost all western European countries, which cannot only be explained by secularisation and increased permissiveness. Public sensibilities towards 'right-to-die' issues and public debates on euthanasia and terminal patients' rights have likely also contributed to the increased acceptance. If these trends continue, more public and political debate about the regulation of euthanasia can be expected in the near future in western Europe.

Abstract number: 113
Presentation type: Oral Presentation
Session: Ethics

"Age" and "costs" as criteria in end-of-life decision-making. an explication of informal knowledge of clinicians' ethical opinions

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The aim of the paper is to study clinical end-of-life decisions of physicians and nurses regarding withholding and withdrawing life-sustaining measures. Against the background of increasing costs, an ageing population and limited resources, studies suggest that patients may be denied adequate care when curative efforts reach their limits. Do "age" and "costs" function as criteria in clinical decision-making? If "age" is used as a treatment criterion, esp. for costly therapies, this has serious implications for the quality of care and for the ethical orientation towards Palliative Care. An interview study was conducted with a representative sample of 53 physicians and nurses in Intensive Care, long-term and acute Geriatric Care of a University Medical Centre, where staff is confronted with dying and death daily. For content analysis of the semi-structured verbatim protocols of in-depth interviews the methodology of Mayring was applied and a theory-driven coding guide was developed for standardized and anonymized data analysis. Results yield evidence that "age" and "costs" function as criteria in clinical decision-making. Quotations from the interviews indicate that erosion of values or ethical conflict regarding adequate end-of-life care are more often expressed in third-party description of the behaviour of colleagues rather than in self-report statements. We conclude that data analysis reveals that aspects of age discrimination and to a lesser degree bedside rationing are present in the centre. The evidence is strengthened by the fact that the interview focused on end-of-life care and treatment limitation, not on ageism or rationing which prevents biased answers. Conclusions will have to be discussed at institutional and political levels in order to support the rights of a vulnerable group of patients.

Abstract number: 114
Presentation type: Oral Presentation
Session: Ethics

Are 'causing death' and 'letting die' considered equally acceptable by the general population?

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Background: The moral distinction between acts and omissions that result in death is the subject of ethical debates, but few empirical data have contributed to the discussion. Our objective is to determine whether public opinion toward 'causing death' differs from public opinion toward 'letting die' by natural causes and if so, to examine possible explanations.

Methods: A telephone public opinion poll was conducted in 2002 with a representative sample of the general population of Quebec (n = 991; response rate = 49.8%). Respondents were asked about their support for euthanasia (causing death) and treatment withdrawal (letting die). Sociodemographic characteristics (age, sex, socioeconomic status, religion), data from questions on the distinction between euthanasia and other end of life practices (treatment withdrawal, withholding treatment, double effect, assisted suicide) were collected.

Results: Public support was 16% higher for treatment withdrawal than for euthanasia (85.8% vs 69.6%). Multinomial regression analysis revealed that those who consider treatment withdrawal acceptable, but not euthanasia, had lower income, were more likely to be religious and were also less likely to identify a situation of treatment withdrawal or of withholding treatment as being "euthanasia," compared to those who found euthanasia and treatment withdrawal equally acceptable. No statistical difference was found between those who consider both practices unacceptable and those who consider only treatment withdrawal acceptable.

Conclusions: A majority of the population is in favour of treatment withdrawal (letting die) and euthanasia (causing death). However, there is more support for treatment withdrawal. People who found "letting die" practices acceptable but "causing death" unacceptable are more likely to distinguish between these practices, as do medical associations and legislative authorities in most industrialised countries. Implications of these results will be discussed.

Abstract number: 115
Presentation type: Oral Presentation
Session: Ethics

Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands

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Background: There has been much theoretical debate about the validity of advance directives if a patient has become demented. The 2002 euthanasia legislation in the Netherlands explicitly deals with advance directives concerning euthanasia: physicians are allowed to comply with such directives, provided that "the requirements of due care" are met.

Objectives: To estimate the incidence of (compliance with) advance euthanasia directives of patients suffering from dementia in the Netherlands and to gain knowledge about the experiences of physicians.

Methods: Four hundred ten physicians were interviewed retrospectively about their demented patients who had an advance euthanasia directive. Nursing home physicians were interviewed more extensively.

Results: Approximately 2200 demented patients with an advance euthanasia directive die annually after being treated by a physician who knows about this directive. In 76% of such cases, compliance with the directive was discussed, but euthanasia was seldom performed. In two thirds of the cases of demented nursing home patients with an advance euthanasia directive, the physician was able to identify during the course of the disease a situation for which the patient had intended the directive. One-quarter of the nursing home physicians thought that their most recent patient suffered unbearably to a (very) high degree, and half of them thought that the patient suffered hopelessly to a (very) high degree. In three-quarters of the cases, the relatives did not want the nursing home physician to comply with the directive, but they did want to respect the patient's wishes by forgoing life-prolonging treatment, which occurred in approximately 90% of cases.

Conclusion: Most nursing home physicians think that the suffering of patients with dementia can be unbearable and hopeless as a consequence of dementia, but most physicians do not consider dementia to be grounds for euthanasia, unless perhaps the patient has an additional illness.

Abstract number: 116
Presentation type: Oral Presentation
Session: Ethics

Implicit ethical conflicts of physicians and nurses regarding withholding and withdrawing treatment in neonatology

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The aim of the study is to understand the attitudes of clinical staff in the care for severely ill and dying newborn patients. It is expected that the change of treatment goals from curative to palliative care and the decision to withhold or withdraw life-sustaining measures, stimulates ethical difficulties among physicians and nurses. Which ethical difficulties are present among physicians and nurses regarding decisions to withhold or withdraw treatment and in the practice of palliative care in neonatology? In-depth-interviews were carried out (12 physicians, 7 nurses) complementary to a prospective study of 40 patients case series. For content analysis of the semi-structured interviews protocols, the method of Mayring was applied. A theory-driven coding guide was developed for standardized and anonymized analysis. Physicians and nurses indicated ethical conflicts regarding withholding and withdrawing treatment, especially in cases with uncertain medical prognosis, conversation with parents about end-of-life decision-making, and emotional burdens for all participants. Interviewees reported that medical reasons were mostly the first (or the one-and-only) criteria for end-of-life decision-making rather than explicit ethical reasoning. Interviewees reported that physician-assisted dying was only an implicit topic in most of the healthcare professional-parent onversations despite physicians' role in decision-making. There is evidence that longer professional experience of physicians and nurses contributes to their feeling competent facing situations of critical decision-making. Most interviewees when asked about relevant guidelines, reported that they were unfamiliar with those, even with the most popular national guideline on end-of-life care. We conclude that the presence of ethical conflicts proves a need for support or training in end-of-life decision-making.

Abstract number: 117
Presentation type: Oral Presentation
Session: Ethics

A prospective study for demands for euthanasia and assisted suicide (EAS)

Karine Moynier, **Gilbert Zulian**, Cesco, Collonge-Bellerive, Switzerland

Objectives: To document EAS and reasons behind them and their impact on patients' future. Such demands may disappear with appropriate PC.

Methods: One-year prospective longitudinal study was conducted in a 104 beds PC university hospital. EAS were recorded as soon as they were mentioned to health carers. EAS were considered if active help for dying was requested at any time during hospitalisation. Pts' gender, age, diagnosis, disabilities were recorded. Demanding and receiving EAS persons were identified. Motivation of the demander was detailed. Statistical considerations are under progress.

Results: During study period 295 pts died. 44 EAS were made from 42 persons related to 40 pts, 60% with cancer. Median age was 72 y (44–97) and 47.5% were male. 92.5% EAS came from pts and 20% from others. Over 75% of EAS were received by health carers. Reasons for EAS were: physical (66%), psychological (54%) and existential suffering (36%) and physical dependence (33%). 35 EAS were made by pts whereas 9 were not. 5 pts concerned by these 9 EAS did not agreed with it. One month later, 16 pts had died from natural cause, 3 were discharged home, 2 were transferred to psychiatric unit. Two returned home in order to commit assisted suicide. 21 were still hospitalized, 5 of them persisted with EAS.

Discussion: Despite adequate symptom management, EAS persisted in few pts. The vast majority of pts was substantially relieved in their physical symptoms and could end their life under acceptable circumstances. Specific profile for EAS was not identified but there was a tendency towards physical dependency as one main reason for it. In addition, a significant number of EAS came from the family, raising questions about true autonomy of vulnerable pts arriving at the end of life. More research is needed to improve our understanding of these ethical issues. In the meantime adequate professional preparation is of utmost importance.

Abstract number: 118
Presentation type: Oral Presentation
Session: Ethics

Are preferences for treatment really a barrier to hospice enrollment in the United States?

David Casarett, University of Pennsylvania, Philadelphia, U. States

Research aims: In the United States, patients who wish to enroll in hospice must give up access to life-sustaining treatment. This requirement is assumed to be the most significant barrier to hospice enrollment. However, this assumption has never been tested. Therefore, this study was designed to determine whether a desire for life-sustaining treatment is in fact a barrier to hospice enrollment.
Sampling frame: Seriously ill patients were recruited from ambulatory clinics and general medicine inpatient units in a single metropolitan area.
Methodology: Prospective cohort study.
Method of analysis: Each interview assessed preference for high- and low-burden life-sustaining treatment. Patients were followed for up to 2 years with multiple interviews and multiple periods of observation. Cox regression modeling with time-lagged covariates was used to test whether preferences for life-sustaining treatment predicted subsequent enrollment in hospice.
Results: This study enrolled 203 patients with cancer ($n = 65$;32%), Congestive Heart Failure ($n = 77$;38%), and Chronic Obstructive Pulmonary Disease ($n = 61$;30%). In multivariable Cox regression models, patients with non-cancer diagnoses who desired low-burden treatment were less likely to enroll in hospice (hazard ratio [HR] 0.46; CI 0.33–0.68). Among patients with cancer, preferences were not associated with hospice enrollment. Nevertheless, most patients whose preferences were consistent with hospice did not enroll before the next interview.
Conclusions: A desire for life-sustaining treatment may be a barrier to hospice enrollment for patients with non-cancer diagnosis, but not for patients with cancer. In addition, for all diagnoses, many patients do not want life-sustaining treatment yet still do not enroll in hospice, suggesting that poor communication about preferences may be a more important barrier to hospice enrollment.

Abstract number: 119
Presentation type: Oral Presentation
Session: Bereavement

Accessing routine patient data and preferred place of care: methodological challenges in a study of carer bereavement outcomes.

Gail Ewing, University of Cambridge, Cambridge, Great Britain, **Gunn Grande**, University of Manchester, Manchester, Great Britain, **On behalf of National forum**, Great Britain

Aims: Studies have shown both positive and negative impact of home death on carers in bereavement. We aimed to utilise routine service data combined with carer survey to investigate how preference for place of death, having that preference fulfilled and actual place of death influence carer bereavement.
Sampling frame: Informal carers of deceased patients who had been referred to five UK Hospices at Home (H@H) over a four month period.
Methodology: Routine prospective recording of patients' preferred place of care (PPC) and demographic data collected from H@Hs. Postal survey of carers three months post bereavement to measure quality of life (SF-36v2), grief response (Texas Revised Inventory of Grief) and views of end of life care. Place of death data returned by Office for National Statistics.
Results: Methodological and practical challenges in conducting this study arose in three main areas. First, considerable time was spent resolving uncertainties about consent and conflicting views on data protection regarding access to data from deceased patients. Second, there was a lack of familiarity with research involving voluntary organisations on the part of gatekeepers such as ethics committees, R&D committees and ONS, resulting in delays and inappropriate advice. Third, different practical challenges arose from working with H@H services themselves. There were particular challenges involved in co-ordination and collection of data recorded within independent and very diverse voluntary organisations. These methodological issues, insights gained and steps taken in their resolution will be discussed.
Conclusions: Routinely recorded service data are an important resource for palliative care research, in particular PPC, in the light of new initiatives in place in the UK to increase choice in end of life care, but collection of these data is not without difficulty. Useful lessons can be gained from this study for researchers wishing to use a similar methodology.

Abstract number: 120
Presentation type: Oral Presentation
Session: Bereavement

The impact of preferred place of care and place of death on carer bereavement outcome

Gunn Grande, University of Manchester, Manchester, Great Britain, **Gail Ewing**, University of Cambridge, Cambridge, Great Britain, **On behalf of National forum**, Great Britain

Aims: Place of death influences carer bereavement outcome. However, some studies show beneficial and some detrimental outcomes following a home death. This study investigates how fulfilment of preference for place of care and death influences bereavement outcome, alongside place of death itself. Carer demographics and assessments of end of life care are also considered.
Sampling frame: carers of deceased patients referred to five UK hospice at home services (H@H) during four months. So far 175 carers have been recruited, representing a 33% response rate.
Methodology: Demographic data and prospective data on preferred place of care and death were collected by H@Hs. Carers were surveyed by mail three months post bereavement. Measures included health related quality of life (SF-36), grief response (Texas Revised Inventory of Grief), perceptions of care and place of death. Place of death will be confirmed with the Office for National Statistics.
Analysis: ANOVA will be used to investigate how place of death, fulfilment of preference and their interaction affect bereavement outcome. Associations between other variables and bereavement outcome will be explored and controlled for.
Results: Retrospective carer data so far show that carers of patients who died at home were more likely to feel the place of death was right than carers of those who died elsewhere ($X2 = 29.22$, $df = 1$, $p < 0.001$). Those that felt place of death was right scored higher on SF-36 Energy/vitality ($t = 2.363$, $df = 164$, $p = 0.019$) and the Mental Composite Summary ($t = 2.000$, $df = 156$, $p = 0.047$). Prospective data on preferred place of care/death and ONS data on place of death will be considered in the final analysis.
Conclusion: It is the circumstances around place of death rather than the place in itself that is likely to affect bereavement outcome. The ability of care services to fulfil patients' and carers' preferences for place of care and death is likely to be an important explanatory factor.

Abstract number: 121
Presentation type: Oral Presentation
Session: Bereavement

How well do family caregivers cope after caring for a relative with advanced disease and How can health professionals enhance their support?

Peter Hudson, University of Melbourne & St Vincent's Health, Melbourne, Australia

Background: Support for families during a person's advanced disease and also into the bereavement period is a major component of palliative care.

However, because of the gaps in bereavement research in this area, there is a lack of evidence-based direction for health professionals.

Aim: This study aimed to explore family caregiver perceptions of their relative's death and assess how well they were coping. Caregivers were also asked to identify which health professional strategies helped them prepare for and respond to their relative's death.

Methods: Two months after their relative's death primary family caregivers (n = 45) of patients with advanced cancer (who had received home based palliative care) completed a structured interview and were also assessed to determine if they were confronted by traumatic grief.

Analysis: Descriptive statistical approaches were used to describe the socio-demographic profile and content analysis techniques were employed to analyse structured interview data. Traumatic grief was assessed via the Inventory of Traumatic Grief.

Results: Seven percent of caregivers were confronted by traumatic grief; most caregivers perceived they were coping reasonably well and could identify positive outcomes related to their experience. Caregivers noted the significant benefits of receiving comprehensive information to prepare them for the future and expressed appreciation for the support provided by specialist palliative care services.

Conclusions: There is a large body of literature that highlights the negative consequences of being a family caregiver to a person with advanced disease. The sample population in this study, however, seemed to be reasonably well functioning; the results were therefore somewhat surprising. A research agenda and key clinical implications are outlined in order to aid direction in targeting bereavement interventions.

Abstract number: 122
Presentation type: Oral Presentation
Session: Bereavement

Hospice-based bereavement support: assessing the effectiveness of service delivery

Amanda Roberts, National University of Ireland, Maynooth, Co. Kildare, Ireland, **Sinead Mc Gilloway**, NUI Maynooth, Co. Kildare, Ireland

Background: The rapid development of hospice-based bereavement support services reflects an increasing recognition of the need to provide designated support for bereaved family members. However, few studies have evaluated the effectiveness of these services.

Aims: This is the first of a two-part study designed to evaluate a bereavement support service provided in a large hospice in Ireland. The service comprises three strands including a liturgical service, a Bereavement Information Evening and a Volunteer Bereavement Support Service.

Method: All bereaved clients who were invited to one or more of the above three services during the previous 12 months (n = 530) were asked to participate in a postal survey. This included: (1) a detailed questionnaire designed to elicit background information on clients and their utilisation and views of each of the above services; (2) a measure of grief reaction (TRIG); and (3) a measure of religiosity (Santa Clara Strength of Religious Faith). A small sub-sample of service attenders and non-attenders also agreed to be interviewed.

Results: A total of 246 (46% response rate) people returned completed questionnaires, the majority of whom were satisfied with the service. However, a number of improvements were highlighted. Several statistically significant differences ($p < 0.05$) emerged between service attenders and non-attenders with respect to grief reaction and other key factors such as the age of and the relationship to the deceased and the nature of their relative's death. Further findings will be presented on staff views of the service.

Conclusions: This is the first comprehensive study of its kind to describe and appraise the effectiveness of a bereavement support service. Importantly, the findings highlight the needs and views of both attenders and non-attenders and provide important lessons for the implementation, development and effective functioning of hospice-based bereavement support services both in Ireland and elsewhere.

Abstract number: 123
Presentation type: Oral Presentation
Session: Bereavement

Research on the recovery process of widows and young children of firefighters killed in 9/11/01 attacks

Grace Christ, **Adolph Christ**, Columbia University, New York City, U. States, **Heidi Horsley**, **Lauren Cardillo-geller**, Columbia University School of Social Work, New York City, U. States, **Dianne Kane**, FDNY Counseling Service Unit, New York City, U. States

Research Aims: This five-year study aims to understand the recovery processes of widows and children whose firefighter husband/father perished in the WTC attacks. Modification of previously tested home-based intervention with families confronting parental death at a major cancer center informed the research approach in this traumatic circumstance.

Sampling frame: 48 families with 118 children of firefighters killed in 9/11 attacks participated in family guidance intervention research including evaluation, monthly follow-up in years 1–2, varying intensity in years 2–5.

Methods: Prospective mixed-method approach. Interviews were transcribed. Repeated standardized measures assessed behaviors, complicated and normal grief, and psychiatric symptoms.

Method of analysis: Qualitative analysis of transcribed interviews (N-Vivo-2) and quantitative analysis of standardized measures describe population changes(SPSS).

Results: Stresses included: 1) Multiple colleague deaths, 2) continuing trauma and grief reminders, 3) prolonged recovery period, 4) conflict between individual and community memorial needs. Recovery trajectory included overlapping phases of trauma/grief, positive memories, re-organization/restoration and identity restructuring for widows. Children's recovery was characterized by intermittent grief and rapid return to functioning. Unique findings include 1) interaction of trauma and grief, 2) disynchrony between mother and children's grief, 3) unexpected severe late symptoms in some children, 4) phases of restoration and identity restructuring especially stressful in 2nd and 3rd year.

Conclusions: A collaboration of a firefighter organization with university faculty, and the use of an oncology based model permitted unique prospective longitudinal research on traumatically bereaved widows and children Specific symptoms, recovery and bereavement themes and processes for young widows and their children were identified.

Abstract number: 124
Presentation type: Oral Presentation
Session: Bereavement

Bereavement support policy: does it go far enough to support the bereaved?

Alison McNulty, University of Manchester, Manchester, Great Britain

Palliative care continues beyond the patient's death and into the bereavement, yet policy for bereavement support provision is in its infancy and promotes information giving as a minimum. As part of a larger study comparing support after home and hospice deaths, the objectives were to examine factors related to provision, and perceptions of support, with implications being to highlight the strengths, weaknesses and areas for future policy development. The study took place prior to policy implementation. Support providers completed 1 questionnaire per death over 3 months. This included what support was provided and to whom. Focus groups asking the bereaved about their needs, and perceptions of supportive/unsupportive methods of support were also held. 595 completed questionnaires were received from 10 home and 12 hospice services. 67% were offered support. Factors related to the offer of support included the patient dying in a hospice, being in a spousal relationship, and residing together. In the home these factors extended to include being in a full-time caring role. Hospices offered more methods of support and were associated with information letters, leaflets, and counselling. Home services were associated with home visits (all $p > 0.00$ to 0.02). Focus groups ($n = 5$, bereaved $= 20$) revealed complex information needs which, when met by providers were found to be very supportive. However other methods involving personal contact were also highly valued such as support groups and counselling/listening. Not all bereaved were offered support and not all services met the minimum requisite of information giving. Both may have been addressed by policy, however adherence would entail change. The policy's strengths are to standardise support so all are offered. Its weakness is the neglect of other methods perceived as supportive, thus removing any obligation for services to provide them. Policy development should focus upon other, more personal forms of support which are value greatly.

Abstract number: 125
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

Rapid pleurodesis with doxycycline thorough a small-bore catheter for the treatment of metastatic malignant effusions

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Goals of work: To evaluate the safety and efficacy of bedside pleurodesis with doxycycline using a short-term indwelling chest catheter for the palliative treatment of malignant effusions.

Patients and Methods: A prospective study of 36 rapid pleurodesis procedures in 34 patients with malignant pleural effusions was conducted over a 5-year period in a university hospital. A 12F chest catheter placement was facilitated utilizing the Seldinger percutaneous entry technique. Patients received 500 mg of intrapleural doxycycline combined in half of cases with local mepivacaine. We assessed efficacy at 30 days, in addition to the frequency of complications and survival.

Main results: Chest tubes were removed within 24 hours in 69%, and within 48 hours in 94% of patients. Of the 30 patients who were alive after 1 month, 18 (60%) had a complete response, 11 (37%) had a partial response and 1 (3%) had no response. Thus, the overall success rate of pleurodesis was 96%. Four patients (13%) had a late recurrence of the pleural effusion. Toxicity was mild and included pain (36%), fever (8%), and pneumothorax (6%). Median survival was 105 days. There was no relationship between instillation of intrapleural anesthetics and development of pain.

Conclusions: Rapid pleurodesis with doxycycline, which can be accomplished within 24 to 48 hours, is a valid option for the symptomatic treatment of malignant effusions. This technique can be used as a first-line procedure in the majority of cases, particularly if thoracoscopic facilities are not available.

Abstract number: 126
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

Respiratory parameter monitoring in palliative care patients treated with strong opioids for dyspnoea: combined continuous oximetry and cutaneous carbon dioxide tension monitoring. A prospective study

Katri Elina Clemens, **Friedemann Nauck**, **Eberhard Klaschik**, Malteser Hospital Bonn, University of Bonn, Bonn, Germany, **Ulrike Stamer**, University of Bonn, Bonn, Germany

Objective: Respiratory depression is a feared side effect of therapy with WHO III opioids. The influence of opioids on arterial carbon dioxide partial pressure, arterial oxygen saturation and heart rate in patients (P) receiving opioids for the treatment of dyspnoea has not been investigated up to now. In a prospective study a non-invasive measurement of these respiratory variables as well as subjective dyspnoea scores were investigated.

Methods: In a prospective, non-randomized study 11 P were included. All P suffered from mild to severe dyspnoea. Transcutaneous measurement (earlobe sensor) of carbon dioxide partial pressure (ptcCO2), pulse oximetry oxygen saturation (SpaO2) and heart rate (HR) were monitored with SenTec Digital Monitor (SenTec AG, Therwill, CH). The following monitoring data were compared: Baseline recording for 15 min, 30 min with nasal O$_2$-insufflation and 30, 60, 90 and 120 min after opioid application. P were asked to score their subjective dyspnoea (NRS 0–10). Demographic, diagnosis-related data and opioid doses were documented. Statistics: mean $\pm$SD, ANOVA, median, Wilcoxon-Test, significance $p < 0.05$.

Results: Diagnoses (age 67.3 ± 15.0 years; 45.5% men) were lung- and breast cancer and ALS (n = 8/2/1). 5 P suffered from severe, 4 from moderate and 2 from mild dyspnoea (NRS at rest/exertion: 5/8). Mean SaO$_2$ at admission was 95.3 ± 5.5%, ptcCO$_2$ 38.9 ± 7.5 mmHg and HR 85.1 ± 13.6/min. After opioid application, respiratory variables remained unchanged (SaO$_2$ 92.4 ± 8.4%, ptcCO$_2$ 37.8 ± 6.8 mmHg, HR: 81.7 ± 13.7/min. In contrast, dyspnoea improved after opioid application (NRS 1/3; $p = 0.003$). First oral morphine dose was 9.1 ± 7.6 mg.

Conclusions: Transcutaneous measurement of ptcCO$_2$ and SaO$_2$ represents a simple, non-invasive technique for continuous monitoring of ventilation during an initial therapy of dyspnoea with WHO III opioids. Both variables did not deteriorate after opioid application, whereas dyspnoea scores improved significantly.

Abstract number: 127
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

Open label phase III study of the efficacy and safety of low-dose levomepromazine in the treatment of nausea and vomiting in palliative care patients previously uncontrolled on drug therapy-interim analysis

Miriam Johnson, Scarborough, Great Britain, **Jacqueline Dentith**, LINK pharmaceuticals, Horsham, Great Britain

Background: Nausea and vomiting are distressing symptoms in patients with advanced disease. The cause is often multi-factorial and a broad-spectrum anti-emetic indicated. This study aims to determine the efficacy and safety of low-dose levomepromazine for patients with nausea and vomiting uncontrolled on previous therapy.

Methods: This was an open-label study designed to follow current clinical practice. Patients nauseated or vomiting despite first-line treatment were allocated, at the investigator's discretion, to receive either levomepromazine 6 mg orally twice daily or 5 mg/24 hour parenterally by continuous sc infusion. Patients on parenteral drug controlled at 48 hours could continue with 6 mg orally twice daily. The dose could be altered (within protocol limits) based on the investigator's judgement. Diary cards were completed throughout the 7 day study to record severity and control of nausea and vomiting, impact on daily functioning, drowsiness and patient satisfaction.

Results: 63 patients were enrolled at the time of the interim analysis. 47 completed 7 days and constitute the evaluable group. At day 7, 25/47 (53%) patients had complete control of nausea and 37/47 (79%) complete control of vomiting. At day 7, 33/47 (70%) of patients had complete or partial (score of 1 or 2 on a scale of 1 = none to 7 = severe) nausea control. Sedation worsened on day 2 but improved compared to baseline by day 7. Patient satisfaction increased over 7 days, and symptom impact on daily functioning was less. The study drug was well tolerated. Somnolence was the most common clinically relevant adverse event (36 reports).

Conclusions: Low-dose levomepromazine is effective and well-tolerated for the management of nausea and vomiting in this difficult to treat patient group. Complete or partial control of nausea and vomiting was seen in the majority; a clinically important benefit reflected in daily functioning and satisfaction.

Abstract number: 128
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

The prevalence of nocturnal hypoxaemia in advanced cancer: effect on daytime sleepiness, fatigue and quality of life

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Background and objective: Fatigue is a common and distressing symptom in patients with cancer which is difficult to relieve. One approach is to identify causes amenable to treatment, e.g. anaemia. There is a known link between nocturnal hypoxaemia and daytime sleepiness; fatigue and daytime sleepiness are likely to be related phenomena. This is the first study to examine the prevalence of nocturnal hypoxaemia in patients with cancer and its relationship with daytime sleepiness, fatigue and quality of life.
Methods: 100 patients with cancer admitted to a specialist palliative care unit with an estimated prognosis of over 4 weeks, completed the Epworth Sleepiness Scale (ESS), the Multidimensional Fatigue Inventory (MFI) and the Short Form-36 health questionnaire (SF-36). Nocturnal oxygen saturation (SaO2) was measured with a Minolta Pulsox 3I wrist oximeter worn for at least five hours. Significant nocturnal hypoxaemia was defined as an overnight SaO2 of less than 90% for more than 2% of study time.
Results: All patients had high levels of daytime sleepiness (mean ESS >11), and 35 patients had nocturnal hypoxaemia. There was no association between nocturnal hypoxaemia and excessive daytime sleepiness, but there were significant associations between nocturnal hypoxaemia and mental fatigue, emotional limitation and change in health perception ($p < 0.05$ for all).
Conclusion: Nocturnal hypoxaemia is prevalent in this group of patients. It is associated with some dimensions of fatigue and quality of life, and further work is warranted.

Abstract number: 129
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

Perspectives of Patients, Next of Kine (NOK) and nurses on symptom control in treminally ill hospitalised patients

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Aim: The most important player in the end stage of life is the patient. Ironically most palliative literature does not include patients' views. This may be due to the difficulty to obtain such data due to patient frailty or ethical issues. This study explores whether patients' views are best reflected by their NOK's or nurse's views.
Method: A prospective study was undertaken in a U.K hospital in 2005. Terminally-ill patients, their NOK and nurse were asked to complete the "Patient Outcome Scale" symptom questionnaire. Participants were asked to mark the questionnaire according to how they perceived patient's symptoms were affecting the way the patient felt over the previous 3 days. Patients with cognitive impairment were excluded.
Analysis: Descriptive statistics and paired samples T test were used to analyse differences in responses between the patient, NOK and nurse.
Results: 65 patients were recruited and 50 sets of patient, NOK and nurse were compiled. The mean age of patients was 75.3 years (SD 8.4 years), and next of kin was 56.5 (SD 15.5). The mean number of years of experience for the nurses was 9.3 (SD 11.0). The Male: Female ratio for patients was 1:1, for nurses was 0:1 and for NOK was 2:3. There was no statistically significant difference between patients' NOK or nurses' responses in: pain, breathlessness, nausea, vomiting, anorexia, constipation and mouth problems. Furthermore, there was no statistically significant difference between patients' and nurses' responses on drowsiness and immobility. However, both NOK and nurses' responses were statistically significantly different from patients' responses in terms of weakness (p 0.02 and <0.01 respectively).
Conclusions: Terminally ill patients' perspectives on symptom control were reflected very closely in their NOK and nurse. However, NOK's perspectives were different on drowsiness and immobility. Moreover, weakness was misinterpreted by both NOK and nurses.

Abstract number: 130
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

The role of the three step antiemetic ladder in the treatment of chronic nausea and vomiting and inoperable bowel obstruction in patients with advanced cancer

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Introduction: Three step antiemetic ladder for chronic nausea and vomiting (N & V): first step metoclopramide, haloperidol, tiethylperazine, second step dimenhydrynate, promethazine, levomepromazine, dexamethasone, hyoscine derivatives, third step setrons, octreotide, benzodiazepines. For patients with inoperable bowel obstruction (BO): first step metoclopramide, dexamethasone, second step haloperidol, dimenhydrynate, promethazine, hyoscine derivatives, third step levomepromazine, octreotide.
Aim of the study: Assessment of three step antiemetic ladder in the treatment of N&V in patients with advanced cancer Material and methods: 420 patients with advanced cancer suffered from chronic N&V induced by different causes, including 95 patients with IBO. Symptoms intensity assessed by verbal scale: 0-lack, 1-weak, 2-moderate, 3-strong N&W three times: (1) at the beginning of care, (2) during symptomatic treatment and (3) at the last week of life. Treatment was beneficial when decrease from strong or moderate N & V to mild or no symptoms and maintaining mild N&V or symptoms disappearance. Treatment failure when increase from no or mild to moderate or strong N&V and when moderate or strong N&V maintained during treatment.
Results: In all patients when comparing N & V (2) to (1) beneficial results in 344 (82%), lack of effect in 76 (18%) patients. In comparison N&V (3) to (2), beneficial effects in 357 (85%), lack of effect in 63 (15%) patients In patients with BO comparing N&V (2) to (1), beneficial results in 56 (59%) patients-most frequently decrease of N&V to weak intensity. Comparing (3) to (2) therapeutic benefits in 49 (51%) of patients.
Conclusions: Treatment of N&V according to three step antiemetic ladder is beneficial in over 80% treated patients. In above 40% patients with BO control of N & V was unsatisfactory, which indicates for necessity of seeking more intensive and more effective therapy methods.

Abstract number: 131
Presentation type: Oral Presentation
Session: Nausea, Vomiting & Shortness of Breath

Drug Interactions in Palliative Care

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Aim: To evaluate how many drugs the patients on our palliative care (pc) ward had and how many possible (harmfull or not) drug-drug interactions could occur in this population.
Method: We checked retrospectively all the charts of our patients who were on the ward from January 1st, 2003 to May 1st, 2003. All the medication the patients had at the time of entry, the number of drugs at maximum and the number of drugs at the time when they left the hospital were counted. We did these countings for all drugs and the medication without the PNR. In a second step we checked with a free available and evaluated computer program (www.pharmavista.ch) all the possible interactions between all the drugs prescribed.
Results: There were 69 patients (36 men, 33 women), aged from 22 to 92 years. Overall there were 181 different drugs prescribed, 56 of them 5 times or more in this population. During this period, our patients had up to 30 drugs (minimum 2) with a mean of 15.6 ± 5.7 over all and 12.3 ± 5.2 drugs per patient without the rescue drugs. At the time of discharge there were 11.4 ± 3.4 drugs prescribed or 8.1 ± 2.8 drugs per patient without the rescue drugs. The patients who died hadn't prescribed less drugs three days before death than the patients who could be discharged. In the study population, 73

different drug interactions were found. The total number of interactions in the population under study was 359. 153 of them were considered as important. We found that with the number of drugs prescribed the number of possible interactions increased. 19 of 36 patients who were discharged (53%) had no severe interactions. 14 of 33 patients who died (42%) had no severe interaction three days before death (but 58% did).
Conclusions: Drug-drug interactions in our palliative care population are very frequent. The number of interactions increases with the number of drugs prescribed. Also physicians on a pc ward prescribe drug combinations which can be harmful.

Abstract number: 132
Presentation type: Oral Presentation
Session: Policy & Place of Care

Building the infrastructure to sustain palliative and end-of-life care research in Canada: from networks to knowledge translation

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Health Canada's Secretariat on Palliative and End-of-Life Care is developing a national strategy which includes engagement of federal government departments, intergovernmental partners, and foundation-building community-level activities. Since 2002, central issue areas have included Research, Surveillance, Education, Best Practices & Quality Care, Public Information & Awareness. Research efforts have focussed on building infrastructural tools and mechanisms. These include networks of researchers such as those funded under the $16.5 million Canadian Institutes of Health Research (CIHR) initiative, a non-cancer research network, and a knowledge translation network, with overlaps among them and to other networks, promoting cross-fertilization of ideas and initiatives. These networks foster collaboration, mentoring, and communication across disciplines, level of expertise, and Canada's vast terrain. This is the foundation upon which Canada will catalyse innovative approaches in improving the evidence base for decision-making and strategic policy development towards higher quality, access and knowledge for palliative and end-of-life care. Building on this foundation of federal and community partnerships, the current goal is to ensure sustainability for the future. To this end, Health Canada is funding the development of an interactive palliative research website, as well as the peer-review panel at CIHR specific to palliative and end-of-life care applications for research grants. These demonstrate that research in this area is becoming "established."Although there is still work to do in forming similar panels at other funding agencies, ensuring ongoing support for regular and strategic research funding, determining priorities for the next era of research, and building durable communities of practice and resources, the research world can celebrate many recent successes and Health Canada's role in gaining these.

Abstract number: 133
Presentation type: Oral Presentation
Session: Policy & Place of Care

Changes in place of death among elderly in Sweden

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During the 1990's, several changes were introduced in the Swedish health care system. A major change was the "Ädel" reform (1992) which involved a transfer of certain health care responsibilities from county councils to communities. One of the purposes was to assure that elderly with long-term care needs would be able to receive social and medical care in their homes. This may have affected where elderly (>65 years) die. The present study aimed to explore the place of death for this group during the last years (1997 to 2003) in Sweden. National data on place of death (inside/outside hospital), discharge from hospital less than 2 weeks before death, gender and age, were collected from the National Board of Health and Welfare. As there was no register showing place of death for those who died outside hospitals, an examination was made of medical journals from four nursing homes. About 80 000 elderly die per year in Sweden. The proportion of deaths outside hospital has increased from 25% (1987) to 63% (2003). This level of about 2/3 deaths outside hospital was stabilised 1997. There was no difference in place of death between men and women. About 50% of the individuals in the age group 65 to 79 years died in hospitals, while 36% of those older than 80 years died in hospitals. The decease rate among inhabitants in nursing homes increased from 20% (1997) to 36% (2003), even if the total number of beds decreased during the same period. About 40 000 elderly per year were discharged from hospitals less than two weeks before death, but a majority returned and died in hospitals. The results show that the "Ädel" reform led to an increasing number of elderly dying outside hospitals, especially individuals older than 80 years. The results also indicate that older and frailer individuals now live in nursing homes. Further, many transfers were made between hospitals and homes in the very last stage of life.

Abstract number: 134
Presentation type: Oral Presentation
Session: Policy & Place of Care

What is the evidence on the factors shaping place of death in cancer?

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Background: In many countries most patients die in hospitals, despite a wish to remain at home. The evidence to explain the gap between preferences and reality is poorly understood.
Aim: To describe and appraise the evidence on factors shaping place of death in cancer, looking at (1) progression of research, (2) research gaps, (3) heterogeneity between studies and their quality, and (4) consistency of findings.
Methods: The appraisal was based on a systematic review of risk factors for place of death among patients where more than 80% had cancer. Datasources include databases (MEDLINE, psycINFO, CINAHL and ASSIA), handsearches and contacts with experts. The evidence was described for sources of heterogeneity, studies' quality (established scorings) and consistency of findings.
Results: The review included 58 studies with over 1.5 million patients from 13 countries. Research has increased through the years, with over a third of the studies generated in the last 4 years, though most data reported to early 90's. There were research gaps in various illness-related, personal and social factors, health care, social support and macrosocial factors. Studies were heterogeneous in 5 main areas: study design, methods of data collection, compared categories of place of death, study setting and quality (scores ranging 33–88%). Nevertheless, there were 25 high quality studies that performed a multivariate analysis. They generated quality and consistent evidence for the effect of 17 factors.
Discussion: Despite a number of limitations, research on the risk factors for place of death in cancer provides strong evidence that must inform policy and practice. Further research will need to address: (1) the need for a reduction of the time gap between the data collection and publication, (2) the research gaps (3) methodological improvements and standardization of methods across countries (e.g. multinational studies).

Abstract number: 135
Presentation type: Oral Presentation
Session: Policy & Place of Care

Where do we die and why?

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Background: Studies suggest that a majority of patients with advanced illness wish to die at home. Patient preferences, however, seem to be of minor importance compared to the relative number of hospital beds in a population.
Aim: To explore whether accessibility of institutional beds over time has influenced Norwegian cancer patients' place of death in general, and in two adjacent counties in particular.
Method: Official statistics were analyzed. Annual place of death registrations for cancer patients from 1964 to 2002 were compared to available somatic hospital and nursing home beds. Five year files on hospital death (cancer patients) for all 30 municipalities in two neighboring counties from 1986 to 2000 were also analyzed and compared regarding distance to hospital, age and number of hospital beds.
Results: Nationally, a decrease of hospital beds from 26 000 to 14 000 preceded a decrease of cancer death in hospital from 72% to 56%. Home deaths declined to 11%. Nursing home beds increased from 24 000 to 42 000, and nursing home deaths rose from 8% to 32%. Concurrently the population rose from 3,5 to 4,5 mill. In two neighboring counties, long distance to hospital was inversely related to hospital death ($p < 0.001$) Younger patients (< 40 years) mainly died in hospitals in both counties. For older patients (70 years +), hospital death was reduced from 72% to 54% and from 55% to 36% in the two counties respectively.
Conclusion: In Norway, place of death in for the last forty years is associated with accessibility of hospital beds. Despite a decline in hospital deaths, there was no increase in home deaths, probably due to an increasing number of nursing home beds. In the two counties analyzed, distance to hospital was significantly associated with hospital death for older, but not for younger patients. The results support previous reports, suggesting that the organization of health care systems is a major determinant for place of death.

Abstract number: 136
Presentation type: Oral Presentation
Session: Policy & Place of Care

Developing a methodology for costing hospice and palliative care services

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Background: In Irish, European and international healthcare settings, the costs of service development in hospice and palliative care (PC) are relatively complex due to a number of reasons e.g. development of services in both voluntary and statutory contexts; the relative youth of palliative care as a specialty and the involvement of multiple disciplines in multiple locations. The principles of PC demand equitable service regardless of location or illness.
Sample: All specialist PC inpatient units, day care services, hospital teams and home care services and all regional health authorities in Ireland.
Method: A baseline study (Irish Hospice Foundation, 2005) collected service data on a systematic and standardised basis from each service level described above. Salary scales for professional staff were identified along with overhead costs. These were applied to i) existing staff complements and ii) recommended staff levels for comprehensive PC coverage on a regional and national basis (Report of National Advisory Committee for Palliative Care, 2001). Totals for existing staff complements calculated in this manner were validated against actual staff costs for a sample of inpatient units. Comparison of actual and recommended staff levels allowed the calculation of fiscal deficits on a regional and national level. Current spend per-capita was calculated on a regional basis. These data were then transformed to per-capita deficit figures for each region. Services costs were further unravelled through a calculation of inpatient bed costs and the costs of a homecare package.
Results: A wide disparity in current spend per-capita between regions was evident (minimum 1.50 to maximum 31). Marked regional inequities are illustrated with a deficit range from -12 to -36.
Conclusions: The approach provides a framework for objective assessment of financial input to PC service and a means to assess equity. Implications for national policy and lobbying are explored.

Abstract number: 137
Presentation type: Oral Presentation
Session: Policy & Place of Care

Going home for the last time: facilitating end of life care in the setting of choice for the child and family

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Background: Home is the preferred place for end of life care for the majority of children with life limiting conditions. However the majority of children with non-malignant conditions continue to die in hospital. Rapid discharge home from the intensive care unit or the ward is frequently required in order to facilitate end of life care in the setting of choice but is often not considered or is dismissed as impractical. Here we present a retrospective review of rapid transfers for end of life care.
Methods: Retrospective case-note review of all children referred to the team over a 2-year period.
Results: Seventy deaths were identified (median age 11 years). Thirty three children (47%) had malignancy, the majority whom (82%) died at home. Forty six percent of non-oncology patients died at home. Eight children died in children's hospice. Seventeen children were considered for rapid discharge for end of life care. Four of these children had malignancy. For the majority of children (82%) the preferred place for end of life care was home. All children were successfully transferred from hospital to their planned place of care except one 2 year old with congenital heart disease who was not transferred to children's hospice as planned, because of uncertainty around prognosis. Of the 16 successful transfers 9 children were intubated during transfer and extubated at home. Eight children died within 24 hours of transfer, but 4 children survived greater than 2 weeks (range 14–412 days) despite an expectation of death within 24 hours at the time of transfer. All patients had symptoms effectively managed at their preferred place of care by close collaborative working with local services and anticipatory prescribing for symptom management.
Conclusion: Despite the unpredictable nature of many non-malignant conditions, effective end of life care in the setting of choice can be achieved by rapid planned discharge from hospital for end of life care.

Abstract number: 138
Presentation type: Oral Presentation
Session: Policy & Place of Care

When patients and caregivers change their mind about preferred place of death: results from a prospective longitudinal randomised controlled trial in the palliative setting

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Background: There is increasing interest in patient and caregiver preferences for place of death. Research suggests that the majority of patients wish to die at home surrounded by loved ones. Achieving death at the patient's place of choice is an important aim of palliative care.
Methods: The Palliative Care Trial was a longitudinal RCT of 461 patients referred to a regional specialised palliative care service. If appropriate, preferred place of death was collected at all trial time points from patients and caregivers. Actual place of death data was collected from South Australian medical service databases.
Results: 106 trial participants provided a preference for place of death at baseline assessment,44% wished to die at home, 12% in hospital, 34% in a hospice, and 9% in an aged care facility. Caregivers reported similar preferences at 53%, 7%, 30% and 10%, respectively. At the end of the trial, 342 participants had died and actual place of death was known for 297. Forty eight (16%) died at home, 112 (38%) in hospital, 117 (39%) in a hospice, and 20 (7%) in an aged care facility. The trends for a patient's preferred versus actual place of were markedly different ($p < 0.001$). Only

54% of those patients who reported a preferred place of death actually died in that place. Seventy one patient caregivers dyads were followed longitudinally from referral to palliative care till death. 1/3 of dyads changed preferences at least once, and in 10% (n = 7) there was disagreement. In cases where conflict was unresolved the patient had wished to die at home.
Conclusion: While the most common reported preference was death at home, most patients died in medical settings, even when palliative care services were involved. Conflict and changing preferences may represent both caregiver fatigue, and ongoing reassessment by caregiver and patient or the patients' wishes in light of the evolving care needs.

Abstract number: 139
Presentation type: Oral Presentation
Session: Family & Communication

Predicting family caregiver psychosocial functioning in palliative care: a pilot study

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Background: Health professionals are expected to support family caregivers of patients requiring palliative care. However, there is a dearth of empirical evidence to help clinicians identify caregivers who might be at risk of poor psychosocial functioning.
Aims: This secondary analysis of baseline data from a larger study sought to determine if it was possible to predict the psychosocial functioning of family caregivers who were supporting a relative with advanced incurable cancer.
Methods: Data from 35 primary family caregivers obtained at the commencement of home based palliative care services and five weeks later was used in the analysis. Instruments to measure caregiver preparedness, competence, mastery, social support, anxiety and self-efficacy were administered.
Analysis: Cluster and logistic regression analysis approaches were utilised.
Results: Self-reported 'anxiety' and 'competence' sub-scale total scores at time of commencement of home based palliative care services were associated with caregivers 'at risk' of lower levels of psychosocial functioning five weeks later.
Conclusions: This study suggests that it may be possible to identify family caregivers who are at risk for poorer psychosocial functioning. However, replication in a larger sample is required before this screening approach can be recommended for clinical use.

Abstract number: 140
Presentation type: Oral Presentation
Session: Family & Communication

Is prognostic information given by oncologists tailored to patients' preferences?

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The relevance of improving patients' awareness of their prognosis is generally acknowledged since it has major consequences on adjustment to the illness and ability to make optimal medical and life decisions. However, it is unclear whether the prognostic information conveyed and its understanding is consistent with this aim.
Research aims: (1) document prognostic information given in a first cancer outpatient consultation and patients' preference for this information (2) verify patients' level of prognostic awareness.
Methods: Following their consultation with an oncologist, 51 patients (x = 60 yrs old) with colorectal, breast, or ovarian cancer completed a self-report questionnaire, including prognosis.
Results: Descriptive analyses show that prognostic information given is generally in accordance with patients' preferences except for critical survival aspects: a majority of patients would prefer to know survival estimates with (93%) and without (79%) treatment, although they perceive this information to be conveyed three quarters (74%) and half of the time (52%), respectively. More than half of patients would like to discuss extended themes related to prognosis such as practical decisions to make and information/support to be given to their relatives, while they are perceived to be discussed respectively 35% and 29% of the time. Over 70% of the patients incorrectly state the extent of their disease, with 59% being optimistic.
Conclusions: Results are consistent with literature data suggesting that prognostic disclosure remains problematic in current practice. These results call for the development of empirically-based interventions tailored to the patients' specific needs and preferences toward prognostic disclosure throughout the disease trajectory, while striving to prevent undue distress.

Abstract number: 141
Presentation type: Oral Presentation
Session: Family & Communication

Longitudinal study into the evolution of total distress in patients with advanced cancer from referral to palliative care services to death

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Background: The experience of distress is derived from the interaction of physical, psychological, social and spiritual domains. The dynamics of these interactions have not been studied over time.
Aims: To explore distress in the terminal phases of cancer: To examine influential factors, the relationship between distress and time, and the contribution of each domain of distress to global distress over time.
Methods: Longitudinal study combining quantitative (100 consecutive patients) and qualitative methods: 20 purposively selected new community cancer patients (sub sample) are being assessed monthly until death or for 6 months maximum. Assessment involves documentation of socio-demographic factors, medication, performance status and: The Memorial Symptom Assessment Scale (physical), Edinburgh Postnatal Depression Scale (EPDS) (psychological), FACIT-Sp-12 (spiritual), NCCN Global Distress Thermometer (GD) (primary end point) and in-depth interview.
Analysis: Exploration of risk factors for global distress at baseline and death is in progress with univariate analysis. Distress patterns are being examined by plotting distress measures over time. The contribution of each measure to global distress is being analysed graphically and via the correlation coefficient at baseline and pre-death. Interview analysis is with grounded theory.
Results: M:F 1:1. At baseline: 80% were fatigued, 20% depressed, 25% distressed (80% of whom had no partner). Correlation coefficients: Between EPDS and GD 0.84; FACIT and GD 0.79. Preliminary analysis indicates a trend of increasing psychological, spiritual and global distress over the first 3 months. Qualitatively, frustration with debilitation, importance of control and concerns for family persist over time.
Conclusions: Key qualitative concept: Debilitation impacts directly on each distress domain. This will be explored and the quantitative relations between distress domains clarified, as full analysis to death will be presented.

Abstract number: 142
Presentation type: Oral Presentation
Session: Family & Communication

Symptoms and quality of life in dying children with cancer – the parent's perspective

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Objective: As part of the nationwide PATE project we investigated the present quality of palliative care for paediatric cancer patients from the family point of view.
Methods: 50 Families from 6 out of the 18 regional departments of paediatric oncology consented to cooperate. The parents were visited by an especially trained nurse or doctor to perform a semistructured interview.
Result: 76% of the children had died of malignancy progression, and 24% of treatment-related medical complications. 47% of the patients had died at home, while 53% had died in a clinic, a third of them on the intensive care unit. Main troublesome symptoms were pain (86%), fatigue (82%), loss of appetite or unintended weight loss (71%), or dyspnea (63%). Between 41% and 49% of the patients suffered anxiety, constipation, or emesis/vomiting. As perceived by the parents, treatment was most effective against pain and constipation. 79% of the parents judged the received quality of care as "very good" or "good", 21% as "satisfying" or "moderate", and none of them as "bad/unacceptable". The parents assigned special importance to good symptom control, to the opportunity for overt communication with the caregivers, and to being accepted by the caregivers as serious partners. Even more than 3 years after the death of their child many parents felt left alone with/in their grief/mourning. Relatives and friends still tried to avoid talking about the process of dying, or the death of their/the beloved one.
Conclusion: Troublesome physical and psychosocial symptoms are expressed by most of the dying children. Most of the parents expressed their gratefulness of having got the opportunity to communicate this experience to us. Acknowledgments: PATE was initiated by the German Society of Paediatric Oncology and Haematology (GPOH). It was funded by the German Children's Cancer Fund (Deutsche Kinderkrebshilfe) and Mundipharma GmbH, Limburg, Germany.

Abstract number: 143
Presentation type: Oral Presentation
Session: Family & Communication

Defining cancer patients as being in the terminal phase: who receives a formal diagnosis and what are the effects?

Birgit Aabom, **Jakob Kragstrup**, **Leiv S Bakketeig**, **Henrik Stovring**, Istitute of Public Health, Odense, Denmark, **Hindrik Vondeling**, Istitute of Public Health, Odense, Dominica

Abstract Purpose: Physicians either do not define cancer patients as being terminal or their prognostic estimates tend to be optimistic. This might affect patients' appropriate and timely referral to specialist palliative care services or can lead to unintended acute hospitalisation. In this population-based study, we analysed patient-related factors leading to an explicit terminal diagnosis and effects of the diagnosis on end-of-life cancer care.
Patients and Methods: We used the Danish Cancer Register and four administrative registers to perform a retrospective cohort study in 3445 patients with cancer as primary cause of death between 1996 and 1998. We used the Danish "terminal declaration" issued by a physician as a proxy for a formal terminal diagnosis (prognosis of death within six months). The terminal declaration gives right to economic benefits and increased care for the dying. We investigated patient-related factors of receiving an explicit terminal diagnosis by logistic regression, then analysed effects of such a diagnosis on admission rate per week and place of death.
Results: Thirty-four percent of patients received a formal terminal diagnosis. Age 70+ (OR, 0.44; 95% CI, 0.34 to 0.56; $p < 0.001$), women (OR, 0.81; 95% CI, 0.69 to 0.96; $p = 0.02$), haematological cancer (OR, 0.20; 95% CI, 0.09 to 0.41; $p < 0.001$) and less than one month survival time (OR, 0.10; 95% CI, 0.07 to 0.15; $p < 0.001$) were associated with a lesser likelihood of receiving a formal terminal diagnosis. Explicit terminal diagnosis was associated with lower admission rate and an adjusted OR of hospital death of 0.25 (95% CI: 0.21–0.29).
Conclusion: Women and the elderly were less likely to receive a formal terminal diagnosis. The formal terminal diagnosis reduced hospital admissions and increased the possibilities of dying at home.

Abstract number: 144
Presentation type: Oral Presentation
Session: Family & Communication

Family meetings in the intensive care unit during crisis

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Aim: Numerous studies document the fact that a high proportion of deaths in intensive care units occur following decisions to withdraw or withhold life support. Conflicts often occur between physicians and families at this time of crisis. The aim of this research is to gain insight into factors that promote successful end-of-life decision-making during family meetings and reduce the emotional burden of families of recently deceased Intensive Care Unit (ICU) patients. This study is currently in the early stages of data collection.
Methods: The Palliative Care Consult Service's data base is being used to identify families of recently deceased ICU patients that were involved in family meetings and discussions about end-of-life care decisions. Purposive sampling is being used to recruit families and health care providers for in-depth interviews to discuss their experiences and their current attitudes about the quality of those experiences. Qualitative methods involving focus groups and personal interviews are being used. The FAMCARE is also being used to measure family satisfaction with care. Interviews are being transcribed and qualitative software will be used to facilitate coding. Principles from grounded theory will be used for analysis.
Results: Four family groups have been interviewed to date. Three factors have consistently emerged that are associated with lingering concerns: 1) inadequate time to make decisions (or "feeling rushed"); 2) lack of exploration of alternative decisions; and 3) unanswered questions about medical care during the final days.
Conclusions: Even with this small sample of families, useful insights for improving family meetings to reduce the emotional burden after end of life decision making have emerged from follow up interviews. Additional interviews are being completed with families and health care providers to elaborate findings and identify additional factors associated with successful family meetings.

Abstract number: 145
Presentation type: Oral Presentation
Session: Education

Evaluation of palliative care in undergraduate nursing programs

Betty Ferrell, **Rose Virani**, City of Hope National Medical Center, Duarte, U. States, **Pam Malloy**, American Association of Colleges of Nursing, Washington, DC, U. States, **Judy Paice**, Northwestern University, Feinberg School of, Chicago, U. States, **Patrick Coyne**, Virginia Commonwealth University Health Care, Richmond, U. States

Research aims: This presentation reports findings of an educational project, the End-of-Life Nursing Education Consortium (ELNEC), which has implemented a standard end of life/palliative care curriculum in 461 U.S. nursing schools.
Sample: The project's (2000–2005) training programs were attended by 502 faculty teaching in 461 different undergraduate nursing programs representing all 50 states who in turn implemented this curriculum in their own schools.
Methods: Extensive evaluation included pre course assessment of faculty knowledge and beliefs, a curriculum survey and detailed follow up evaluation at 6 and 12 months post attendance.
Results: Results of the 12 month evaluation indicate significant improvement in all nine content domains ($p < 0.01$ by paired t-test) in school curricula. A mean of 10 hours of EOL content were added to the curriculum at 12 months post course attendance. Faculty also reported significant ($p < 0.01$) improvement in their perceived effectiveness of new graduates, teaching and overall curriculum in end of life care. Twenty six (26) schools participated in pre and post testing of students who received the curriculum and

demonstrated significant mastery in six of nine content domains and overall knowledge.
Conclusions: The ELNEC-Undergraduate project has been extremely successful in improving faculty knowledge, curriculum change and student outcomes. This project has major implications for basic preparation of nurse's worldwide.

Abstract number: 146
Presentation type: Oral Presentation
Session: Education

Effect of palliative care courses on healthcare workers' state of mind and attitudes towards death

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Introduction: In Hungary we have been organizing 40 hours (5 days) basic PC courses and 40 hours (5 days) advanced courses since 1994, and these were attended by more than 3300 healthcare workers. The courses include not only lectures but stress-handling communication training (12 hours) as well. In consideration of the fact that healthcare workers dealing with the seriously ill are burned out and having high level of fear of death we decided to measure the effectiveness of the courses.
Method: On the first and last day of the basic PC courses (1st and 5th day) and then 2–3 months later, on the first day of the advanced courses the participants fill in the Shortened Beck Depression Inventory (SBDI) (9 items) and Neimeyer and Moor Multidimensional Fear of Death Scale (NMMFDS) (42 items). The results are processed with SPSS 11.0 program.
Results: According to the first results ($N = 80$) participants of the basic courses show significant decrease ($p = 0.017$) in 'fear of early death' factor of NMMFDS and in depression ($p = 0.006$); and those participating also in advanced courses ($N = 30$) show significant decrease in 'fear of consciously experiencing death' factor of NMMFDS ($p = 0.025$). Survey among medical students who only listen to lectures in the PC courses ($N = 55$) didn't show significant change in neither of the items. Surveys are performed continuously; refinement of the results is expected in the next months.
Conclusion: PC trainings including skill-developing exercises too may promote an improvement in the state of mind and reduce fear of death in healthcare workers dealing with the seriously ill.

Abstract number: 147
Presentation type: Oral Presentation
Session: Education

A dignified death accordning to Swedish medical students

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Aim: To die with dignity is an important but ambiguous concept and it is used in contradictory contexts, both for the promotion of palliative care and euthanasia. Our aim was to explore medical students' definition of a dignified death.
Methods: A questionnaire containing open-ended questions was answered anonymously by 165 first and fifth year medical students. The data were analysed using qualitative content analysis with no predetermined categories.
Results: The students' descriptions of a dignified death resulted in five categories: 1) death without suffering, 2) death with limited medical interventions, 3) death with a sense of security, which implied dying in a safe environment and nursed by professional staff, 4) death with autonomy, respect for the individual and empowerment to the patient and 5) death with acceptance.
Conclusions: The data suggest that the students perceive that the medical system is over-treating patients and sometimes causing harm to dying patients. The results reveal a potential misunderstanding and contradiction in a death without suffering and the use of necessary palliative interventions. These findings are important when planning education as regards palliative care and dignified death.

Abstract number: 148
Presentation type: Oral Presentation
Session: Education

A Randomised Controlled Trial (RCT) to evaluate the effectiveness of a three day communication skills training programme for palliative care nurses.

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Aim: This multi-centred RCT tested the hypotheses:nurses' communication skills scores will improve after a 3 day communication skills course to a significantly greater extent than for nurses who do not undertake a course.
Method: All senior hospice and community nurses in the organisation were invited to participate. 160 were required to detect a difference in the primary outcome with 90% power at the 5% significance level with 20% attrition. Ethical approval was granted by MREC. After recruited nurses had submitted 2 audio taped nurse/patient interviews they were randomised to intervention (3 day course) or control (no intervention). Intervention nurses submitted a 3rd audio taped nurse/patient interview 12 weeks post course. Control submitted a 3rd audio taped nurse/patient interview 12 weeks post 1st submission. The intervention was modelled on the national DoH cancer care communication skills training programme. The primary outcome was an improvement in communication skills scores measured by the Communication Skills Rating Scale (Wilkinson 1991). Audiotapes were rated by 2 raters who completed a reliability study.
Analysis: The data were analysed using STATA. Primary outcome, repeated measures analysis of variance was used to test differences between pre and post scores. The Cohen kappa statistic tested levels of agreement for the audiotape ratings.
Results: 157 nurses completed the trial. Audiotape rater agreement was 95%. The mean total score for the intervention group increased 9.9 pre test to 13.8 post test compared with control 9.4 pre test and 9.4 post test ($P = 0.001$). Qualitative data indicates nurses' confidence levels in communicating increased. 96% stated they would definitely recommend the course to other health care professionals.
Conclusion: This RCT addressed criticisms levelled at previous trials; it is the largest communication skills RCT involving nurses. The results indicate this 3 day model of training improves palliative care nurses' skills.

Abstract number: 149
Presentation type: Oral Presentation
Session: Education

What impact did the English national education and support programme for District and community nurses in the principles and practice of palliative care have on their confidence and knowledge?

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Introduction: Limited palliative care knowledge and expertise may be one reason why some dying patients receive inadequate home care in England. In 2001, the Department of Health launched a 3 year national education and support programme for district and community nurses (DNs) in the principles and practice of palliative care. We conducted a national mixed methods evaluation of the programme. We report on the impact of the

programme on DNs' confidence in their palliative care competence and knowledge.
Research aim: To evaluate the impact of the national education programme.
Sampling frame: 1280 DNs were randomly selected from 8 cancer networks, stratified by old Health Region together with a sample of DNs attending the programme.
Methodology: A'before and after' design was used: the national spread of the programme precluded controls. Postal questionnaires on palliative care competence and knowledge were sent to DNs at the start of the programme and one year later. A semi-structured interview was undertaken with a subsample of DNs.
Methods of analysis: Scores for matched pairs of DNs responding at both times were compared using t tests. A multiple linear regression was undertaken on a score measuring change to identify factors associated with improvement in scores. Analysis of the qualitative sample was undertaken using the Framework Approach.
Results: 56.5% replied at the start of the programme, and 56.9% one year later. A sample of 374 matched pairs found statistically significant improvements on all nine scales measuring DN confidence in palliative care competence and in knowledge scores. Most DNs thought the programmes had improved their confidence and knowledge. The interviews revealed how the programmes helped. Improvements were not accounted for by participation in other initiatives. Conclusion: We conclude that the national programme had a positive impact on DNs confidence in palliative care competence and knowledge.

Abstract number: 150
Presentation type: Oral Presentation
Session: Education

Effective use of the subcutaneous route: learning from each other

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Background: The subcutaneous route is the parenteral route of choice in symptom management in palliative care when oral medication is impossible. In UK practice, this means continuous subcutaneous infusion (CSCI) administered via a syringe driver. This is not the case elsewhere.
Aim: To investigate, via a pilot study, the use of the subcutaneous route in palliative care in contrasting international settings to gain insight into its most effective use from a variety of perspectives.
Method: Semi-structured recorded interviews with seven physicians practising palliative care in six countries (Argentina, Australia, India, Nigeria, Romania, Spain).
Analysis: Full transcriptions were subject to a constant comparative method analysis based on grounded theory approaches.
Results: The subcutaneous route was considered valuable in all settings. Various devices, including the syringe driver, were employed to deliver CSCI. Intermittent subcutaneous injections, however, were cited as an effective, often preferable, alternative for clinical and social reasons including cost, increased patient contact and family carer empowerment.
Conclusion: The subcutaneous route is useful in symptom management. Internationally, various approaches are employed, with intermittent subcutaneous injections often considered preferable even in settings with resources available for CSCI. This challenges accepted practice, notably in the UK, and raises questions about clinical 'norms' and the role of the evidence base. These issues will be further explored in a doctoral research project comprising a systematic review of the literature and interviews with practitioners internationally. This qualitative study would be complemented by investigation of the comparative effectiveness of intermittent subcutaneous injections compared to CSCI both pharmacologically and clinically.

Abstract number: 151
Presentation type: Oral Presentation
Session: Education

Pioneer of more than care – a bibliometric tribute to the role of Dame Cicely Saunders (1918–2005) in the formation of knowledge systems and structures for palliative care

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Aim: Cicely Saunders is acknowledged as "founder of the modern hospice movement". However, her pioneering work in direct care often obscures her role as pioneer of related knowledge systems and structures. This research aimed to investigate and highlight that role.
Methods: Using databases, catalogues and previously-published lists, a comprehensive bibliography of Dame Cicely's publications was developed and analysed bibliometrically.
Findings: Two doctors surnamed Barrett were early influences on her writing. Every tenth year from 1947 to 1997 saw a significant event in her life, the development of hospice and palliative care, or relevant knowledge structures and systems. A total of 328 works by her were identified, 125 of which had not been reported in previous lists, including her first publication in the BMJ, on 26 Sep 1959. Although 311 were published in English and 220 in the UK, the rest were translated into eight other languages and published in 16 other countries. The bibliography contains 109 journal articles, 53 book chapters, 36 prefaces, 21 letters to journals, 19 books or booklets (co) written by her, 14 conference contributions, 12 books or booklets (co) edited by her, and 5 journal editorials. She was published in 86 different journals, and on the boards of three. Her pioneering role is highlighted by the fact that from the 1960s to 90s she was often published in the earliest issues of new (generalist and specialist) journals. Later in her career, she was invited to contribute many forewords and prefaces to major textbooks. Bibliographic databases reveal that her work was extensively cited, with the first edition of the book she edited "The management of terminal disease" cited most often.
Conclusion: Those who carry on the kind of care which Cicely Saunders inaugurated continue to benefit from her efforts in pioneering the structures and systems associated with the knowledge they create, discover, disseminate or use in the course of their work.

Abstract number: 152
Presentation type: Oral Presentation
Session: Assessment

Is Pain Intensity predictive for complexity of cancer pain (CP) management?

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Background: CP is a complex construct. The development of a standardized classification system that is comprehensive, prognostic and simple to use could provide a common language for the clinical management and research of CP. Construct, inter-rater reliability & predictive validation research have resulted in the development of the Edmonton Classification System for CP (ECS-CP). The five features of the ECS-CP- Pain Mechanism, Incident Pain, Psychological Distress, Addictive Behavior and Cognitive Function-have demonstrated value in predicting pain management complexity. Pain Intensity (PI) on initial assessment has been proposed as having further predictive value.
Hypothesis: Patients with moderate to severe cancer PI on initial assessment will take longer to achieve stable pain control, use higher opioid doses, & require more complicated analgesic regimes.
Methods: A secondary analysis was performed on a multicenter validation study involving 619 advanced cancer patients with a pain syndrome from two hospice settings, an acute care consultation service and a tertiary palliative care unit. Associations between PI and time to stable pain control (Cox regression); final opioid dose (Kruskal Wallis one-way ANOVA); adjuvant modalities & opioid escalation index percentage (OEI%) (chi square) were calculated. PI on initial assessment was defined as Mild (0–3), Moderate (4–7), and Severe (8–10), using a numerical pain scale.
Results: Patients with moderate and severe pain required a significantly longer time to achieve stable pain control ($p < 0.001$): median time was 4 (mild), 9 (moderate) & 23 (severe) days. Patients with moderate to severe pain required significantly higher final opioid doses ($p < 0.001$) and more adjuvant modalities ($p = 0.003$).

Conclusions: PI at initial assessment is a significant predictor of complexity of pain management & time to achieve stable pain control. The incorporation of this feature into the ECS-CP needs further consideration.

Abstract number: 153
Presentation type: Oral Presentation
Session: Assessment

Measurement scales for the effective assessment of breathlessness in palliative care patients: a systematic review

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Introduction: There is no universally accepted scale to assess breathlessness in adult palliative care.
Aim: To systematically identify and appraise scales which have been validated for use in palliative care or show promise.
Methods: Electronic search (01/09/05) using Cochrane databases 2005, MEDLINE 1966–2005, OLDMEDLINE 1950–1965, EMBASE 1980–2005, PsycINFO 1872–2005, AMED 1985–2005, CINAHL 1982–2005, SIGLE 1980–2005 and hand searches.
Basic search strategy: "Dyspnoea (etc.) AND Measurement (scales etc.) AND Palliative care/heart failure/COPD/cancer etc."; no language limits. We included patient-based scales with at least 2 psychometric characteristics reported, identifying those with face and construct validity, test–retest reliability and responsiveness.
Results: There are 6 scales to measure breathlessness severity, 4 questionnaires with descriptions of breathlessness, and 19 scales to assess its functional impact. Severity: The numeric rating scale (NRS) and modified Borg scale (mBorg) have been tested in chronic lung disease and ventilated patients (NRS also in cancer). Both need more assessment of responsiveness and test–retest reliability. Visual Analogue Scales need larger sample sizes than the NRS.
Descriptions: The Dyspnoea Descriptor Questionnaires (DDQ) and Cancer Dyspnoea Scale (CDS) have been evaluated in cardiorespiratory disease and cancer respectively, but need more testing of construct validity and responsiveness.
Functional impact: The Chronic Respiratory Questionnaire dyspnoea subscale (CRQ-D) has been evaluated in COPD, other lung diseases and heart failure. It is similar to a subscale of the MND Respiratory Scale. It is valid, reliable and responsive, with potential for palliative care.
Conclusion: The NRS, mBorg, CRQ-D, CDS and DDQ seem most suitable for further testing in palliative care.
Acknowledgements: This review is supported by a grant from the Breathlessness Research Charitable Trust. It will be published and updated as a Cochrane review.

Abstract number: 154
Presentation type: Oral Presentation
Session: Assessment

Adjusted physician assessments of the health related quality of life of palliative care patients

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Objective: Many palliative care patients are too ill to participate actively in research. Therefore, studies in palliative care are often based on a non-representative sample of patients. This may result in biased findings. Using physician assessments to evaluate the patients' health related quality of life (HRQL) may reduce these problems. If physician assessments are used these should be in agreement with the patients' own view. However, results of previous investigations indicate that the validity of physician assessments of the patients' HRQL is inadequate. Therefore, we investigated whether adjustment of physician assessments improved the agreement with patient assessments.
Study Design and Setting: In a palliative care department patient and physician assessments of 12 EORTC QLQ-C30 domains were obtained at the patient's first contact with the department (N = 115). Follow-up data from the following weeks was also collected. We used both logistic regression and multidimensional linear regression analysis methods to adjust the physician assessments. As explanatory variables (predictors of the patient assessments) we used the physician assessments and information about the patients' clinical and sociodemographic characteristics.
Results: Improvements from using adjusted physician assessments ranged from negligible to moderate across the 12 HRQL domains investigated, but for none of the domains did the adjusted assessments result in close agreement with patient assessments. Evaluations on the follow-up data did not confirm the findings of improvement.
Conclusion: Because of the modest improvements and the lack of reproducibility of the findings such statistical adjustments of physician assessments could not be shown to have practical relevance.

Abstract number: 155
Presentation type: Oral Presentation
Session: Assessment

Validation of an Italian questionnaire (QIDEI) for the screening and assessment of breakthrough pain in advanced cancer

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The prevalence and clinical impact of breakthrough (BKP) or severe episodic pain is considered relevant in the management of cancer pain. The definition of BKP and its diagnosis is based on clinical experience and different opinions exists even among palliative care clinicians in applying the concept to clinical practice. For this reason we designed a questionnaire (QIDEI) by modifying the instrument used by Portenoy and Hagen in 1990 and validated it in the Italian cancer pain population. The QIDEI was administered to 240 consecutive patients with cancer pain in a cross-sectional study involving 8 Italian palliative care and oncology centres. The questionnaire validity was examined through its comparison with expert opinion as golden standard for the presence of BKP. The 17 experts involved in the study, had to agree on a grid of 10 cases representing 5 diagnoses of BKP present and 4 of BKP absent. Concordance was good (Cohen K 0.68) highlighting the presence of some controversial situations. In particular the recognition of BKP as a result of insufficient titration of baseline analgesic therapy with opioids gave raise to lower concordance. Test retest reliability was evaluated through Cohen's Kappa between two administrations of the questionnaire performed two hours apart by two different interviewers in a subgroup of 60 patients. The prevalence of BKP based on expert opinion was 72.5% (95% CI 66.4%–78.9%), 90% of patients were treated with opioids. The QIDEI showed good sensitivity (85.6%) and specificity (86.3%) as well as a very good test retest reliability (K = 0.87). The QUDEI descriptive part is reported in another presentation. We conclude that the QIDEI is a sensitive, specific and realiable tool for the screening of BKP in patients with cancer pain undergoing opiod therapy but also that it should be used in conjunction with a clinical judgement on the adequacy of baseline opioid treatment.

Abstract number: 156
Presentation type: Oral Presentation
Session: Assessment

The experience of introducing the confusion assessment method to a specialist palliative care unit

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Introduction: Delirium may be described as an acute disorder of attention and cognition. It occurs in up to 83% of patients towards the end of life, but clinicians fail to recognise its presence in up to two-thirds of cases. Unless delirium is recognised, it cannot be treated. The use of screening tools for delirium, such as the Confusion Assessment Method (CAM), has therefore been recommended.
Methods: The CAM was used by Non-Consultant Hospital Doctors (NCHDs) to assess all patients on admission to St. Francis Hospice, a 19 bedded specialist palliative care unit.
Analysis: We reviewed the medical records of 200 consecutive admissions. We detailed the number of times that the CAM was recorded, and, on the occasions of non-compliance we documented the reason why. We compared the CAM result recorded by the attending NCHD with the clinical opinion of the Consultant in Palliative Medicine, and with review of the medical records.
Results: The CAM was recorded in 166 (83%) patients. 27 patients were documented as having a posityive CAM by the NCHDs and 114 as having a negative CAM. The diagnosis was challenged in 25 cases by the Consultant and by review of the notes. It was judged that the NCHDs had made a false negative diagnosis of delirium in 23 cases, and a false positive diagnosis in 2 cases. A final diagnosis of delirium was therefore made n 50 (30%) patients. CAM sensitivity (95% CI) was 0.54 (0.39–0.68) and specificty was 0.98 (0.93–0.99). Positive predictive value was 0.92 and negative predictive value was 0.83.
Discussion: In the original validation study carried out in the hospital setting, the CAM had a sensitivity of 94–100% and a specificty of 90–95%; however we clearly encountered difficulties in its use. We discuss the possible reasons for this and the lessons that can be learnt from our experience. We also consider the implications of the unquestioning use of tools that have not been validated in the palliative care setting.

Abstract number: 157
Presentation type: Oral Presentation
Session: Assessment

'Assessing cognitive impairment in palliative care patients: the utility of the clock drawing test'

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Aims: The aim of the study was to assess the validity and reliability of The Clock Drawing Test (CDT) in a hospice population.
Design: Cross sectional comparative study.
Subjects: Palliative care patients admitted to a hospice unit. Methods: The Abbreviated Mental Test Score (AMTS) was selected as the most appropriate measure against which to assess the criterion validity of the CDT in a hospice population. Both the AMTS and the CDT and other selected measures were administered to 82 eligible patients within 72 hrs of admission. Concurrent validity was assessed by comparing the CDT to the Digit Span Forwards, Months of the Year Backwards and 3 Item Recall Test. Inter rater reliability was calculated by comparing the scores of 20 CDT as assessed by three independent raters.
Results: Using a cut off score of less than or equal to 7 for the AMTS, 25 patients were found to be cognitively impaired. There was a moderate significant correlation and agreement between the CDT and AMTS ($\text{rho} = 0.57$, $p < 0.001$, $k = 0.57$, $p < 0.001$). Sensitivity of the CDT was very high 0.92 (95% CI = 0.72–0.99) and specificity moderate 0.73 (95% CI = 0.59–0.84). Its positive predictive value was 0.61 and negative predictive value 0.95. IRR was high ($k = 0.85$). The CDT had moderate concurrent validity and was able to detect both attention and memory problems in this patient group.
Conclusions: Cognitive impairment is a frequent and distressing problem that palliative care patients and their carers experience, yet it is often not recognised. Previous research has highlighted the need for a simple, portable screening tool in this population, however most tools lack simplicity and are often burdensome to patients and staff. Findings in this study suggest that the CDT is a valid and reliable cognitive screening test in hospice patients. Its brevity and acceptability in clinical practice could make it an ideal tool in this population.

Abstract number: 158
Presentation type: Oral Presentation
Session: Assessment

The last 72 hours – symptom assessment in palliative care services in Iceland using the minimal data set – palliative care (MDS-PC) instrument

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The Minimal Data Set – Palliative Care (MDS-PC) is the newest member of a group of instruments commonly used in geriatric and mental care, and is still under development. It is a comprehensive instrument covering physical, emotional, cognitive and social aspects of PC and is filled out by the attending nurses and doctors. During six months a clinical epidemiological study was conducted using this instrument in home and in-patients' PC settings in Iceland. Assessments were made at entry to the service, 2 weeks later and at discharge, always covering the last 72 hours. Seventy patients died during the period, 64 in in-patients' units and 6 at home. Men accounted for 47%, mean age was 73 yrs, 47% were cohabitating but 36% lived alone. The most common diagnoses were lung cancer (27%); GI-malignancies were 18%, prostate 13% and breast cancer 10%. The median service time was 28 days (1–113). Twenty-five symptoms were assessed and the 3 most common were fatigue (96%), pain (86%) and loss of appetite (84%), as expected. About 11% of the patients had 4 or fewer symptoms, 30% had 5–7, 42% 8–10 symptoms and 17% had over 10 symptoms the last 72 hours. Pain was the most frequent symptom reported. Two-third had intermittent pain, 4% had constant pain and new pain was accounted for in 35% of the cases. However, three-fourth of the patients was assessed to have satisfactory pain control. The MDS-PC instrument gives comprehensive and detailed information about the PC patient population and both the severity and diversity of symptoms. It has proven to be a valuable addition to earlier PC assessments.

Abstract number: 159
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

Effectiveness of aromatherapy massage in improving anxiety and depression in cancer and palliative care patients: A randomised controlled trial

Susie Wilkinson, Royal Free & UCL Medical School, London, Great Britain, **Amanda Ramirez**, Cancer Research UK, London, Great Britain, **Jane Maher**, Mount Vernon Cancer Centre, London, Great Britain, **Sharon Love**, Cancer Research UK Medical Statistics Group, Oxford, Great Britain, **Maureen Gambles**, Marie Curie Cancer Care, London, Great Britain

Aim: To test the effectiveness of aromatherapy massage in treating anxiety and depression in cancer and palliative care patients.
Method: 214 patients were required to find a difference in improved anxiety and/or depression between the aromatherapy group and control group, at 5% level of significance with 80% power. In anticipation of a 25% attrition rate 288 patients with significant anxiety and/or depression were recruited to a pragmatic multi-centred RCT. The intervention was 4 weekly sessions of aromatherapy massage. Primary outcome, improvement in clinical anxiety and/or depression score at 10 weeks post randomisation/6 weeks post intervention, assessed by structured psychiatric interview with standardised diagnostic criteria. Secondary outcomes, improvement in clinical anxiety and/or depression at 6 weeks post randomisation (2 weeks post intervention), self-reported anxiety, depression, pain, fatigue, nausea and vomiting and global quality of life using the STAI, CES-D and EORTC QLQ-C30 at 6 and 10 weeks post randomisation. Data analysis, investigation showed that

analysis of complete cases was biased, multiple imputation was used to impute missing data, logistic regression was used for binary outcomes, ANOVA for continuous outcomes.
Results: Patients who received aromatherapy massage reported a significantly greater improvement in clinical anxiety and/or depression at 2 weeks post intervention ($p = 0.01$) the improvement was no longer significantly different at 6 weeks post intervention. Patients receiving aromatherapy massage also reported significant improvement in self-reported anxiety according to the SAI at both 2 ($p = 0.04$) or 6 ($p = 0.04$) weeks post intervention.
Conclusions: Levels of clinical anxiety and/or depression among cancer and palliative care patients are significantly improved, by four weekly sessions of aromatherapy massage, up to 2 weeks afterward the intervention. This improvement appears to be attenuated at 6 weeks post intervention.

Abstract number: 160
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

The last 48 hours: Delirium and the mental status of dying cancer patients

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Background: Delirium is a major problem in terminal cancer care. Prevalence rates described in previous studies vary widely. However, few studies describe terminal delirium occurrence, and the mental status of patients dying in palliative care units.
Objective: To describe the prevalence of delirium and the mental status of dying cancer patients in the last 48 hours of life.
Methods: 1911 terminal cancer patients admitted in 7 palliative care units in Canada were followed prospectively from October 2001 to December 2004, from admission until patient's death. Demographic data was recorded upon admission. The Confusion Rating Scale (CRS) was used for delirium screening. A score of 2 and higher on the CRS chart at one point during the last 6 nurse's shift (48 h) is associated with significant terminal delirium symptoms. When the patient could not be assessed with the CRS, the bedside nurse noted if the patient was comatose, under pharmacologic sedation, sleeping, or for other non-specified reasons.
Results: On 1911 patients, 378 (20%) had significant delirium symptom in the last 48 hours of their life. During the last nursing shift before the death of the patient, 242 (13%) could be assessed with the CRS, 1227 (64%) could not be assessed, and for 442 (23%), data were missing. Among those who were assessed with the CRS, 69% ($n = 166$), 15% ($n = 37$) and 16% ($n = 39$) had no, mild, or significant delirium symptoms, respectively. The reasons preventing patients from being assessed with the CRS were: in 53% ($n = 482$) comatose state, in 30% ($n = 278$) pharmacological sedation, in 4% ($n = 35$) natural sleep, and 13% ($n = 117$) could not be assessed for others reasons.
Conclusions: 1-It remains difficult to characterize the mental status of the last hours of life since nurses often stop rating dying patients; 2-Significant delirium symptoms seem to be present in only a minority of patients; 3-Coma or pharmacological sedation precedes death in a significant number of patients.

Abstract number: 161
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

Survey of current practice: management of delirium by palliative care, psychogeriatric, geriatric and oncology specialists in Australia and New Zealand

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Introduction: Delirium is prevalent and has high morbidity/mortality. Limited prospective data for management exists and treatment relies on expert opinion. Understanding current practice will help develop prospective studies of delirium management.
Aim: To survey current practice of Palliative Care, Psychogeriatric, Geriatric and Medical oncology specialists for delirium management.
Methods: A questionnaire to identify assessment and management, in relation to two case vignettes (reversible and terminal delirium) was used.
Results: Response rate ($n = 303$) was 30%. 60 to 70% of physicians would care for a patient with reversible delirium at home, with exception of oncologists (35%). For terminal delirium 50 to 70% of physicians, would be prepared to provide care at home. The mean number of investigations was 6.5 for reversible delirium, with over 90% of specialists doing electrolytes, full blood count and calcium, compared to terminal delirium-mean of 2. The rating of usefulness of nonpharmacological measures was variable. The agent most commonly used for reversible delirium was a neuroleptic (chosen by $> 80\%$ of all specialists), mainly haloperidol to treat hallucinations and agitation. However 30% of palliative medicine specialists would use neuroleptic for cognitive impairment, and impaired concentration. In reversible delirium benzodiazepines were used by $< 5\%$ of physicians, except oncologists (19.7%). For terminal delirium haloperidol was used by 23.2–57.8% of physicians, however midazolam use was higher (up to 58.9% by oncologists). The dosing schedules used were highly variable.
Conclusion: The survey identifies some key similarities in delirium management, however there are still significant areas of variability. There is a need for further evidence to guide management and delineate the patient populations seen by each speciality. This will assist in understanding the spectrum of eminently reversible delirium to delirium as part of physiology of dying.

Abstract number: 162
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

Spiritual issues in palliative care consultation in the Netherlands

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Introduction: Although spiritual needs are regarded as important in palliatieve care, physicians and nurses often feel unskilled and uncertain in addressing spiritual and religious concerns. For information, support and advice these professionals can, in the Netherlands, consult Palliative Care Consultation teams (PCC teams). This study aims to understand which spiritual issues are discussed and to determine which factors are of influence.
Methods: The national registry of the consultations of the PCC teams was analysed for a two year period.
Results. Spiritual issues played a role in 8.4% of palliative care consultations; in 4.1% of the consultations by phone and in 18.3% of the bedside consultations. Spiritual issues were raised in 2.3% of consultations as initial question of the requesting professional, and in 6.1% of consultations they were identified during the exploration of the initial request. In the consultations, on average, 1.3 different spiritual topics were identified. 'Acceptance of the illness' was more identified as spiritual issue than 'meaning of death' or 'loss of confidence in God'. Medical specialists as consultant less often than nurses, nursing home physicians and GPs identified spiritual issues. The main support given by the consultant was coaching the professional caregiver how to address these issues.
Discussion: This study demonstrates the important role for consultants in exploring and identifying spiritual needs of patients about whom consultation is asked. It was the discipline of the consultant and not the discipline of the requesting professional, nor the patient characteristics, which determined whether or not spiritual issues were discussed. Although continued education on spiritual care for nurses and physicians involved in palliative care will be essential, consultants of PCC teams will be important in drawing

the attention of these professionals, on the need to recognise and address the spiritual needs of their patients.

Abstract number: 163
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

Modifications of sexual behaviour in cancer palliative patients

Mario Barmaki, Centre Hospitalier Lyon Sud, Pierre Benite, France

Goal: This multicentric study has been started in July 2005 to collect information about the changes in sexual behaviour of palliative patients in cancer. The approach focuses on the patient's own evaluation and perspectives about sexual concerns.
Methodology: These information are collected through an anonymous questionnaire proposed to a population of cancer patients between 18 and 60, selected in 4 cancer units in Lyon (France) – [Oncology, Gynaecology, Dermatology, and the out coming palliative care consultation patients]. The study has received the approval of the local ethics committee.
Results: The objective is 100 patients with complete questionnaires. The primary results (94 questionnaires) show an expected diminution of the frequency of sexual relations throughout the evolution of cancer. These data are confirmative with former studies conducted concerning the same subject. But the auto evaluation of pleasure during sexual relations seems to be preserved with time, in compensation of quantity, because patients elaborate new behaviour in their sexual approach. They also analyse all different reasons of these modifications, and the difficulties to talk about this intimate problem with their medical referent or partners.
Perspectives: The study is still running during the abstract submission. The expected end of this study is March 2006.

Abstract number: 164
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

Feeling like a burden: exploring the perspectives of patients at the end of life

Christine McPherson, Elisabeth Bruyere Research Institute, Ottawa, Canada, **Keith Wilson**, Institute for Rehabilitation Research and, Ottawa, Canada, **Mary ann Murray**, University of Ottawa, Ottawa, Canada

The burdens associated with providing care to a family member at the end of life have received considerable attention. Much less attention has been directed at the care recipients and their perceptions of being a burden to others, referred to as "self-perceived burden". Yet the available data show that feelings of burden are a common source of distress for the terminally ill. To date, however, little is known about the construct. Therefore, the purpose of this interpretative phenomenological study was to gain a better understanding of self-perceived burden from the patient's perspective. Fifteen terminally ill patients with advanced cancer were interviewed, and the data analyzed using constant comparative techniques. Findings indicated that patients were not only concerned with their current situation and its negative impact on others but also with future concerns as health and functioning declined, and worried about the effect their death would have on others. Responsibility for these burdens, resulted in feelings such as guilt, regret and sadness, and had negative implications for the patients' self-concept as a consequence of the inability to continue in usual social roles. Attempts to alleviate burden influenced decision-making and communication of needs, with patients reluctant to ask for help so as not to bother others or upset those around them. Patients also engaged in active strategies, such as making preparations to minimize the responsibility on caregivers. The findings indicate that there is a need for further research into factors that influence the experience of self-perceived burden, with a view to developing interventions to alleviate distress.

Abstract number: 165
Presentation type: Oral Presentation
Session: Delirium, Depression & Sex

Use of semantic equivalents to explore depression in patients with cancer

Ana Chopitea, Clinica Universitaria de Navarra., Pamplona, Spain, **Carlos Centeno**, **Ana Carvajal**, **Julia Urdiroz**, **Jaime Espinos**, Clinica Universitaria de Navarra. Universidad de, Pamplona, Spain

Background: In patients with cancer, using one or two easy questions to explore depression is well documented and approved. In Spanish, the word "depression" could have negative connotations. It is possible that patients score lower in questionnaires only because of the use of "depression" word.
Objective: To explore the possibility that semantically equivalent words could be useful to detect depression in Spanish speaking patients with cancer.
Methods: Forty ambulatory or hospitalized patients with local and locally advanced cancer ($n = 6$) or metastatic cancer ($n = 34$), from the oncology department were included. All answered the HAD questionnaire and three questions which successively explored "sadness", "discouragement" and "depression". The items were formulated as a verbal numeric scale.
Results: The median score for the HAD questionnaire was 13.5/42; for the scale of "depression" it was 4/10, 4.5/10 for "sadness" and 5/10 for "discouragement". Five patients (12.5%) scored >20 in the HAD questionnaire (clinical problem). The three questions of "depression", "sadness" or "discouragement" correlated directly, as well as to the subscale of depression in the HAD questionnaire and to the total score of the HAD questionnaire ($p < 0.01$, Tau b of Kendall test). A score $= 6$ in any of the questions about "depression", "sadness" or "discouragement correlated directly to the clinical problem of depression in the HAD questionnaire" ($p < 0.01$, Spearman test).
Conclusion: In conclusion, our results suggest that semantically equivalent words such as "sadness" or "discouragement" can be used for screening depression in patients with cancer. A score of six of above in any of verbal numeric scales of "depression", "sadness" or "discouragement" detects a clinical disorder of depression. Patients tend to score lower when they are directly asked about "depression".

Abstract number: 166
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

Providing optimal pain control for cancer patients. The impact of the hospital specialist palliative care team

Barbara Jack, Edge Hill College of of HE/ Marie Curie, Liverpool, Great Britain, **Valerie Hllier**, **Jackie Oldham**, University of Manchester, Manchester, Great Britain, **Anne Williams**, Cardiff University, Manchester, Great Britain

Background: Pain is reported to occur in the majority of patients with advanced cancer varying with tumour type, spread of disease and disease treatments. Pain control is one of the main reasons for referral to a hospital specialist palliative care team. Yet despite this, there is limited research into the effectiveness of the hospital specialist palliative care team on pain control in cancer patients. The aim of this study was to assess the effect of the hospital palliative care team on cancer patient's reported level of pain.
Method: A non equivalent control group design using a quota sample investigated 100 cancer patients who had been admitted to a UK University Hospital for symptom control. 50 patients received specialist hospital palliative care team intervention, compared with 50 patients receiving traditional care. Outcome was assessed using the self reported Palliative Care Assessment (PACA) tool on three occasions (within 24 hours of admission/ diagnosis or referral to the palliative care team, day 3 and day 7) that measured patients reported level of pain.
Results and Discussion: The results indicated that all cancer patients admitted to hospital had a significant improvement in their pain control. There was no difference between the groups on the initial assessment of pain, which allows comparisons to be made between the groups. The patients who had the additional input of the palliative care team demonstrated a statistically significant greater improvement than the control group

(P <0.001). Potential explanations are made for the results including the enhanced knowledge and skills of the hospital specialist palliative care team.

Abstract number: 167
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

Bisphosphonate-associated Osteonecrosis of the Jaws

Tiziana Campa, **Elena Fagnoni**, **Enrico Cislaghi**, **Franco De conno**, **Massimo Maniezzo**, **C Ripamonti**, Istituto Nazionale dei Tumori, Milano, Italy

Osteonecrosis of the jaws is a new emerging complication in patients with bone metastasis and osteoporosis treated with bisphosphonates. We report the experience of the National Cancer Institute of Milan where, every year, about 3900 infusions of bisphosphonates are administered to our patients. From 1st October 2004 till October 2005, we came up with the following: 17 patients (mean age 62,1: range 43–77; 16 females of whom 13 with breast cancer) with a confirmed osteonecrosis of the jaws (56.2% mandible, 31.2% maxilla, 2 patients in both areas). These are all patients treated within the Palliative Care Operative Unit (PCOU). During this period, at the PCOU, 350 patients have been treated with pamidronate (65%), zoledronate (30%), clodronate (5%) for bone metastasis (87.5%) and osteoporosis (12.5%). None of the patients treated with clodronate developed osteonecrosis. It was possible to document that the lesions initially occurred after dental extraction in 17 patients. Patients underwent various therapies such as antibiotics, curettage, sequestrectomy, hyperbaric oxygen therapy. Only the antibiotic therapy administered repeatedly seemed to contain progression of the infected and necrotic process. Precautionally, the bisphosphonate therapy was stopped in all patients with suspected and documented osteonecrosis of the jaws, however, this created anxiety in our patients because they felt that they were not receiving any therapy for bone metastasis. At the moment, our aim is to prevent the onset of osteonecrosis of the jaws by identifing patients at risk. Since October 2004, all new patients candidate for treatment with any kind of bisphosphonate undergo a meticulous dental and oral cavity examination and eventually X-rays for thorough care of their teeth and gums. Since then, treatment with bisphosphonates is begun only after we have been given approval by the Consultant Dental Team and to date we have not had any further new cases of osteonecrosis of the jaws.

Abstract number: 168
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

A retrospective study of prescribing practice in palliative care patients with renal failure

Feargal Twomey, **Claire a Douglas**, **Andrea Anthony**, Marie Curie Palliative Care Institute Liverpool, Liverpool, Great Britain

Background: Renal impairment in palliative care patients is common and often multi-factorial. The literature advises caution with many commonly used analgesics in patients with renal impairment, and morphine sulphate and codeine in particular. Limited evidence suggests that alfentanil, hydromorphone and oxycodone may be safer. The 2005 UK Chronic Kidney Disease (CKD) Guidelines recommend that renal impairment be graded by Stages 1–5 according to estimated glomerular filtration rate. Defining renal impairment using serum creatinine alone leads to under-diagnosis and potential drug toxicity.
Aim: To investigate prescribing practices in patients with significant renal impairment at two specialist palliative care units following an extensive literature review to.
Method: A retrospective case-note review of 40 hospice inpatients with serum urea >10 mmol/l and serum creatinine >150 µmol/l.
Results: (n =40) Patients were 57.5% male. Median age was 72 years (37–89). All had cancer with lung (20%) renal tract (17.5%) and colo-rectum (15%) the most common sites. 82.5% had metastatic disease. Using the 2005 UK Guidelines, 11 patients had stage three, 22 stage four and seven stage five CKD. NSAIDs were discontinued in 15 of 21 (71%), diuretics in 8 of 11 (63%) and ACEIs in 3 of 6 (50%) patients. Thirty-four patients were prescribed opioids. Of these, 18 (53%) received codeine, morphine sulphate or, diamorphine only, nine (26%) received oxycodone only and seven (21%) received a combination of opioids. Thirteen patients developed opioid toxicity. This was managed by opioid reduction, rotation, change of administration route or fluid challenge.
Conclusions: Renal impairment in palliative care patients is under-diagnosed. Estimated GFR should be used to establish the degree of renal impairment. Opioid selection in this group of patients should be evidence-based. This study has led to the development of new prescribing guidelines in our palliative care network.

Abstract number: 169
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

The use of pain descriptors in hospitalised cancer patients

Ulf Kongsgaard, The Norwegian Radium Hospital, Oslo, Norway, **Anders Holtan**, Ulleval University Hospital, Oslo, Norway

Introduction: Pain descriptors have been used to characterize different types of pain. A survey among hospitalised cancer patients was performed and pain descriptors as well as pain intensity registered for all patients with cancer pain.
Methods: The survey was performed as a single day prevalence study in public somatic hospitals in Norway. Pain scores (using BPI) were performed and patients asked to describe their pain experience from a list of descriptors common in pain questionnaires. The list included descriptors usually regarded as typically nociceptive, neuropathic, or visceral.
Results: Data from 1337 patients in 57 hospitals was analysed, 453 patients confirmed experience of cancer pain and were included in the final evaluation. The 3 most common pain descriptor used were aching (272), stinging (140) and burning (93). There were no differences in the use of pain descriptors regarding age or sex. There was no relationship between pain intensity and the number of descriptors used, and the pattern of descriptors used was equally distributed between different pain intensity groups. We found a significant correlation between pain descriptors typical for nociceptive pain and the occurrence of break-through-pain. We found a significant correlation between pain descriptors typical for neuropathic pain and abnormal sensibility in the area of pain, however 73% also used nociceptive pain descriptors.
Discussion: Cancer pain often has a complex presentation with components of both nociceptive as well as neuropathic pain, demanding a tailored analgesic approach. Although there are some relations between typical pain descriptors and different pain states that should be informative in clinical settings, discrimination of pain mechanisms must primarily be based on clinical examination. It may be difficult to translate the results of our study to patients from other countries due to semantic comprehension of pain descriptors and cultural differences.

Abstract number: 170
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

Prevalence and characteristics of breakthrough pain or severe episodic pain in cancer patients. The Italian ‘Questionnaire for Severe Episodic Pain (QIDEI) study.

Ernesto Zecca, **Tiziana Campa**, **Franco De Conno**, **Augusto Caraceni**, National Cancer Institute, Milan, Italy, **Caterina Modonesi**, Hospice Forlimpopoli, Forlì, Italy, **Furio Zucco**, Garbagnate Hospice, Garbagnate Milanese, Italy, **Michela Bagnasco**, **Luigi Lanata**, Dompè Farmaceutici, Milan, Italy, **Oscar Bertetto**, Ospedale Le Molinette, Torino, Italy, **Cecilia Moro**, Ospedali Riuniti, Bergamo, Italy, **Patrizia Ferrera**, La Maddalena Cancer Centre, Palermo, Italy, **Antonella Paladini**, Aquila University, L'Aquila, Italy

Background: The prevalence and clinical impact of breakthrough (BKP) or severe episodic pain is considered relevant in the management of cancer pain.
Aim: of this study is to show the prevalence and the clinical characteristics of BKP in advanced cancer patients. Methods a cross-sectional study involving 8 Italian oncology and palliative care centres was carried out on consecutive cancer patients with pain. The study used expert opinion as screening tool for assessing the presence of BKP and patients had to be classified according to a grid where 5 cases of BKP present and 4 cases of BKP absent are classified. The concordance of the experts' opinions about BKP diagnosis was assessed to be 0.68 (Cohen's Kappa) in a testing and training session held in preparation to the study highlighting the presence of some controversial situations.
Results: The study involved 240 advanced cancer patients and BKP was diagnosed in 72.% of cases (95% CI 66.4–78.9%). In 88% of cases pain was due to the tumor, and 89.2% were treated with opioids for their baseline pain. In 40.6% of cases BKP was due to voluntary or partially voluntary action inducing incident or posture related pains, in 38% of cases it was due to spontaneous exacerbation of baseline pain not due to voluntary actions and for only 8.6% of cases opioid end-of-dose failure was considered the cause. BKP was treated in 59.2% of cases with extra doses of opioids in 19.5 with NSAIDs while 21.3% of patients had no specific treatment for BKP. Mean number of BKP episodes was 2.6 per day. 60% of BKPs had a duration of no more than 30 minutes. The most frequent location of BKP was the low back lower limbs and the back in general. 85.8% of BKPs were rated from severe to very severe on verbal 6-level scale and 83% from 6 to 10 on a numerical (0 to 10) pain rating scale.
Conclusions: BKP is a prevalent phenomenon in advanced cancer patients treated with opiod analgesic and is often unrecognized and under treated.

Abstract number: 171
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

Proposed 5 step analgesic ladder with an algorithm to determine the need to switch to an alternative opioid at step 4

Julia Riley, **Joy Ross**, Royal Marsden Hospital, London, Great Britain, **Ken Welsh**, **Michael Thick**, Imperial College, London, Great Britain

The WHO analgesic ladder is the "gold standard" for pain management. The ladder focuses on the presence or absence of pain relief but, does not take into account side effects. We believe that debilitating side effects are an equally valid reason for changing analgesia. Opioid switching involves changing a patient's strong opioid to an alternative strong opioid with the aim of improving analgesic response and/or reducing adverse side effects. In a prospective study of 228 cancer patients, 75% responded to morphine. The remaining 25% experienced a lack of analgesic control or suffered intolerable side effects. Their symptoms improved when switched to an alternative opioid and overall, pain control was achieved in 97% of patients. We propose adding two additional steps to the WHO analgesic ladder to build an alternative five step ladder. The proposed fourth step involves 'opioid switching' and includes both pain and side effects as criteria for switching analgesics. From the evidence, we have developed an algorithm, to determine a fourth step, derived from analysis of intervention patterns based on our recent trial data to identify the point at which a switching to an alternative opioid is indicated. We identified four main factors which predict the need to switch. If patients have received less than 30% pain relief from their morphine in the previous 24 hours ($p < 10-7$), if they are experiencing grade 3 ("severe") toxicity levels of confusion or hallucinations ($p < 0.001$), grade 3 drowsiness ($p < 0.001$) or grade 3 dry mouth ($p = 0.008$). Thus, once a strong opioid has been commenced (Step 3) and a patient has had an adequate trial of titration on their first line strong opioid, the need for opioid switching (Step 4) is identified in the clinical setting once side effect scores fall within a critical range, triggering a change of treatment. If switching opioids fails, a fifth step should involve anaesthetic intervention.

Abstract number: 172
Presentation type: Oral Presentation
Session: Pain – Clinical Aspects

MERITO Study: an Italian multicenter longitudinal trial for pain control evaluation in cancer patients with moderate to severe pain treated with immediate release oral morphine (IRM)

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Background: Cancer pain treatment is still a controversial matter and quick pain control achievement is one of the main goals of an effective pain management. Aim of the present study is to estimate the percentage of initial treatment phase period with controlled pain in patients treated with immediate release oral morphine (IRM).
Methods: According to EAPC recommendations patients with moderate to severe cancer pain and never treated with strong opioids were administered IRM 5 mg/4 h or 10 mg/4 h in the titration phase (first 5 days). Pain intensity was evaluated five times a day through a diary self compiled by the patients and for each patient the percentage of time with controlled pain during the titration phase was then calculated as main outcome measure. Results 159 consecutive cancer patients were enrolled in the study. Their most frequent cancer site was lung (22% of pts), most had metastasis (85%) and a KPS > 60 (85%). 75% of pts were under step II WHO analgesic ladder, while 23% under step I. Nociceptive pain was present in 81% of pts, neuropatic pain in 31%, mixed pain in 43% and breakthrough pain in 54% of pts. IRM was administered at the two different dosages of 5 and 10 mg/4 hours in respectively 29% and 71% of patients. The mean percentage of time with controlled pain during the titration phase was 74% (95% CI: 0.69–0.78). 50% and 75% of pts reached their first pain control respectively within the first 8 and 24 hours. The pain score was 7.63 at baseline, and 2.43 and 1.67 respectively after 3 and 5 days of treatment, and both data indicate statistically significant differences ($p < 0.001$).
Conclusions: The results obtained confirm the EAPC recommendations that IRM is still today a very good choice to reach a quick and satisfactory pain control in the titration phase in patients with moderate to severe cancer pain.

First Group of Posters

Abstract number: 173
Presentation type: Poster
Session: Bereavement and Family

When patients have incurable cancer: A study of oncologist communication issues with patients and their families

Nathan Cherny, **Rama Sapir**, Shaare Zedek Medical Center, Jerusalem, Israel

To evaluate Oncologists (MOs) communication with patients (Pts) with incurable cancer and their families.
Method: Surveys were sent to the department directors in Israel. 70 responses were received from 8/10 centers. 51% male, 82% >5 yr experience in oncology.
Results: Despite high frequency of family members (FMs) not wanting the Pt to be told about their Dx (55%) or poor prognosis (Px) (71%), diagnostic information was usually disclosed to the Pt initially, usually with FMs present (73% vs 25% without). When FAM asked that info be withheld, MO's usually explain that it is the Pt's best interest to be given any information requested (70%), partially respect FAM wishes by obfuscation (50%) or ask the PT if they want information (44%). When chemo is not working, more than 65% of MOs would tell the Pt and suggest an approach of PC only, or offer a range of options (including PC, alternative chemo and experimental therapies). 18% would avoid a confrontation that may undermine the Pt's hope and suggest further chemo despite the low likelihood of benefit. In a scenario of a 45yo man with metastatic CA

pancreas most MOs would explain that chemo may palliate (83%) and ensure that the Pt and his wife understood the nature and extent of the disease (77%) including curability (70%). Only 18% reported that they would tell him that life expectancy is unlikely to be different with or without chemo. Disagreement on were observed regarding: the quality of MO training in disclosure, whether FMs tend to exaggerate risks of disclosure to Pts, if permission should be sought from FMs before PT disclosure, the impact of knowledge of poor Px on coping and if it is important to convey hope for recovery.
Conclusion: Communication with patients with advanced cancer is often complicated by family concerns. There is no consensus as to the validity of these concerns and oncologist responses are variable and often include obfuscation.

Abstract number: 174
Presentation type: Poster
Session: Bereavement and Family

Interviews with relatives about physician–assisted death

Petra Van Wigcheren, **Bregje Onwuteaka-philipsen**, **Mette Rurup**, **Gerrit Van der wal**, VU University Medical Center, Amsterdam, Netherlands, **Agnes Van der heide**, Erasmus Medical Center, Rotterdam, Netherlands

Objective: When a patient asks his or her physician for physician-assisted death (PAD) and the physician decides to grant the request, it is important that the performance of PAD takes place in a prudent way. Objective is to describe the performance of PAD and whether the performance took place according to the way the patient and the relatives would have wanted it to take place.
Method: Relatives of people for whom euthanasia was performed were interviewed. A random sample of doctors ($n = 167$) who had reported a case of PAD in the period November 1999 and January 2002 to one of the regional review committees were asked to contact the relative most involved to ask him/her if he/she was willing to give an interview to one of the researchers. The physicians contacted a relative in 97 relatives of which 87 were willing to participate.
Results: In 3 of the 87 cases the physician assisted in suicide. In the other cases (97%) euthanasia was performed. The majority of patients had, according to their relatives, not mentioned wishes concerning the method to be used (63%), while 32% preferred euthanasia over physician-assisted suicide. Patients were accompanied by their children (69%), other family members (38%) and their partner (23%) at the time of the performance. While, according to the relatives, the performance took place according to way the patient the patient wanted it in 94% of the cases, the relatives themselves considered the performance not taking place according to the way they wanted it to take place in 25% of the cases. This was mainly because the time between administration and death was too short.
Conclusion: Although PAD is firstly something between the patients who asks for it and the physician, it seems also important to inform relatives about the way the performance of PAD can take place.

Abstract number: 175
Presentation type: Poster
Session: Bereavement and Family

What really matters at the end of life care. A study among relatives of deceased patients

Marina Martínez, **Carlo Centeno**, Clínica Universitaria, Universidad de Navarra, Pamplona, Spain, **María josé Almaraz**, Servicio Cuidados Paliativos Hospital Txagorritxu, Vitoria, Spain, **Elena Aldasoro**, Departamento de Sanidad del Gobierno Vasco, Vitoria, Spain, **Alberto Melendez**, Hospital San Juan de Dios. Cuidados Paliativos, Pamplona, Spain

The aim of this study is to assess the family of deceased patients about the importance and the satisfaction about different aspects at the end of live care.
Methods: A prospective study was carried out in 6 hospitals of te Basque Country. 1046 questionnaires were sent, and 555 were used for the present study. In order to estimate the satisfaction level, an adaptation of the FAMCARE questionnaire was used. The FAMCARE has 20 items about different aspects of the attention received by a patient and his or her family. The scale also evaluates the accommodation of the patient and the family during their staying at the hospital. So as to know the preferences of relatives, a different questionnaire was elaborated including, among others, questions about the degree of importance given by the family to aspects included in the satisfaction questionnaire.
Results: The response rate was of 54%. The three aspects of care that families consider more important are relative to: the direct attention given to patient, the speed of response given by the professionals and the relief of symptoms. Families are satisfied with: the kindness and respect received, the availability of nurses and the pain relief of patients. The dissatisfaction was related to the facilities comfort.
Conclusions: This study has especial implications because it contributes to improve the results of studies on satisfaction. It brings in the point of view of the family in the factors they consider determinant to care. It shows the importance of listening to the family about their needs at the end of life. That could help us, as professionals, to set up priorities in our interventions. However, further evaluations are needed in order to see if there is any relationship between what is important for the family and what is important for the patient.

Abstract number: 176
Presentation type: Poster
Session: Bereavement and Family

A mixed methods approach to defining bereavement support

Alison McNulty, University of Manchester, Manchester, Great Britain

Bereavement support is an essential feature of palliative care; however it lacks an inclusive definition. The objectives were to explore provision of bereavement support following home and hospice deaths, and examine provider and bereaved perceptions of support. The implications being to create a definition of support which encompasses aspects of provision and its value. To satisfy the objectives a mixed method approach was fitting. Support providers completed 2 questionnaires; 1 per death over 3 months to measure provision and 1 ascertaining their perceptions of support. Participatory evaluation methods were used in focus groups of bereaved, questioning them about their needs, and what they found supportive and what not. Provision of support differed widely in both settings (12 hospice = 396 bereaved: 10 home services = 199). Hospices were more likely to offer support and in a greater number of forms. Home services offered support earlier and it was more often accepted (all $p > 0.000$). Conversely provider perceptions differed little with definitions of bereavement support including assessment, meeting needs, and respect. 5 focus groups ($n = 20$ bereaved) revealed 2 groups of needs. Some needs, such as information and counselling, could be met by the provider and when met were valued as supportive. Other needs, such as adaptation and distraction, may only be partially assisted by the provider. The former group offset the latter, with the bereaved believing many of their needs could be provided for. However unsupportive factors were also noted ranging from practical barriers when attending a support group to poor/absent support compounding their grief. Use of mixed methods was integral to the objectives being met and an operational definition being created with perceptions of bereaved and providers contributing to this. However provision does differ. Recommendations are made for services to collaborate and pool resources in order to achieve the optimum outcome for the bereaved.

Abstract number: 177
Presentation type: Poster
Session: Bereavement and Family

Survey of bereaved relatives of patients who died in an acute general hospital

Barbara Whyte, **Siobhan Hollingsworth**, **Olga Price**, **Millie Devenish**, **Ita Harnett**, St. Vincents University Hospital, Dublin, Ireland

Aim: To gain insight into bereaved relative's perspectives and experiences of the standard of care provided for imminently dying patient's and their families in St Vincent's University Hospital.

Design: The survey questionnaire was designed to collect both quantitative with qualitative data.

Methods: A 32-item postal questionnaire was designed to explore bereaved relatives experience concerning symptom control, information giving, spiritual care and environmental issues. A total population of 348 relatives were identified. Quantitative data was analyzed using SPSS program (version 11.0); qualitative data was analyzed using content analysis.

Results: Response rate was 54.3%. ØRelatives were satisfied with overall treatment of symptoms in > or equal to 75% of cases. Ø67% of relatives were informed of the patient's condition/treatment plan, with information shared in a sensitive manner. Ø59.8% of relatives reported that spiritual issues had been adequately addressed. ØUp to 54% of bereaved relatives considered environmental conditions, e.g. space, privacy, to be either fair or poor. ØThere was a positive correlation between whether relatives were asked about their own well-being and their overall satisfaction with the care of their dying relative. Ø82% of bereaved relatives in the last few days of life considered the hospital to have been the most appropriate place for their loved one to die.

Conclusion: Though overall the next of kin were satisfied with the care given to their dying relative, some areas for improvement were identified in particular communication was highlighted as the key issue to be addressed.

Abstract number: 178
Presentation type: Poster
Session: Bereavement and Family

The Psycho – Tactile – Affective contact

Benedetta Bonato, **Pierina Lazzarin**, **Franca Benini**, **Luca Callegaro**, Antalgic therapy and palliative care unit, Padova, Italy, **Massimo Melo**, Community medicine and epidemiology unit, Padova, Italy

Preference: poster. The Psycho-tactile-affective contact is a special way of taking care of people, expecially illness and terminal patients, that we're now triyng to apply and evaluate. It can be used with adults (sick or parents of illness children) and also with children to help them feeling the operators near them in their personal and fatiguing journey and dealing with it. According to the bio-psycho-social paradigm, taking care of the whole person, we matched together some theories such is the C. Roger's Person Centered Approach, the Haptonomy, some elements of Hypnotherapy and basic rules of Counseling and Psychotherapy. The three elements of the approach are: Psycho: is the way of create a faciliting climate to welcome and accompany a person, to be truly in empathy, to have a right closeness and distance, to help a person to express and clarify feelings and emotions, to use counseling and psychotherapist tools when is needed, even hypnotherapy, always being careful abuot the operator's congruency.

Tactile: according to the instinctive importance to the touch for humans, the touch's language may be a way to apply Haptonomy with persons. It should be done carefully, using the rule of PTP (Presence, Trasparence and Prudence), respecting the person's sensitivity and the bents of the operators. Touching and holding persons is an activity nowadays often neglected, but expecially important for adults and children that loose contact with their body because the illness.

Affective: is the way to express a real, genuine interest for the person, to have a positive and unconditioned acceptance to create a faciliting relation that helps to be aware of what's happening without feeling alone with emotional-corrective-experiences. In conclusion, we use this kind of approach, balancing the three elements on the individual person and needs, expecially with children for taking supportive care of them during illness and terminal period and even reducing anxiety and pain.

Abstract number: 179
Presentation type: Poster
Session: Bereavement and Family

Taking care of siblings

Benedetta Bonato, **Pierina Lazzarin**, **Franca Benini**, **Luca Callegaro**, Antalgic therapy and palliative care unit, Padova, Italy, **Massimo Melo**, Community medicine and epidemiology unit, Padova, Italy

As results from many studies, and according to the bio-psycho-social paradigm, when a child suffer of a chronical or terminal condition, become necessary to take care of all family members. Expecially, siblings needs more care because the increasing risk of less attention (loss of family time and space for normal and extra activity, and above all less emotional attention). Two major extreme exits for siblings are apathy, and on the opposite side, a form of hyperactivity for gaining attention. Our intervention, after reviewing bibliography (moreover extremly poor) consists in using counselling and psychoteraphy approach to prevent and decrease the impact of this distress. We took four groups of siblings in account from researches and direct application: 1. Those that needed support or even psychotherapy for dealing with sibling's illness. 2. Those that were encouraged in visiting siblings in hospital, to start being confidence with sibling's illness and to better understand the behavior and the often unexplained absence of their parents. 3. Those, that were directly involved in sibling's illness cause the donation of bone marrow for transplantation in severity onco-ematological disease. 4. Those that needed support or even psychotherapy after sibling's death. We worked directly with siblings and indirectly always talking abuot them when meeting parents or the illness child. We took care of them using a person centered approach, and our counseling and psychotherapy strategies consist in active listening, using drowing, tales, play-therapy, taking them into the hospital, helping them dealing with extreme feelings and emotions and understanding these conditions. In conlusion, all children need to understand and be aware when a illness came, to them or to a sibling. We suggest to improve taking care of all the family and giving support to siblings even individually or in goup when possible, to help them gaining the right attention according to the changed situation.

Abstract number: 180
Presentation type: Poster
Session: Bereavement and Family

Psychological effects of recieving soft tissue massage to spouses in palliative home care

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Background: Previous studies indicate that spouses to patients in palliative home care sometimes show higher levels of stress and anxiety than the patient herself. In the present study we have introduced soft tissue massage in the support of spouses to dying cancer patients.

Aim: To evaluate psychological effects of soft tissue massage amongst spouses to dying cancer patients.

Method: Twenty spouses received daily massage (hand or foot) for twenty minutes during a period of nine days. Each participant was interviewed after the massage treatment. The semi-structured tape-recorded interview lasted for 60 minutes. The interviews are being analysed using a hermeneutic approach. As background data Symptom Distress Scale, VAS, blood pressure, heart and respiratory rate were registered before and after massage.

Findings: At this stage we are analysing the results. Preliminary results indicate that soft tissue massage promote feelings of trust, security and existential trust, self-worth, closeness, feeling recognised "to be someone". It also generates energy, a sense of peacefulness and relief of stress, pain and worry.

Importance: If the present study can verify positive effects, the method could be used more frequently to reduce stress levels amongst spouses in a difficult time of life. If so, soft tissue massage could also be a tool during the grieving process of bereavement.

Abstract number: 181
Presentation type: Poster
Session: Bereavement and Family

Enabling safety for relatives in palliative care – an evidence based theory

Birgitta Andershed, Nursing, Örebro, Sweden

Part 1 The first part of this study was a systematically review of the last five years research surrounding families situation and needs in palliative care. The results from 94 studies were categorized in two main themes and several sub themes: 1. Situation: a) Exposed position, b) Burden and capacity, c) Positive values, and 2. Needs: a) Good patient care, b) Being present, c) Knowing and communicating, d) Trusting relationship with the staff. An important need on the part of relatives was an assurance that the patient got care of high quality. It was also seen that many relatives had the need to be present, to be at hand and do what was good for the dying person. The fact that this also involved risks was apparent from the findings; for example, when relatives had to assume a great deal of responsibility for the care in combination with inadequate support from the professional.

Part 2 The starting point of the second part of the study was the literature review described in the first part. We merged this current knowledge with clinical experience. We found that there is a need for a family focused approach based in humanistic values. The aim of this part was to develop a theory of enabling safety (including security and confidence) for relatives when a patient is close to end of life. Safety is enabled through: an attitude of openness, affirmation of the relatives that the patient has as good life as possible, supporting relatives in mastering the end of life situation and guiding patient and relatives to live the end of life period the way they prefer.

Abstract number: 182
Presentation type: Poster
Session: Bereavement and Family

Patterns of grief and satisfaction with care in a palliative home care setting

Christoph Wiese, Georg-August-University, Goettingen, Germany, **Hannah Morgenthal**, **Margrit Kriegler**, Support II, Goettingen, Germany, **Natascha Seidel**, **Gerd-gunnar Hanekop**, Department of Anaesthesiology, Support II, Goettingen, Germany

Introduction: Palliative homecare for terminally ill patients is making progress in Germany. In 1996 our hospital established a palliative-care-team (PCT) of expert nurses and physicians providing palliative care at home on a 24/7 basis. In addition to administering pain and symptom control for the patients these teams also try to address the psychosocial needs of patients and their relatives. However, data is scarce on whether care-giving relatives feel sufficiently supported by these PCTs. Also it is unclear how receiving support from and interacting with a PCT will influence the grieving of relatives after the patient has died.

Aim of study: To evaluate satisfaction with care, paths for improvement, and patterns of grief among bereaved persons whose relative had died while enrolled in our palliative home care program.

Methods: After informed consent a structured questionnaire was administered to a sample of 50 adult subjects whose partner had died from cancer 2 to 24 months earlier while receiving palliative homecare from our PCT. Questions covered satisfaction with care, suggestions for improvement, and patterns of grieving.

Results: All participants were "satisfied" or "very satisfied" with the received care. Their expectations regarding medical, psychosocial and spiritual care were met. Level of satisfaction was not related to type of cancer, age and sex of patient, duration of disease or intensity of care. Main points of satisfaction were perceived staff competence and attitude, guaranteed availability of help and proper communication regarding course of disease and treatment options. As improvement 60% of the respondents proposed on going counselling for grieving relatives. According to the signs proposed by Prigerson (1999) a "complicated grief" could be found in 25%.

Conclusions: Palliative homecare is perceived as a valuable means of relief by the relatives of terminally ill patients. We have found a "complicated grief" in 30%.

Abstract number: 183
Presentation type: Poster
Session: Bereavement and Family

Patient and family involvement in hospice interdisciplinary team meetings in the United States

Debra Parker Oliver, **George Demiris**, **Karen Courtney**, University of Missouri, Columbia, MO, United. States, **Davina Porock**, University of Nottingham, Nottingham, UK

Home hospice, as delivered in the US faces many challenges as they seek to integrate the family system into the team. The purpose of this project was to explore the following questions: 1) How do US hospices integrate the patient and family into the IDT structure and process, 2) What are the benefits of patient and family participation in the IDT team meetings, 3) What are the challenges to patient and family participation in the IDT meeting? This study used semi-structured telephone interviews with hospice professionals to explore the answers to the research questions. A random sample of hospices was drawn from the list of hospices on the website of one US State Hospice Organization. Program Directors were contacted and asked to participate in the project by identifying staff from different disciplines to be interviewed. Thirty professionals from 12 different home hospice programs were interviewed by phone to identify the extent of patient and family involvement in their IDT meetings. Descriptive statistics described the participants and quantified the structured question responses. Transcripts of the open ended questions were co-coded by two of the members of the team. Initial codes were developed using a specific conceptual framework. Each of the coders took the initial classification list and their own identified subthemes. The expanded sub themes were compared between the two reviewers and consensus reached regarding the final codes and classification. A few programs had direct experience with patients and families attending IDT meetings, but attendance was not routine. Better communication was recognized as a potential benefit. The patient's frailty and the burdens of caregiving for the family were noted challenges to participation. Video-mediated communication is offered as a potential solution.

Abstract number: 184
Presentation type: Poster
Session: Bereavement and Family

Evaluation of an aspect of a bereavement follow up protocol in a palliative care setting

Liz Beresford, **Virginia Morris**, North Coast Health Service, Tweed Heads, Australia

Background: Palliative Care does not cease at the time of death of the patient. Bereavement follow up is offered to families and survivors of the deceased to enhance their coping abilities (Bromberg & Higginson (1996:1).

Purpose: The purpose of this small study was to examine the response of recipients of bereavement follow up cards with a view to developing a formal policy.

Method: This study focussed on the response to the follow up card that was sent to the intimate network of the deceased. It provided information about the availability of bereavement counselling/support from the unit social worker and details of how to make contact. A telephone interview survey was chosen as the method of study with formatted questions. Respondents were chosen randomly irrespective of age, gender or relationship to the deceased. Content of verbatim responses to open and closed questions formed the core data, thereby delivery a qualitative and quantitative analysis.

Results: Our statistics demonstrate that we have an average of approximately 300 deaths per annum. For this study 66 of the bereaved were randomly selected. 19 recipients were interviewed. 42% discussed their loss and current status in the bereavement process. 21% felt socially isolated and 100% were appreciative of the card. 21% stated that the card acted as a prompt to contact a member of the palliative care team. 47% stated that they kept the card and said they felt reassured that the palliative care team was still accessible to them.

Conclusion: The research demonstrated that the card at six weeks after bereavement was appreciated. Whilst few people contacted the service for bereavement support a larger proportion identified that the card was useful as it indicated that the service was there if needed.

Abstract number: 185
Presentation type: Poster
Session: Bereavement and Family

Sharing the cancer experience; Prostate cancer patients and spouses

Eeva Salminen, Turku University Hospital, Turku, Finland

Background: The aim of this study was to characterize the sharing the experience of cancer between prostate cancer patients and spouses.

Patients and methods: The survey study was conducted at Turku University Hospital (AD; $N = 109$ patients, 103 spouses) and at a Rehabilitation Centre (RC; $N = 113$ patients and 107 spouses). The subjects completed a validated survey including also a short depression test.

Results: AD patients were less depressed than RC patients (0.64 vs 0.80, $p = 0.03$) and AD spouses were significantly less depressed than RC spouses (0.48 vs 0.75, $p < 0.001$). Younger patients and spouses tended to score more than older ones. The mean score of depression was 0.76 for RC pts and 0.75 for RC spouses. The difference within RC pairs was 0.01 (95% CI 0.11 to 0.13, p: 0.86). For the AD pairs the mean score was significantly higher in patients compared to spouses (0.66 vs. 0.48), and the within pair difference was 0.18 (95% CI 0.04 to 0.31, $p = 0.01$). Significant association was observed between patients and spouses. Concentration and decision making ability deteriorated (Chi-square $p = 0.004$) and somatic symptoms worsened (Chi-square $p = 0.02$). The use of alcohol/drugs increased significantly (Chi-square $p = 0.003$), as did tiredness of living (Chi-square $p = 0.02$), and irritability (Chi-square $p = < 0.001$). Patients treated with androgen deprivation tended to be more depressed that untreated ones (0.81 vs 0.64, $p = 0.024$). The global mood measure indicating depression was significantly stronger among patients compared to spouses ($p = 0.05$). With longer time since diagnosis the difference between patients and spouses was not significant ($p = 0.86$).

Conclusion: With time the experience became similar among patients and spouses and the spousal mood became influenced by the patients' experience of cancer. The degree of sharing between prostate cancer patients and spouses is strong and has an impact on mood.

Abstract number: 186
Presentation type: Poster
Session: Bereavement and Family

Talking to strangers: an analysis of young people's experiences of bereavement counselling

Emma Lupton, **David Oliviere**, St. Christopher's Hospice, London, Great Britain

This study aimed to gain an understanding of young people's experiences of bereavement counselling: to pay specific attention to age, gender and ethnicity within the counselling relationship and to capture service-users' voices to inform further research. This qualitative study involved 10 bereaved young people aged between 13 to 19 years old. 7 participants were female and 3 male; 3 were Black British Caribbean, 1 Dual Heritage Black Caribbean-White British and 6 White British. The young people, all of whom had received bereavement counselling, participated in a focus group and semi-structured interviews. A phenomenological approach was used to analyse the young people's experiences. Bereavement counselling was valued as a protected and liberating space by the young people, which is contingent upon talking to a stranger. It enabled them to talk confidentially with freedom from judgement and without upsetting their family. The counsellors working with the young people were white, 'middle-aged' women; generally the young people did not identify social differences as important to the counselling relationship. When difference was noted, age was most commonly identified. The young people valued the professional wisdom and personal bereavement experiences they associated with older practitioners. 9 participants stated a preference for female counsellors, reflecting perceptions that women 'listen more' and are 'better at feelings'. Ethnicity signified skin colour, culture and religion to the young people, who felt it had little impact on the counselling relationship. Bereaved young people value talking to a stranger; an opportunity provided by specialist services outside of existing networks. This has implications for current debates on the viability of specialist services in view of increasing mainstream responses to childhood bereavement. It highlights the importance of eliciting what service-users value from services to inform future research.

Abstract number: 187
Presentation type: Poster
Session: Bereavement and Family

Just as long as someone is there

Inger Benkel, Sahlgrenska University Hospital, Goteborg, Sweden, **Helle Wijk**, Sahlgrenska Academy Institute of Nursing, Gothenburg, Sweden

Aim: To investigate the need of social support after death and see who gives social support to the bereavement family and loved-ones and if it is helful in the bereavement Sampling frame: Family and loved-ones to a patient who died on the Palliative Unit, University hospital during 2002–2004. Methodology adopted: Questionnaires with multiple choice and possibilities to comments and in-depths interviews.

Method of analysis: Quantitative analysis of questionnaires and content analysis of the interviews.

Results: The most families and loved-ones having social support from their network – Few needed support from professional staff and more for emotional than practical support. Most of the needed support were close to the death moment and some time after. The family and relatives were given more practical support than emotional support. There are different forms of social support. -Which form of support were needed depends on the relation to the death person and how they handle with the grief. The bereavement persons had different ways of handle with the grief and was:Taking a break-to rest from the grief moment, Understanding and prepaparation for the coming death, To make a closure of time the grieving person have had with the death person. The most person serve that they felt better after a year and that the social support has beeen helpful during the grieving process.

Conclusion: The results of the study shows that social support is giving most from the network and are helpful in the grieving process. Some persons needs social support from professional staff. Which form of support depends on the relation with the dead person and how they handle with the grief. The studies results can be helpful to make follow-up methods in palliative care for families and loved-ones in order to find the person who needs professional support.

Abstract number: 188
Presentation type: Poster
Session: Bereavement and Family

A family's beliefs about cancer and death

Inger James, **Birgitta Andershed**, **Britt-marie Ternestedt**, Department of Health Sciences, University Orebro, Sweden

Background: An incurable cancer diagnosis can create anxiety and chaos in life. When we are stricken with chaos in our daily life, we can make use of our beliefs to help us understand what is happening.

Objective: The aim of this study was to describe beliefs about cancer and death held by the family as a whole and the family members individually and how the beliefs affected their daily lives.

Methods: The study is a prospective, qualitative, study. A 70-year-old woman with advanced cancer and five family members were followed during the woman's final stages of life. Data collection was carried out in the form of repeated interviews, and informal conversations and diary notes. The data was analyzed inductively using categorical aggregation. The categories crystallized into six themes.
Results: Cancer as a mortal threat: some of the family members envisioned cancer as fatal; others saw it as both fatal and non-fatal; all of them saw it as a destructive intruder, the family members held a picture of cancer being about waiting and agonizing over death. Struggle with death: several of them shared the belief that the woman's sister's care and the woman's will to live could keep death at bay. Reconciliation with death: while family members struggled with death, they also envisioned that they had got used to the thought of the woman's death. Death as a rescuer: some of the family members envisioned that euthanasia saving them from the threat, the waiting and agonizing over death. Death appears: family members saw that the woman was fading away, she changed beyond recognition, and they envisioned it was not her. Life's goes on: some of the family members imagined she is still with them in their lives, as a guardian angel.
Conclusion: It is important that health-care professionals have knowledge about family members' beliefs throughout the illness trajectory. The nursing plan should be accommodated to the family members' complex situation.

Abstract number: 189
Presentation type: Poster
Session: Bereavement and Family

The lived experience of closeness in partners of cancer patients in palliative home care

Inger Palm, Vrinnevi Hospital, Norrköping, Sweden, **Maria Friedrichsen**, Faculty of Health Sciences, Dept of Welfare and Care-Palliative Care Faculty, Linköping University, Norrköping, Sweden

Background: At present there are few data available on the experiences of closeness among partners of patients with advanced cancer. Closeness is still not a concept in nursing science or in palliative care. A holistic approach within nursing implies providing the necessary prerequisites for patient and partner to be able to experience closeness. The aim of this study was to explore the lived experience of closeness in partners of patients with advanced cancer in palliative home care. Ten partners of patients with cancer admitted to a pallative, hospital-based home care unit, participated. Gender: three females, seven males. Age; 48–86 years. Duration of relation; 23–59 years. Semi-structured tape-recorded interviews were conducted and Giorgi's phenomenological analysis was used.
Findings: The interviewees described closeness variously as togetherness, sharing and daily concern. Prerequisites, such as carpe diem, living at home and privacy influenced this process. Obstacles were identified, such as the vulnerable body, communication problems and the caregiver role. In essence, the interviewees described closeness as a changing process that is expected to end. The fact that the time for experiencing closeness was limited forced the couples to live day by day. They described how the feeling of closeness fluctuated, and the relationship increased and became more intense for the moment.
Conclusions: This study has revealed the importance of closeness in partners of patients with advanced cancer. To have possibility to achieve closeness in daily life is of great importance. Closeness is a basic human need that every individual should have possibility to experience till the end of life. Experiencing closeness and maintaining sexual relations are of great importance when the disease no longer is curable and time is limited. The partner of the patient with advanced cancer in palliative care may need professional support to be able to provide closeness.

Abstract number: 190
Presentation type: Poster
Session: Bereavement and Family

Gender differences in spousal caregiving at the end-of-life

Kevin Brazil, McMaster University, Hamilton, Ontario, Canada, **Julie Vohra**, St. Joseph's Health System Research Network, Hamilton, Ontario, Canada, **Michel Bedard**, Lakehead University, Thunder Bay, Cayman Isl

Background: Although past studies provide insightful details about the differential experiences of women and men as informal caregivers, little is known in the case of end-of-life care.
Objective: This study examined gender differences among spousal caregivers at the end-of-life.
Method: A sample of 283 spousal caregivers were extracted from a larger study of informal caregivers ($N = 373$) who participated in a cross-sectional study that included a telephone interview.
Measures: Data collection included care recipient and caregiver characteristics. Care recipient characteristics included: sex, age, diagnosis, living arrangements, assistance with activities of daily living and caregiving supports. Formal services used by the patient were also recorded. Caregiver characteristics included: sex, age, education, income, self-report of health status, number of hours in a week spent caregiving, number of weeks caregiving, and caregiver strain.
Results: Spousal caregivers were more likely to be female and younger than male caregivers. The gender of the caregiver had no effect on the number of formal services that were provided to the care recipient. However, male caregivers received more informal supports from extended family and friends, specifically concerning personal care tasks. There was no difference by caregiver gender on the level of dependence the care recipient had in activities of daily living. While there was no difference on the number of hours a week spent caregiving, females reported caregiving for a longer period of time. Female caregivers were assessed to experience greater levels caregiver strain. A relationship was found for female caregivers on the number of weeks caregiving and reported caregiving strain.
Conclusion: Service providers must recognize the effect of gender when planning supportive interventions for informal caregivers.

Abstract number: 191
Presentation type: Poster
Session: Bereavement and Family

A palliative home care service and the couple

Marianne Lang meier, Hospice Ticino, Lugano, Switzerland, **Sistiana Nava santinelli**, Hospice Mendrisio, Mendrisio, Switzerland, **Lorenza Ferrari**, Hospice bellinzona, Bellinzona, Switzerland

Research aims: our palliative home care service gives support to cancer patients and their partners and families. Together with other figures we enter into their privacy, in a moment of great distress. Our object of study was to find out to what extent our service is influencing the relationship of couples with one patner in a terminal phase of cancer. In the same time we intended to create an instrument suitable to measure the quality of our work. We also wanted to amplify our insights to psychosocial aspects in this setting.
Sampling: We conducted an inquiry among two groups: one group of actually followed patients being sustained by their partners, and one group of left-behind-partners of patients followed by us in the past.
Methodology: We elaborated a questionnaire of 15 items that we adapted to the 2 situations (actual vs. deceased patient). Over a time of 3 month selected couples and partners were interviewed.
Results: The majority of the actually followed couples doesn't believe that we are influencing their relationship which is mainly conditioned by the disease. They experience our service as a provider of technical and moral help to manage the disease, and not as helpers for relational problems. Also the partners of patients followed in the past view us as technical support in a difficult moment.
Conclusions: Our palliative home care service doesn't influence on the relationship. The patients and their partners experience us as providers of support for the disease. The fact that we ourselves had a double

role as interviewers and as providers of the service left some questions. Patients and partners may not dare to say negative things about us. We think that it would be preferable to have indipendent interviewers. The inquiry itself gave us a lot of suggestions to amplify psychooncological knowing and abilities.

Abstract number: 192
Presentation type: Poster
Session: Bereavement and Family

Bereavement support – the indian context

Mary Ann Muckaden, **Jadhav Sunita**, **Pinto Mariadas**, TATA Memorial Hospital, Mumbai, India, **Sowani Anuradha**, Mumbai University, Mumbai, India

Research aims: Explore the Indian parameters of bereavement, whether there are any marked cross-cultural differences. Parametres covered include choosing place of death, handling initial shock, grief and financial implications for family. Results discussed qualitatively for unique attitudes of bereaved in India, function of their life situation and philosophy. Quantitatively as potential areas for bereavement-support. Sampling frame: 191 bereaved primary caregivers, from the Palliative Care OPD of Tata Memorial Hospital, Mumbai, obtained through incidental sampling. They were interviewed using a structured format created by research team. These questions will later be validated against standardized questionnaires, to create a short tool for regular use.
Methodology: Face to face individual interviews with the bereaved, in home setting, during the course of the grief counseling visit. Created to side-step ethical implications of asking recently bereaved to complete lengthy standardized scales, for peer reviewed research.
Method of analysis: Qualitative and simple descriptive analysis carried out presenting frequency and graphical data. Results obtained show preference for dying at home, wish for gradual and peaceful death, caregiver's first reaction most often being relief and sadness. Despair and loss of meaning in life was rare. Only 50% of the deceased had been principal bread winners, although most were around 50 years.
Conclusions: The key findings for the Indian setting were: Spiritual beliefs run high, help in adjustment. Home care preferred over hospital or hospice care. Families have very low expectations, are grateful for every help given. Resources are meagre; offset by presence of impressive family support. Joint families ensure constant income, however paltry the amount. One cannot afford to sit and grieve, therefore caregivers prefer to be up and going as soon as possible.

Abstract number: 193
Presentation type: Poster
Session: Bereavement and Family

Nurse's perspectives on quality of care provided for dying patients in an acute hospital setting: Questionnaire study

Eoin Tiernan, **Barbara Whyte**, **Millie Devenish**, **Olga Price**, **Siobhan Hollingsworth**, St. Vincents University Hospital, Dublin, Ireland

Aim: To obtain a greater understanding of the standard of care provided for dying patients and their families in St. Vincent's University Hospital by seeking nurses' perspectives.
Design: A 32-item questionnaire survey was designed to collect quantitative and qualitative data. Items assessed included hospital environment and facilities, symptom control, communication, spiritual care and care for families after death.
Methods: The questionnaire was distributed to 350 nurses throughout hospital wards excluding casualty, day wards and ICU. 213 (61%) completed the survey.
Results: ØNursing staff were very positive about the level of symptom control provided, though patients' emotional distress appeared to be less well treated compared with physical symptoms. 37.5% of nurses reported it to be inadequately managed whereas 90% felt pain was well controlled. ØSpace, privacy levels and facilities provided were considered inadequate by 80–90% of respondents. ØOver 70% considered patients' information needs to be inadequately met. ØAbility to communicate with dying patients appears to pose significant difficulty for many; 48% of respondents reporting moderate -extreme difficulty communicating with dying patients and 41.4% with families. A significantly greater proportion of staff whose first language is not English reported communication difficulty. ØOnly half of nurses provide practical information for relatives about contacting undertakers, mortuary arrangements, process of death certification etc, many citing lack of information as an explanation. ØUp to 80% of nurses felt confident about their skills in caring for dying patients and relatives. 23% had participated in extra education in this area. ØMost reported that further education, support from senior staff and provision of protocols would benefit them in this aspect of their work.

Abstract number: 194
Presentation type: Poster
Session: Bereavement and Family

Experience of the moment of death at home

Sinéad Donnelly, **Natasha Michael**, **Cliodhna Donnelly**, Mid West HSE, Limerick, Ireland

The aim was to enquire qualitatively into the phenomenon of the moment of death at home as experienced by the carer. Published work on the moment of death has been by anthropologists and sociologists, not by those directly involved in the care of the dying. Palliative Care programmes continue to demonstrate that enlightened and dedicated care markedly reduces the suffering of patients with advanced cancer and their families. The experience acquired has not yet been translated into a vision of the moment of death. Using a purposeful sampling strategy, rural and urban families were identified in the mid west of Ireland. Semi structured interviews were conducted with the main carer 2 to 21 days (average 10 days) after the death. The proximity of the interviews to the death was a unique aspect of the study. Twenty two subjects were recruited with ten completing the interview. Recruitment ceased when data saturation occurred. Interviews were audio taped, transcribed, analysed using grounded theory. Emergent themes include significance of the actual moment of death; mutuality of relationship between carer and the person who is dying; paradoxical experiences of the process of dying; characteristics of the carer, which enables death at home; professional as guide; role of ritual and prayer. The moment of death deserves our professional attention. To date it has become increasingly marginalized into the endpoint of a biomedical experience. This study provides in-depth insight into the extraordinary ability of the carer to stay present to the person who is dying. Reflecting on the experiences of death at home for the lay carer teaches the professional what is important to people. We acknowledge the innate skills of carers and are alerted to the risk of disempowering them. As we aspire to specialise in Palliative Care, we must remember who and what are special to those who are dying.

Abstract number: 195
Presentation type: Poster
Session: Bereavement and Family

In what ways can the narratives of those caring for a person approaching death from cancer and other illnesses be used to inform policy and practice and provide support to patients and carers in the future?

Thomas Lynch, **Amanda Bingley**, **Carol Thomas**, **David Clark**, Institute for Health Research, Lancaster, Great Britain

Aims: To identify and analyse a sample of narratives written since 1950 by the lay carers of people approaching death as a result of cancer or other illnesses.
Method: A bibliographic search of libraries, journal and World Wide Web sources located English-spoken literature including books, poems, newspapers, journal articles, and internet postings of writings by the carers of people approaching death.

Analysis: Bibliometric and qualitative content analysis explored changing authorship, experiences, purpose in writing and reported impact on readers.
Results: The search strategy yielded a possible sample of millions of writings, fuelled by the internet. Application of first inclusion/exclusion criteria yielded 541 samples and application of second inclusion/exclusion criteria provided us with a purposive sample of 171 writings. A sub-sample of 70 writings was then subjected to content and thematic analysis. A significant change was observed in the quantity of literature relating to caring for a person approaching death over the specified timescale. Narratives ranged from a dearth of published literature in the 1950s to unprecedented internet communications in the 2000s. Patterns of writing changed over this period and differences were observed in writing about caring for a person approaching death as opposed to other life-threatening illnesses. The narratives revealed ethical, social, and emotional issues involved in caring for a person approaching death. Therapeutic benefits of sharing the story with others included the restoration of self-identity and the ability to provide a sense of meaning to the caring situation.
Conclusion: Carers' personal narratives may represent a neglected source of evidence to inform policy and practice. Selected writings reviewed in this study are displayed on the Macmillan Cancer Relief website, as an example of how others' personal experience may be used to support patients and carers.

Abstract number: 196
Presentation type: Poster
Session: Bereavement and Family

Support for the family in the hospice: do they have unmet needs?

Tracy Smith, Marie Curie Cancer Care, Edinburgh, Great Britain

Background: The support needs of families affected by cancer will be wide ranging. Key issues such as trustworthiness and safety of care in addition to professional skill have been identified as factors that influence the level of support perceived by families. Following a framework of clinical governance, formal evaluation of the care given to the family is a priority to determine if these identified needs are being met.
Aim: To ascertain if family members had a perception of unmet need in the hospice and to identify the factors influencing this.
Method: A qualitative approach within a phenomenological framework was used. Seven family members, nominated by hospice patients, were purposively selected from an opportunistic sample. Each took part in a semi-structured taped interview. The tapes were then transcribed, coded and thematically analysed. Codes were verified by an independent palliative care specialist and summaries of each interview returned to each respondent to ensure trustworthiness.
Results: The findings identified 3 main themes (1) information sharing, (2) knowledge and expectations of palliative care, and (3) environmental influences.
Conclusion: Overall satisfaction was expressed from those interviewed regarding the level of support received from the palliative care team in the hospice but unmet needs were identified within each of the three stated themes. Each family member required different levels of information, which was demonstrated by the degree to which they sought out staff and asked questions. There was more consistency in the second theme where the families' knowledge and expectations of palliative care were limited. The impact of the environment was highlighted as a significant factor influencing perceived levels of support raising some concerns of the impact of an open awareness environment where exposure to death and dying was inevitable.

Abstract number: 197
Presentation type: Poster
Session: Bereavement and Family

"We didn't know where to turn". A study of family experiences of services when a parent has cancer

Vida Kennedy, **Mari Lloyd-williams**, University of Liverpool, Liverpool, Great Britain

Background: A diagnosis of advanced cancer is known to have a great impact on the whole family, and on the individuals within the family affecting all aspects of their lives. There is, however, a lack of specific research with families where a person with advanced cancer has dependent children.
Aims: The main aim of the study is to explore experiences of services from the perspectives of families identifying families' priorities for these services, in order to aid service development.
Method: Semi-structured interviews with family members are conducted to access their views and experiences regarding services. We aim to recruit between 30 families, and each family will include a parent diagnosed with advanced cancer, a main carer, and where appropriate any children above the age of 7. Subsequent focus groups with health professionals will provide a deeper and more integrated understanding of service provision.
Analysis: Interviews and focus groups are recorded and transcribed fully, and analysed using the grounded theory approach.
Results: A total of seven interviews have been completed to date, which include 4 families comprising of 3 ill parents, 2 carers, and 2 children. Participants in general reported that they were well supported by formal and/or informal sources, highlighting the importance of genuine, caring, and approachable healthcare professionals, as well as accessible and continuous support from both community and hospital sources post palliative diagnosis. Problem areas identified included 'telling the children', supporting the children, post-death planning, access to information, and social isolation, reflecting the need for additional support where children are concerned.
Discussion: Themes emerging from current and future data will be taken for further discussion with healthcare professionals in focus groups where their views and needs will also be explored and used to inform the development of family centred care when a parent has advanced cancer.

Abstract number: 198
Presentation type: Poster
Session: Bereavement and Family

Evaluation of the palliative care needs of families which have lost a child

Patricia Fahrni-Nater, **Claudia Mazzocato**, **Sergio Fanconi**, Centre hospitalier universitaire vaudois, Lausanne, Switzerland, **Eric Masserey**, Sercice Santé Publique, Lausanne, Switzerland

Introduction: In the context of the regional development of palliative care, semi-directive interviews were conducted with eight families having lost a child between 1999 and 2003 in order to identify their specific needs.
Method: The interviews took place between December 2004 and March 2005. Five children died of cancer, the other three due to, respectively, cardiac disease, an internal bleeding and infection. The families' principal concerns are presented.
Results: The families reported that symptom control was not always satisfactory; symptoms could have been anticipated. Information was unclear, particularly when the attitude was no longer curative, due to the indirect language used by the professionals. Families insisted that they wanted to be told the truth, even if it was difficult to bear and without it being constantly repeated by the professionals. They underlined the importance of being considered as partners in their child's care. They wanted their wishes to be taken into consideration as to, for instance, the place of death, the use of alternative medicine and their presence during their child's last moments. These elements are essential both during the illness and during bereavement. Another subject which was raised was the difficult and stressful question of telling the child the truth. Parents would have liked to do this themselves, at the "right" moment and in appropriate terms. Whereas they felt that they had received adequate support during their child's illness, this support was sorely lacking in the period immediately after his/her death. The families felt abandoned by the doctors and the nurses and said that they had not received the help they needed.
Conclusions: The interviews revealed several unsatisfied needs: symptom control, communication and bereavement support. Further interviews will be performed to enhance the preliminary data. Concrete propositions as to how to improve the service will be made.

Abstract number: 199
Presentation type: Poster
Session: Children

Pediatric palliative care: review of practice and need in the county of vaud trough a questionnaire completed by pediatricians and pediatric nurses

Patricia Fahrni-Nater, **Claudia Mazzocato**, **Sergio Fanconi**, Centre Hospitalier universitaire vaudois (CHUV), Lausanne, Switzerland, **Eric Masserey**, Service Santé Publique, Lausanne, Switzerland

Introduction: In the context of the regional development of palliative care, a study was carried out in June 2004 to explore the current practice of and need for pediatric palliative care.
Method: Five hundred and forty eight staff members, all pediatricians or pediatric nurses working in hospital, the home care service or institutions for handicapped children in the county of Vaud, were sent or mailed a questionnaire.
Results: The response rate was 42%; 80% of the replies came from hospital-based nurses. More than a third had cared for more than five terminally ill children in the last two years; 89% have plurisdisciplinary discussions as to the attitude and plan of care. A minority has care protocols; 56% of doctors and 88% of nurses use pain evaluation scales, which 53% consider satisfactory results. A minority is aware of an evaluation tool for other symptoms, for which only 33% judge management to be totally satisfactory. Psychological support for the child and his/her family is currently proposed in 75% of situations. Bereavement care is not formalized. In general, staff members are satisfied with the psychological support which is available for them. Eighty eight percent are prepared to care for a terminally ill child as long as they have sufficient training (35%), can call on appropriate resource people (65%) and have access to specialized advice (66%). These requirements are the same for all staff and in all work places.
Conclusions: Staff members make use of several different measures when caring for terminally ill children. However, they feel that they lack adequate training and express the need for expertise in the field of pediatric palliative care. This expectation raises the question of the creation of a mobile team for pediatric palliative care, a subject which has been explored in a second research project with pluridisciplinary focus groups.

Abstract number: 200
Presentation type: Poster
Session: Children

Qualitative research with children in palliative care: Forgotten or feared?

Vida Kennedy, **Mari Lloyd-williams**, University of Liverpool, Liverpool, Great Britain

Research with children has always been a difficult, complex and emotionally charged topic. Although an important research area, there is currently little known of children's experiences of services when a parent has advanced cancer, what kind of help they would value the most and when and by whom it would be best delivered. Such information is crucial if we are to deliver the best possible care. This gap in knowledge may be due to lack of awareness, however, we believe a more plausible explanation could be researchers' fear of the ethical dilemmas involved in research that involves children, particularly within the area of palliative care. Gaining information directly from children is important for many reasons including respecting the rights of children, the non-representative nature of proxy accounts, and not least because the needs of children are likely to differ to those of adults. In addition to expressing the importance of conducting such research, we highlight particular ethical issues that may arise in such research. Issues of debate include most commonly those issues surrounding consent, vulnerability and welfare, and confidentiality and privacy, however, further concerns involve the implications of these issues on study design. This poster highlights the ethical issues arising in research with children, as well as implications of these issues on study design. We conclude by urging that a complex ethical topic area is by no means less crucial to study, and that if ethical issues are addressed and considered thoroughly from the start embarking on such research may not be as fearful as one might expect.

Abstract number: 201
Presentation type: Poster
Session: Children

Online communication and pediatric palliative care: A needs assessment for the canadian virtual hospice

Carla Ens, **Mike Harlos**, **Harvey Chochinov**, University of Manitoba, Winnipeg, Canada, **Anita Stern**, University of Toronto, Toronto, Canada, **Josette Berard**, Canadian Virtual Hospice, Winnipeg, Canada

The internet is a tool for communication, community, and content with advantages including absence of geographic barriers, anonymity and increased self disclosure. Internet technology is being applied to end-of-life due to factors such as limited access to palliative care, an aging population, and available technology. With the 2004 launch of the Canadian Virtual Hospice (CVH), an online forum was created to provide assistance during end-of-life for family members, patients and care providers. However, as CVH deals largely with an adult population, the potential need within the pediatric population is not well addressed.
Methods: To complete the needs assessment, a comprehensive literature review and key informant interviews were completed. With the assistance of the CVH team, the lead researcher determined what CVH could potentially offer online to dying children, parents, siblings, other family members, and friends. The literature review was summarized using a content analysis of major themes; the interviews were coded into similar themes; the final analysis included recommendations.
Preliminary results: Over 3500 children die in Canada annually and approximately half might benefit from palliative care services. When considering grieving children and parents, it is clear that a substantial number of people may benefit from online services. Although websites are available that may be applicable to terminally ill children (i.e. health information sites), nothing was found that would meet needs of children and family members throughout the trajectory of illness. Preliminary data analysis indicates that CVH may be successful at providing a website for children and families; one that may be applicable before and after a death. Potential attributes would be privacy, anonymity and ease of use while limitations may include finding appropriate human resources to staff the site as well as providing developmentally suitable material.

Abstract number: 202
Presentation type: Poster
Session: Children

'On the cusp of chaos'; Collaborative inquiry with children living with parental illness

Gillian Chowns, Hants, Great Britain, **Sue Bussey**, East Berks Palliative Care Team, Windsor, Great Britain, **Alison Jones**, Thames Hospice Care, Windsor, Great Britain

There is relatively little research on children living with a seriously ill parent and almost none conducted from the child's perspective. This qualitative study bridges the gap, breaking new ground in its methodology and medium, and enabling the voice of young people (a marginalised group of users in palliative care) to be heard. A significant output was a video of their experiences, aimed at other families, and now also widely used as a training tool for professionals. This piece of action research uses collaborative inquiry; it starts from the premise that good research is research 'with' rather than 'on' or 'for' others, and that those who are actively experiencing a situation have as much knowledge as outsiders. It claims to respect multiple perspectives, to capture the richness and diversity of individual experience and to shift the power differentials inherent in more conventional research. Nine children, aged from 7 to 15, met for seven weeks to research their own experiences, and to make the video. Using participatory video techniques, they planned, filmed, and interviewed each other. A second camera recorded all the sessions, so that the collaborative inquiry process was also captured. Data sources included all the tapes, a reflective diary, facilitator debrief and supervision tapes, 'products' of the group sessions, such as paintings, and written reflections from the children. Data analysis yielded significant themes related to the children's experience, but this paper focusses on those findings related to methodology only, and discusses the following:- Collaborative working-catalyst for change or recipe for conflict? Competing models of childhood Competence and capacity in young co-researchers Video as a method and medium Conclusion Despite its limitations, collaborative inquiry may enable palliative care to benefit from its more egalitarian partnership between professionals and users.

Abstract number: 203
Presentation type: Poster
Session: Children

UK childhood bereavement services: containing the grief of bereaved children and their families

Liz Rolls, University of Gloucestershire, Cheltenham, Great Britain

Objectives: The study examined the organisation and work of UK childhood bereavement services. It also explored the benefits that bereaved children and their families felt they gained from using a service.
Methods: Both quantitative and qualitative methods were used within an organisational case study design. A survey of UK childhood bereavement services was administered, and service providers interviewed to explore the range and purpose of their interventions for bereaved children and their families. Bereaved children and their families were interviewed, and participant observation of service interventions was undertaken to explore the impact and the perience of these on their bereavement experience.
Results and discussion: Although they may be structured differently, UK childhood bereavement services used a similar range of interventions designed to achieve key outcomes that supported bereaved children and their families, including the provision of a secure place for the exploration of their feelings. The death of a parent or sibling presented children with a range of intense emotions and experiences, and their bereavement occurred in a context where their caregiver's potential to provide the support they needed was severely compromised. Through their capacity to work with the intense emotions of bereaved children, staff provided a 'containing' experience, enabling them to express, understand and manage their grief, and begin to make sense of the events that had surrounded them.
Conclusions: In working with intense experiences of bereaved children, childhood bereavement services provided an 'ecological niche' in which their grief could be 'contained'. Through this process, children were able to develop meaning from their experience, and integrate it into their life narrative.

Abstract number: 204
Presentation type: Poster
Session: Children

Collaborative relationships: supporting the researcher in palliative care and bereavement

Liz Rolls, University of Gloucestershire, Cheltenham, Great Britain, **Sheila Payne**, University of Sheffield, Sheffield, Great Britain, **Marilyn Relf**, Sir Michael Sobell House, Oxford, Great Britain

Objectives: A study was undertaken exploring UK childhood bereavement service provision, the reasons why bereaved children and their families had used a service, and the benefits they felt they drew from the experience.
Methods: Within an organisational case study design, a range of quantitative and qualitative methods was used, including two postal surveys of service providers, interviews with service providers and bereaved children and their parents, and participant observation of six service interventions. To support the researcher in this sensitive and complex study, a number of research-focussed relationships were developed.
Results and discussion: Each of the three types of research support offered different benefits to the researcher. Academic consultancy provided a forum for discussion on research-based issues, including the collection and analysis of data. 'Bracketing interviews' provided support for managing the emotional and ethical issues that arose, and for an exploration of the subjective experience of 'researching' and the relationship of this to the knowledge that was being generated. A Project Advisory Group contributed through broad guidance on matters related to the specific field of enquiry, and through the provision of a timetabled reporting structure.
Conclusions: In contract or funded research where researchers are no longer within the supervisory framework of a Masters or doctoral programme, the combination of these three relationships provided a comprehensive framework that contributed to ensuring the methodological integrity of the research, the safety of the researcher and the participants, and the embeddedness of research within its service constituency.

Abstract number: 205
Presentation type: Poster
Session: Children

Prevalence of symptoms among children with brain tumors and sarcomas at the end of life

Bilal Moaed, **Sergey Postovsky**, **Ruth Ofir**, **Myriam Weyl ben arush**, Rambam Medical Center, Haifa, Israel

Background: Children suffering from cancer demonstrate various symptoms at the end of life and their recognition may facilitate the comprehensive management thus improving quality of life.
Aim of the study: to estimate the prevalence of symptoms among pediatric patients with brain tumors (BT) and sarcomas (S) at the end of life.
Patients and Methods: A retrospective review of medical charts of 24pts suffering from various types of BT (12 pts) and S (12 pts) was performed and symptoms of physical disstress noted during the last three months of life were registered. The mean age of pts with BT was 10.2 y (range, 1–22 y), and of pts with S-13.6 y (range, 0.5–26 y).
Results: Among pts with BT the following symptoms were registered: headache-10 pts, problems with swallowing-7 pts, respiratory problems (RP)-5 pts, constipation (C)-5 pts, nausea and vomiting (N&V)-4 pts, insomnia-3 pts and neurogenic bladder-one pt. Among pts with S the prevalence of symptoms was as following: pain -12 pts, weight loss-7 pts, C-7 pts, RP-4 pts, insomnia, neurogenic bladder, fatique-one pt each. All pts received comprehensive palliative care directed at the alleviation of their symptoms. In the group of pts with BT and headache there was satisfactory or complete control in 8/10 pts, RP-4/5 pts, C-3/5 pts, N&V-3/4 pts, insomnia-1/3 pts, neurogenic bladder-1/1 pt. In the group of pts with S satisfactory or complete control was achieved in following cases: pain-8/12 pts, weight loss-5/7 pts, C-3/7 pts, RP-3/4 pts, insomnia-1/1 pt, fatique-1/1 pt, neurogenic bladder-1/1 pt.
Conclusion: 1. Prevalence of symptoms during last period of life differs between children with BT and S with pain being the most common symptom in both groups. 2. Comprehensive palliative care of such pts allows to achieve good control of the majority of symptoms in these pts. 3. It appears that achieving good control of symptoms in pts with S is a more difficult task than in pts with BT.

Abstract number: 206
Presentation type: Poster
Session: Children

Management of refractory symptoms in pediatric cancer patients: the experience of the miri shitrit pediatric oncology/hematology department, rambam medical center, haifa, israel

Sergey Postovsky, **Bilal Moaed**, **Ruth Ofir**, **Myriam Weyl ben arush**, Rambam Medical Center, Haifa, Israel

Background: The goal of therapy for a dying child is to maintain comfort and support for the child and his family. It is the responsibility of health care team to provide adequate pain control along with control of other noxious symptoms for a child during the last phase of his life. The aim of the study: to develop an understanding of the local experience and assess the potential for improved management of terminally ill pediatric cancer patients (pts).

Materials and methods: A retrospective-prospective consecutive chart review of 18 pts with various solid tumors suffering from refractory symptoms was undertaken. Since 01.01.1997 till 01.10.2001 18 pts with end stage of their cancer were treated by applying palliative sedation (PS) after their symptoms had been proved to be not amenable for alleviation by any other interventions. Age of pts ranged from 1.5 to 22 years (mean = 9.6 years). Eight pts received combination of Midazolam (M) and Morphine (Mo). Eight pts were treated with lytic cocktail consisting of Chlorpromazine (Ch), Promethazine (Pr) and Meperidine (Me). One pt was given Mo and Phenobarbital and one other – M and Pr. The efficacy of PS was assessed by regular measurements of vital signs (pulse, blood pressure, sweating) and by degree of motor activity of a pt. The duration of PS ranged from 12 hours to 45 days.

Results: Most of pts remained apparently quiet during the last phase of their lives. The regular measurements of vital signs did not indicate any significant distress. In the group of pts who was treated by Mo and M there were no seizures during the PS. Three pts who received Me had seizures during PS, most probably due to normeperidine.

Conclusions: 1. PS is an effective method of treatment for alleviating refractory symptoms during the terminal phase of cancer in children. 2. Combination of Morphine and Midazolam appears to be the most convenient for this purpose for the majority of pediatric cancer pts.

Abstract number: 207
Presentation type: Poster
Session: Children

Palliative service in pediatric oncology/hematology department

Sergey Postovsky, **Bilal Moaed**, **Ruth Ofir**, **Myriam Weyl ben arush**, Rambam Medical Center, Haifa, Israel

Background: Currently, about 75 per cent of children suffering from cancer can be cured. Otherwise, it means that every fourth pediatric oncology patient will eventually die; hence there is need in creation of palliative service in the department of pediatric oncology.

Aim: to describe the experience of creation of palliative service (PS) in the pediatric PS's staff: Pediatric oncologist/hematologist with special knowledge in palliative care, three nurses specially trained in the field of pediatric palliative care, social worker, clinical psychologist, art therapist The aims of palliative treatment in the department: 1. Determination of palliative policy in the Pediatric Oncology/Hematology department. 2. Early identification of children who need palliative treatment. 3. Checking family possibilities in areas of physical, psychological, spiritual, and material support. 4. Creation of cooperation with community in order to provide home treatment to the suffering child and his family when it is possible. 5. Creation of palliative care program for every individual child and his family. 6. Regular analysis of PS activity and performance of academic research in the field of palliative care. 7. Providing psychological and spiritual support for the departmental staff (January 2002).

Results: Since initiation of PS every child with incurable cancer becomes a subject of palliative treatment. Every needed child has immediate access to the physician and/or nurse who is responsible for management of pt's problems. Satisfaction of patients and their parents from management of final stages of cancer has risen since PS was created.

Conclusions: 1. PS is acutely needed in everyday practice of pediatric oncology department. 2. PS helps to meet demands both patients and their parents and medical staff dealing with final stages of pediatric cancer. 3. Using rational human and material resources, it is possible to start PS without additional financial spending.

Abstract number: 208
Presentation type: Poster
Session: Epidemiology

"How to estimate the need of home palliative care programs? A study in pediatric popolation in Veneto region"

Massimo Melo, **Anna Ferrante**, **Paola Facchin**, Community Medicine and Epidemiology Unit, Padova, Italy, **Franca Benini**, **Benedetta Bonato**, Department of Pediatrics, Padova, Italy

Preference: oral presentation The aim of the study is to appraise the number of children that need a home palliative care approach in the Veneto region-Italy, and evaluate the accessibility to the care programs. In the first step we examinated the Hospital Discarged Record of all the inpatient children (0–17) in Veneto Hospitals in 2000–2002 period (ordinary + day.hospital), searching for ICD9-cm code related to Chronic Complex Conditions (CCC) that may lead to terminality. This research allow to identify the number of children that may take advantage in home palliative care program, that results included between 800 and 1700, according to the nature of CCC considerated. In the second step, by a questionnaire sent to all the Home care equipe in Veneto region, we detected the number of the children assisted in home palliative care program, and the critical points of it: in 2000–2002 period only 130 children were nursed, regardless the 800/1700 children potentially enrolled. Therefore, we noted great heterogenity in allocation of care among the home care equipe in Veneto region, depending on the modality of performance given, on different organization of the territorial services and on the professional training of the staff.

Conclusions: to assure an adequate planning of home palliative care, the program should be related to the real number of children affected by CCC. Then, many efforts should be done to equalize the organization of the territorial services that must guarantee the same way of approaching to the care, besides free and equal access to all children.

Abstract number: 209
Presentation type: Poster
Session: Epidemiology

Characteristics of hospitalizing dying patients in a tertiary cancer hospital in Brazil

Císio Brandao, **Maria do rosario Dias de**, Hospital do Câncer A.C. Camargo, Sao Paulo, Brazil

When statistics of cancer mortality are available, knowing the characteristics of cancer patients' deaths and duration of terminal period makes it possible to estimate the prevalence of end-stage-cancer, which is essential in order to plan palliative care (PC) program.

Objectives: Describe the characteristics of all inpatients cancer deaths, pattern of demographic profiles and length of last hospital stay.

Methods: A reviewed of medical records of 531 of 673 deaths between Jan and Dec 2000 in a tertiary large urban cancer hospital in Brazil.

Statistical analyses: Descriptive statistics were reported as percentages and means, standards deviation or median for parametric values. The comparison of parametric values was performed using the t and Mann-Withneyy test. Chi-square test was used for comparison of proportions and the Kruskal- Wallis test for comparison between three or more mean. A p value less than 0.005 was considered statically significant.

Results: The mean age was 59.8 years (range 18.9–97 years), median = 60.7. Most patients were whit skin color (88.9%), died in a general ward (79.3%). Cancer sites were gastrointestinal (21.3%), lung/mediastin (11.1%), and genital tract (10.2%). Symptoms were dyspnea (73.1%), pain (54.8%), asthenia (46.7%), agitation (46.5%), infection (45.0%), and anorexia (40.7%). Most patients didn't receive chemotherapy (95.7%) or surgery (71.6%) prior to death. The last hospital stay varied between 1 to 318 days (mean = 14.9 days), was bigger in males ($p = 0.038$), patients who died in ICU ($p = 0.002$), presented with anxiety ($p < 0.001$), anemia ($p < 0.001$), constipation ($p < 0.001$), depression ($p < 0.001$), infection ($p < 0.001$), nausea and vomiting ($p < 0.001$), pain ($p = 0.002$), anorexia ($p = 0.005$) and diarrhea ($p = 0.015$), was on active chemotherapy ($p < 0.001$), palliative radiotherapy ($p < 0.001$), and active or palliative surgery ($p < 0.001$).

Conclusions: This study describes the characteristics of a representative sample of cancer deaths in Brazil.

Abstract number: 210
Presentation type: Poster
Session: Epidemiology

Is there a relation between type of cancer and requests for Euthanasia?

Ebun Abarshi, **BD Onwuteaka-philipsen**, **G Van der wal**, VUmc, Amsterdam, Netherlands

Objective: It is known that 86% of patients who request euthanasia or physician-assisted suicide have cancer. However, it is not yet known whether patients with certain types of cancer request euthanasia more or less frequently and whether there are differences in reasons for requesting euthanasia between patients with different types of cancer.

Method: All general practitioners in 18 of the 23 districts in the Netherlands received a written questionnaire in which they were asked to describe the most recent request for EAS they received (response 60%, $n = 3614$). Of these GPs 1442 described a most recent request for EAS of a cancer patient. Numbers of cancer deaths per ICD10-classification were derived from Statistics Netherlands.

Results: While 14% of all cancer patients requesting euthanasia had colon cancer, 9% of all cancer deaths concerned this group. Other groups for which patients relatively frequently requested euthanasia were pancreas cancer (7% versus 2%), lip, mouth and throat cancer (3% versus 1%), oesophagus cancer (5% versus 3%) and stomach cancer (6% versus 4%). Euthanasia was relatively infrequently requested in prostate cancer (4% versus 6%), lymphoma (2% versus 5%). 'Pointless suffering', 'loss of dignity' and 'tiredness' were most frequently mentioned as a reason for requesting euthanasia in all types of cancer. 'Pain' was mentioned in different frequencies: between 13% for stomach cancer to 39% for prostate cancer. 'Being tired of living' was mentioned relatively frequently in patients with prostate cancer (20% versus 5–11%).

Conclusion: There are differences in the extent to which patients with different types of cancer request for euthanasia. Although it is likely that this is related to the type or extent of suffering per type of cancer, this is not clearly reflected in reasons patients have for requesting euthanasia.

Abstract number: 211
Presentation type: Poster
Session: Epidemiology

Epidemiology of end-of-life care: Patients, family members and patient care setting

Emanuela Porta, **Lia Biagetti**, **Maria grazia Deola**, **Daniela Cattaneo**, VIDAS, Milano, Italy

Premise: As life expectancy continues to rise in today's society it has become clear that new health and social policies are needed to respond to ever growing health concerns. Home care is the health care of the future in that it is more in harmony with the evolutionary changes of society and culture. In this setting we care for 70 to 80% of terminally ill cancer patients.

Aim: To study the epidemiology of terminally ill cancer patients in a metropolitan setting who are cared for at home by a home palliative care (HPC) charity so as to evaluate the social and health issues that must be considered to properly implement HPC.

Methods: Retrospective analysis of terminally ill cancer patients living in the Milan area (pop 1,271,396) who were followed by a non-profit HPC charity in 2004–2005. Requests for this type of care were made directly by the patient, patient's family or by local health institutes. A patient database, comprising personal and clinical information, was begun by the HPC charity in 1997 Results 1189 patients (average age 73.6) died between Jan. 04 to June 05. The most prevalent cancers were of the respiratory tract (25%) and survived an av. of 42.7 days from the beginning of HPC, 92% were not self-sufficient. Average age of patients 70.4. The av. number of family members living at home was 2.4 with an av. of 1.4 offspring. Average age of breast cancer patients (8%) were 69.9, survived an av. of 43.7 days and lived with an av. of 2.1 family members and of 1.2 offspring. Brain cancer patients (3%) survived an av. of 60 days with 88% dying at home. Av. age of brain cancer patients were 67,8 and lived with an av. of 2.5 family members and of 1.4 offspring.

Conclusions: Data analysis which takes into consideration those dying in 2005 will go on evaluating the different cancers (gastrointestinal/hepatic), families and the HPC setting so as to better define human and financial resources needed to adequately assist terminally ill patients in a HPC setting.

Abstract number: 212
Presentation type: Poster
Session: Epidemiology

Monitoring end-of-life care via the sentinel network of general practitioners (GPs) in Belgium: A feasibility study

Lieve Van den block, Vrije Universiteit Brussel, Brussel, Belgium, **Reginald Deschepper**, **Katrien Drieskens**, **Luc Deliens**, End-of-Life Care Research Group – Vrije, Brussels, Belgium, **Viviane Van casteren**, Scientific Institute of Public Health, Brussels, Belgium

Introduction: A challenge in end-of-life (EOL) care research today is to find ways to gather systematic information at population level i.e. across all patient populations and care settings. In this feasibility study we explore whether the sentinel network of GPs in Belgium, an epidemiological surveillance instrument operational since 1979, can be a useful tool to monitor EOL care. Willingness of sentinel GPs to participate in a registration and additional interview study on EOL care is evaluated.

Method: The Belgian sentinel network is a weekly registering network of practices of community based physicians, covering 1.5% of the nationwide patient population and representative for all GPs in Belgium. All sentinel GPs were asked to register general characteristics for all prospectively occurring deaths (aged 1 year or older) during 13 consecutive weeks in 2004. An additional registration for all non-sudden deaths in their practice concerned care received in the last three months before death. We selected 26 GPs of patients who died at home, to be contacted by telephone to evaluate their willingness to participate in an additional interview study.

Results: In our study 170 GP practices (93%) participated and reported 333 deaths: 93% was part of their practice and 67% died non-suddenly. For these non-sudden deaths GPs were able to register the care trajectory, the delivered care and treatments, and medical end-of-life decisions. Of 26 selected GPs, 91.7% was prepared to participate in an interview study.

Conclusion: The use of existing surveillance networks can provide valuable information for EOL-care monitoring. There are several advantages: representativity, weekly registration, a high participation level, willingness to participate in an additional interview study, and moreover important data on several EOL topics. Comparable surveillance networks exist in other European countries, which provides a unique opportunity for cross-national EOL studies.

Abstract number: 213
Presentation type: Poster
Session: Epidemiology

Decision-making in end-of-life care: In search of a registration system

Marc Cosyns, **Tomas Mainil**, **Myriam Deveugele**, **Jan De Maeseneer**, Ghent University, Ghent, Belgium, **Benedicte Abbadie**, **Jeanne Depireux**, **Michel Roland**, University Brussels, Brussels, Belgium

Introduction: Decision making by caregivers (CG) in end-of-life (EOL) care becomes a more persistent field of research, especially with regard

to patient rights and the relation between CG and their patients. Recent publications show a trend in making the practice of CG more transparent and well-defined. The Federal government of Belgium ordered research about the feasibility of organizing a registration system concerning EOL care. The depts. of General Practice and Primary Health Care Ghent University and Univ. of Brussels conducted a pilot study aiming at following topics:
1. attitudes of CG towards EOL care 2. knowledge of the associated laws (Law on Palliative Care (PC)/Law on euthanasia/Law on patient rights) 3. Their communication skills towards EOL care 4. decision-making process and medical acts towards the patient in the end of his/her life.
Methods: A 3 parts questionnaire was developed. The first part contains general questions about the law on patient rights, euthanasia and PC (knowledge). The second part is a retrospective survey about communication, decision making and medical acts in EOL care (attitudes, communicative aspects and decision-making processes) while the third part is a prospective survey about the same topics. Three settings were selected for this three-stage post-survey: GPs, homes for the elderly and specialized services in hospitals. Qualitative research was performed towards MD peer groups. Preliminary results Literature review revealed that methodologically registration of EOL decisions requires major precautions towards ethical procedures. A conceptual framework concerning EOL care is required. Procedures with regard to ethical topics and problems in collecting data will be discussed. The number achieved in the data collection was 193 cases (GPs and specialists), spread over 6 hospitals. It concerned 66% men and 34% women. 33% of the respondents were specialists, 67% GPs. Only 12% of the MD's have followed an institutionalized education in PC. Towards the occurrence of PC acts differentiation between MD's exists. In 62% of the cases PC was offered to the patient. 63% of the MD's agreed on the fact that euthanasia should be integrated in the field of PC. Concerning the knowledge of the law it was indicated that that MD's don't score good on questions about this topic.

Abstract number: 214
Presentation type: Poster
Session: Epidemiology

Prevalence of pain and other symptoms in patients with cancer

Marieke Van den beuken, **Harry Schouten**, **Maarten Van kleef**, Academic Hospital Maastricht, Maastricht, Netherlands, **Marjan De rijke**, **Jaap Patijn**, Pain Knowledge Center, Maastricht, Netherlands

Background: Pain is one of the most feared symptoms in cancer patients and is considered to be a major problem in the majority of prevalence studies. Due to methodological flaws, such as selection bias and small sample sizes, the magnitude of the problem, however, is far from clear.
Aim: A population-based study was performed on the prevalence of pain and other cancer related symptoms in a representative sample of patients with cancer in the Netherlands.
Methods: All cancer patients visiting the outpatients clinics of 5 hospitals and 2 radiotherapy centres were approached during two weeks. Patients not receiving curative or palliative treatment were recruited via general practitioners, hospices and nursing homes. Comprehensive data were collected by means of questionnaires on demographics, localisation of the tumour, stage, medication, quality of life (EORTC-QLQ-C30), pain (Brief Pain Inventory), anxiety and depression (Hospital and Anxiety Scale). Patients who were not able to complete the questionnaire, have had an operation, chemo- or radiotherapy within 5 days before or successful treatment ended before 1 January 2000 were excluded.
Results: 1843 questionnaires were distributed, while1429 patients returned it (response 77.5%). Prevalence of pain and other symptoms will be presented for different groups of patients (according to stage and cancer site etc.). Preliminary results on the associations between quality of life, anxiety and depression and the prevalence of pain will be shown.

Abstract number: 215
Presentation type: Poster
Session: Epidemiology

The prevalence and predictive factors effecting the use of complementary alternative medicine in Turkish cancer patients

Mustafa Ozguroglu, **Ibrahim Yildiz**, **Hande Turna**, Istanbul University, Cerrahpasa, Istanbul, Turkey

Introduction: We aimed to investigate the prevalence of using complementary alternative medicine (CAM) among adult cancer patients.
Materials and methods: We planned to conduct a survey consisting of 29 questionnaires in 1000 patients followed in our outpatient clinic of the department of medical oncology in Cerrahpasa Medical Faculty. All the questionnaires, including a seperate quality of life questionnaire (QLQ-C30) were answered by the patients themselves without any contribution from the physicians.
Results: We hereby report the preliminary results in 100 patients. 50% of patients had used at least one type of CAM since the time of initial diagnosis. Reported uses of CAMs consisted of herbal remedies in 47 patients, religious support in 6 patients, yoga in 4 patients. Main objectives of CAM use in our patient population were "genuine belief that they constitute effective alternative treatment to conventional treatment (19 patients), "encouragement by relatives or friends" (15 patients), "disappointing results with conventional treatment" (4 patients), and "desperate condition" (1 patient). 47% of patients did not inform their physicians about their CAM use. Visit of psychiatrists was only reported in 13% of patients.
Conclusion: Half of our cancer patients in our preliminary report used CAM. Physicians treating cancer patients should be aware of the frequency of CAM use and should share their opinion about CAM use with cancer patients. In this way abuse of CAM by the patients, and also abuse of patients by the CAM dealers may be minimised.

Abstract number: 216
Presentation type: Poster
Session: Epidemiology

The lived experience of lebanese oncology patients receiving palliative care

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The purpose of this study was to uncover the lived experience of Lebanese oncology patients receiving palliative care.
Significance: Most studies of palliative care of cancer patients have been conducted on Western populations. Because of the cultural differences, it is difficult to generalize these findings to non Western population such as in Lebanon. In addition, cancer is one of the leading causes of mortality in Lebanon, and a majority of patients reach the palliative stage. However, very little is known about the lived experience of the Lebanese oncology patients receiving palliative care.
Design: The study design was based on the Utrecht hermeneutic phenomenological research Sample selection and size: This study followed purposeful sampling in which ten participants were selected based on their particular knowledge of the phenomenon and their willingness to share that knowledge.
Ethical considerations: The proposed research was approved by the Institutional Review Boards at the American University of Beirut and Duquesne University. Collection of data and analysis: Semi-structured, in-depth interviews along with observation-field notes were used as the source for data collection. Data were analyzed using the phenomenological approach based on the Utrecht School of Phenomenology.
Results: Analysis of the data revealed eight themes and sub-themes:
Theme I: Distressed From Being Dependent, Sub-theme: Loss of Control, Disease Reminder, and Burden on Others. Theme II: Dislike For Pity, Sub- theme: Threat to Self-Perception. Theme III: Worry for The Family and The Worry about The Family's Worry. Theme IV: Relying on God and Divinity. Theme V: Dislike of The Hospital Stay, Sub-Theme: Feeling Trapped in Time, Place and Disease. Theme VI: The Need to Be Productive. Theme VII: The Fear of Pain and Sufferings, Current and Future. Theme VIII: The Impact of Communication, Verbal and Non-Verbal.

Abstract number: 217
Presentation type: Poster
Session: Epidemiology

Palliative care in Carinthia-findings-physicians, directors of nursing home and heads of mobile nursing services

Rudolf Likar, **Wolfgang Pipam**, General Hospital, Klagenfurt, Carinthia, Austria, **Herbert Janig**, **Carmen Zernig**, University of Applied Sciences-Carinthia Tech, Feldkirchen, Austria

So far there is only little known about the qualification and skills of directors of nursing home, heads of mobile nursing services in palliative care and physicians in palliative medicine. This study aims to find out more about the following issues: professional qualification for palliative care and palliative medicine, number of palliative patients and their diseases and therapies, assessment of pain level, quality of life and satisfaction with the treatment of pain of palliative patients. Directors of nursing home, heads of mobile nursing services and physicians were asked to assess their subjective qualification level in areas like pain therapy, palliative care, psychosocial care and coping strategies as well as their demand for accompanying measures. Data from 150 general practitioners, 46 directors of nursing home and 10 heads of mobile nursing services in Carinthia were collected.

The results show that the physicians obtain little information about palliative medicine and pain therapy during the education at the university and the hospital. Physicians 40 years of age or younger believe that their psychosocial competence, like communication with patients or relatives, guidance till the end of life is significantly lower than that of their colleagues who are older than 40. The demand for accompanying measures in terms of stress coping strategies is higher among female physicians compared to their male colleagues. All in all the directors of nursing home believe that they are well qualified in areas like palliative care, psychosocial care and coping strategies. As to their personal accomplishment competence, like coping with feelings of guilt, own dolor and own powerlessness directors of nursing home under 40 are convinced that they are generally more competent than their older colleagues. For 50 percent of heads of mobile nursing services and for 62.1 percent of the physicians pain therapy and for 23.1 percent of directors of nursing home detect the control of symptoms and own coping strategies are very important in terms of further education.

The intention of the study is that the quality of the medical and custodial care could improved through advanced training. Findings of this study should lead to better interdisciplinary cooperation between in-, outpatient and pastoral services.

Abstract number: 218
Presentation type: Poster
Session: Epidemiology

The prevalence of depression and anxiety in Nottinghamshire cancer patients

Sarah Khan, Nottingham City Hospital, Nottingham, Great Britain, **David Fyfe**, Lancaster Royal Infirmary, Lancaster, Great Britain

Introduction: Prevalence rates of depression and anxiety of between 5 and 53% have been quoted in a variety of different studies assessing symptoms of depression and anxiety in patients with cancer. One of the most used and validated screening tools is the Hospital anxiety and depression scale (HADS), which assesses both symptoms of depression and anxiety and is simple and quick to complete. The aim of this study was to detect the prevalence of depression and anxiety in Nottinghamshire cancer patients attending outpatient clinic.

Patients and methods: Oncology patients attending outpatient clinics were asked to complete a HADs questionnaire whilst waiting for their appointment. Written consent was obtained for each patient. A total of 106 patients completed the questionnaire. HADs A, (anxiety), D (depression) and T (total) scores were recorded for each patient. Information such as age, sex, cancer type, treatment (adjuvant, palliative), history of depression and anxiety, use of antidepressants/anxiolytics was recorded from the patient's medical notes.

Results: The prevalence of depression in this group was 11% and the prevalence of anxiety 23%. The prevalence of depression/and or anxiety was 33%. Subgroup analyses showed no significant relationship between the rates of depression and anxiety and patient age, sex and type of treatment. Both the rates of depression and anxiety were found to be higher in females, particularly so in patients with breast cancer.

Discussion This study's finding of a prevalence rate of depression and anxiety of 33% is consistent with published literature. It is well documented that depression and anxiety are common but remain under detected in cancer patients. The introduction of simple screening tools can help to identify these patients, a holistic approach to their disease and related symptoms can be taken and appropriate treatment initiated.

Abstract number: 219
Presentation type: Poster
Session: Epidemiology

Chronic pain in breast cancer survivors: An epidemiological study

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Aim: To investigate chronic pain in female breast cancer survivors (BCS) >5 years after primary breast cancer surgery in a representative population in Denmark.

Methods: We conducted a survey on a population of 2000 women, aged >18 years, having sur-vived >5 years after breast cancer surgery without recurrence. An age-stratified random sample, representative for BCS in Denmark, was drawn from the database of the Danish Breast Cancer Cooperative Group (DBCG). The DBCG contains comprehensive data on breast cancer and its treatment in Denmark. Data were collected via a self-administered questionnaire and compared with women interviewed in the national representative Danish Health and Morbidity Survey of the year 2000. Both groups were assessed with a question on chronic pain (ongoing pain >6 months). The BCS questionnaire contained additional questions on pain. The sample design was based on a stratified random sample with equal allocation. The population was divided into four strata according to age at time of investigation: 18–49, 50–59, 60–69, 70+ years. From each of the four strata, 500 subjects were randomly sampled. Weights were con-structed to adjust for unequal sampling probabilities.

Results: Response rate was 79%. 1316 questionnaires were analyzed. Age-standardized preva-lence of general chronic pain among all BCS was 42.1% versus 31.9% in the general female popu-lation. BCS classified general chronic pain of different locations independently from chronic pain associated/not associated with former breast cancer disease. As consequence of former breast cancer disease, BCS reported: allodynia 15%; phantom sensations 19%; sensory abnormalities 54%. Analysis of potential treatment impact on pain is ongoing.

Conclusions: Chronic pain prevalence in BCS was significantly higher than in the general female population. BCS have an individual concept of pain.

Acknowledgement: The study was financially supported by the Danish Cancer Society.

Abstract number: 220
Presentation type: Poster
Session: Methodology

It is not just about quality. A method for grading the strength of evidence in palliative care

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Background: Systematic reviews are increasingly used to appraise evidence in palliative care, but are difficult to interpret when there is evidence of different quality or different findings.
Aim: To develop a method for grading evidence addressing the quality of the studies, as well as their quantity and the consistency of the findings, building on the proposal of the Agency for Healthcare Research and Quality (2002).
Methods: We developed an algorithm for grading evidence based in the SORT taxonomy and systems used for grading evidence on risk factors, and applied to research on factors shaping place of death in cancer. Evidence for each factor was judged of high strength when there was a minimum of 3 high quality studies where the findings were consistent across at least 70% of these studies. Studies performing multivariate analysis and with a quality score of 70% were considered of high quality. A sensitivity analysis determined whether a different grading threshold altered the findings (results from high and medium quality studies considered separately were compared with findings if the studies were of equal quality).
Results: The review included 58 studies, 25 of high quality. High strength evidence was found for 17 factors. The effect of each factor was reported by 3 to 8 high quality studies, with total samples ranging 948 to over 1.3 million patients. The consistency of the findings ranged 75 to 100%. There were 9 factors for which findings were 100% consistent across high quality studies. The sensitivity analysis suggested caution regarding the findings for only two factors.
Discussion: This method was useful for tacking evidence on factors shaping place of death. Quantity and consistency should be considered alongside quality, although different thresholds may need to be set up according to the topic.

Abstract number: 221
Presentation type: Poster
Session: Methodology

Development and validation of a scale for socio-economic level

Adel Mishriky, **Amr Hassan**, **Nadia Rizkalla**, **Hani Serag**, **Alaa Shukralla**, Faculty of Medicine-Suez Canal University, Ismailia, Egypt

Background: the determination of the socio-economic level is one of the challenges facing researchers in health and social sciences. Many attempts were done to include various types of indicators into a score measuring it.
Aim: the aim of this study was to develop and validate a scale for assessment of socio-economic level. It is based on an assumption that the ownership of properties or appliances is not only a reflection of the economic status of the person or the family, but is also influenced by the educational, cultural, and social backgrounds.
Subjects and methods: the source of the data used in this study was a community-based health survey carried out by the Association for Health and Environmental Development (AHED), a Non-Governmental Organization in Cairo, Egypt. It has included a total of 1311 households (5005 subjects). Factor analysis was done to classify the types of properties into components with common loadings. Then, the relative weight of each component was determined through regression analysis. Concurrent validity was assessed through using the new scale in a nation-wide survey on school children and their parents to examine how this proposed ''property score'' correlates with other indicators such as income, education of parents, scholastic achievement, IQ, and other health indicators. Statistically significant correlations were revealed with these variables. Moreover, the property score turned to be a statistically significant positive independent predictor of schoolchildren scholastic achievement, as well as their IQ.
Conclusion: a tool for assessment of socio-economic level based on ownership of properties and appliances was developed and validated. Its testing through concurrent validation verified its validity and utility in application in social and health research.

Abstract number: 222
Presentation type: Poster
Session: Methodology

Stakeholder input and marketing were important for the successful completion of the Palliative Care Trial (PCT)

Amy Abernethy, Duke University Medical Centre, Durham NC, US, **Tania Shelby-james**, Southern Adelaide Palliative Services, Daw Park, Australia, **David Currow**, Flinders University, Bedford Park, Australia

Background: Specialised palliative care services rely on referrals from primary clinical providers. Complex end-of-life needs dictate a multidisciplinary approach with input from myriad services. Therefore, research conducted in palliative care will require support from many services, as well as broader community and institutional support. The PCT was a RCT of case conferencing and educational interventions for patients in palliative care that aimed to enrol 460 patients. Study interventions required input from local service providers.
Methods: Pilot data and an evidence review suggested that local buy-in was critical. Print and electronic marketing including newspaper ads, pamphlets, letters, and a website informed local general practitioners (GPs) and the public about the study. Feature articles were incorporated in newsletters. Marketing efforts provided information about palliative care and the role of clinical research in improving quality of care, and did not specifically recruit patients. Trial investigators introduced the study in GP and specialist practice meetings, one-on-one meetings, and conferences. Informational meetings were held with district nursing, domiciliary care, aged care facilities, ambulance services, and governmental agencies. Regular meetings were held with organisations providing health service data. A trial newsletter was regularly circulated. University and hospital administration officials were routinely updated on the trial in face-to-face meetings.
Results: Engagement with a wide number of stakeholders contributed to the successful recruitment of 461 participants within the time frame of the original proposal. GPs were keen to be actively involved in all aspects of the research. Involving stakeholders from the time of initial planning was key.
Conclusion: Committed clinical and community partners enabled successful completion of a community-based palliative care trial, irrespective of the location of patient care.

Abstract number: 223
Presentation type: Poster
Session: Methodology

Use of a factorial cluster randomised design in the palliative care trial

Amy Abernethy, Duke University Medical Centre, Durham, NC, US, **Tania Shelby-James**, Southern Adelaide Palliative Services, Adelaide, SA, Australia, **David Currow**, Flinders University, Adelaide, SA, Australia

Background: The Palliative Care Trial (PCT) utilised a $2 \times 2 \times 2$ factorial cluster randomised design in order to test clinical and service delivery interventions in palliative care. In total, seven $2 \times 2 \times 2$ factorial design trials have been described in the literature to date, the PCT extends this, as the first $2 \times 2 \times 2$ factorial cluster randomised controlled trial (RCT) to be described.
Methods: The factorial design was chosen as a way of evaluating 3 hypotheses simultaneously with the minimum number of participants. Testing the synergy between the interventions was an additional benefit of factorial randomisation. Cluster RCTs are a common way of assessing community interventions, but can suffer from lack of appropriate attention to clustering in the design, analysis, and sample size calculation. The PCT calculated the required sample size to account for these factors. In addition, the factorial design allows for an economy of scale, the trial was already collecting demographic an clinical data, with a few extra fields we were able to answer more questions for the same effort and cost. PCT eligibility criteria were intentionally broad to assess effectiveness of interventions within the

diverse population usually seen in palliative care. This generated high quality evidence to support both routine clinical decision making as well as more general healthcare policy. Inclusion of comprehensive participant health resource utilisation data within the PCT dataset will supplement the patient-reported outcomes, generating meaningful results for clinical decision-making at the patient and health planning levels.
Conclusion: The PCT was able to meet its sample size goal and again demonstrate that it is possible to conduct rigorous research within palliative care. Novel robust trial designs are critical to ensure meaningful results and efficient mechanisms to assess interventions. The results of this effectiveness trial can inform current policy and future research.

Abstract number: 224
Presentation type: Poster
Session: Methodology

Development of the Palliative Care Trial: Pilot testing, an essential first step

Amy Abernethy, Duke University Medical Centre, Durham, US, **Belinda Fazekas**, Southern Adelaide Palliative Services, Adelaide, SA, Australia, **David Currow**, Flinders University, Adelaide, SA, Australia

Background: Few large randomised controlled trials have been undertaken in palliative care. This makes developing study protocols and estimating sample sizes difficult. A pilot study prior to initiating the trial is one method of overcoming this difficulty. We undertook a large $2 \times 2 \times 2$ cluster factorial randomised controlled trial, the Palliative Care Trial (PCT). The PCT was informed by a pilot study conducted 6 months earlier.
Setting: A regional community based palliative care service in South Australia, with >1100 referrals yearly, the majority of whom have cancer.
Methods: Ten patients and their general practitioners (GPs) were recruited to a randomised pilot study of GP vs patient educational outreach visiting. Case conferencing was not specifically included as the intervention had recently been tested in a geriatric setting at the same institution. Eligibility criteria, study setting, measurements and data collection schedule mimicked the planned PCT except that participants were required to have pain at study entry, prognosis >1 mo, and instruments were administered as separate questionnaires.
Results: Of screened patients, 70% were eligible for the study; 60% of patients and 75% of GPs agreed to participate. Pain and prognosis eligibility criteria limited referrals to the pilot. Educational interventions were successfully executed. Four patients withdrew due to excessive burden related to the questionnaires.
Conclusion: The pilot study demonstrated that the PCT could be undertaken and highlighted areas of the methodology that required amendment such as reduction of patient burden and the order of consent (patient before GP). The recruitment rates and changes in outcome measures informed the sample size calculation for the planned large PCT and allowed accurate estimates of withdrawal and attrition due to death. A pilot study can help refine methodology and identify any potential pitfalls, increasing the chance of successfully completing the trial.

Abstract number: 225
Presentation type: Poster
Session: Methodology

Living and dying with cancer: Sensitive methods for sensitive research

Angela Armstrong-Coster, University of Southampton, Southampton, Great Britain

Dying is a period of life, fraught with complex issues and which can often occasion a depth of feeling impossible to capture and analyse. Not surprisingly then there is a paucity in empirical work which explores the experience of dying from the position of the patient. My PhD research, which subsequently formed the nucleus of my book Living and Dying with Cancer. (Armstrong-Coster, 2004) explored the reality of what it is to live whilst dying of cancer in the present day UK. The ethnographic study (carried out in the South East of England and Northern Ireland) took almost seven years to complete, and aimed to capture first hand reports of the coherent dying experience from multiple viewpoints. The investigation examined the experience of living with cancer from the moment of detection of symptoms and continued, examining the chain events which ultimately peaked in death. This paper aims to examine something of the philosophical underpinnings and practical realities which supported the methods employed in that research. In specific it will focus on the issues and difficulties encountered whilst working on a longitudinal basis in such a sensitive field; Problems, such as finding a sample of individuals who were dying but were also able to contribute actively to the research at what was surely the most vulnerable time of their lives, will be raised. Other issues under discussion will include ethical questions raised during the work as well as the more practical concerns which arose both when working in the field and during writing up, for example, the question of analysing what finally transpired to be an almost overwhelming amount of data.

Abstract number: 226
Presentation type: Poster
Session: Methodology

Conducting a pivotal Phase III clinical trial with terminally ill patients: Advice for nursing

Ann Sturley, **Charles Von gunten**, San Diego Hospice and Palliative Care, San Diego, US, **Frank Galasso**, Progenics Pharmaceuticals, Inc., Tarrytown, US

Clinical research must be conducted in the populations with advanced illness cared for by hospice programs if overall quality of care is to improve. However, the study of new drugs in this population presents logistical challenges that exceed those usually encountered in academic medical centers. Successful conduct of clinical research requires administrative infrastructure and staff roles that are not typically encountered in hospice programs. It is a mistake to think that clinical hospice nurses can incorporate research roles without additional training or time for the task. This session will use information obtained from the sites participating in a recent Phase III trial of methylnaltrexone, of which 15 were nursing homes, 9 were hospices, and 9 were clinics. The major predictors of a site's success in this trial were the staff's prior experience conducting clinical trials, and having an adequate patient population. Many of the sites without previous research experience either withdrew from the study or requested support for a dedicated research coordinator. The contract research organization who supplied the monitors for this study also provided training for research-naïve sites. Because most hospice patients are home-bound, the research team needs to be geared to traveling over the area covered by the hospice. Some hospices chose to recruit patients solely from their most central, easily reached area. The nursing homes and clinics did not have this obstacle. In order to gain the experience necessary for conducting research studies, the hospice management first needs to see the value of research and be willing to invest some of their resources into learning how to begin in this field. Even the best-funded studies run at a cost to the organization. Only with backing at each level in the organization do research ventures have a chance of success.

Abstract number: 227
Presentation type: Poster
Session: Methodology

Persistent involvement by the GP important for late stage cancer patients: "Looking back from date-of-death study"

Birgit Aabom, **Jakob Kragstrup**, **Hindrik Vondeling**, **Leivs Bakketeig**, **Henrik Stovring**, Istitute of Public Health, Odense, Denmark

Objective: To analyse the impact of GP home visits in primary end-of-life cancer care.
Design: Retrospective population-based cohort study
Setting: The island of Funen/Denmark.
Subjects: 2,025 patients with cancer as primary cause of death in the period 1997–98.

Main outcome measures: Main outcome: Hospital death. Intermediate outcome: Explicit diagnosis of terminal disease (Terminal declaration)
Results: Thirty-eight (38%) percent of patients received a formal terminal declaration, fifty-eight (58%) died in hospital. We found a strong association (OR: 16.8 (95% CI: 8.2–34.4)) between a GP home visit and TD in the week preceding a TD. The GP home visits' were inversely associated with hospital death stratifying on TD, in the TD strata: OR: 0.18 (95% CI: 0.11–0.29), in the TD strata OR: 0.08 (95% CI: 0.05–0.13). Finally, we found in both strata an inverse dose-response relationship between GP home visit and our primary outcome: hospital death.
Conclusion: GP home visit in this study was an important factor for a non-hospital death in end-stage cancer even without a formal terminal declaration. Provided that the time dimension is considered, the "looking-back from date-of-death" design can be a suitable and an ethical research method to highlight and monitoring end-of-life cancer care.

Abstract number: 228
Presentation type: Poster
Session: Methodology

Measuring fatigue in palliative care – using the "Multidimensional Fatigue Inventory" (MFI-20)

Carina Lundh hagelin, Karolinska Institutet, Stockholm, Sweden, **Yvonne Wengström**, **Carl johan Fürst**, Dept. of Oncology – Pathology, Stockholm, Sweden

Objectives: Language and cultural differences make it necessary to analyse the internal consistency of any new translation of a questionnaire. It is also important to examine the questionnaire for generality in new groups of patients. Aim in the present study was to examine the dimensional structure of the Swedish version of the MFI-20 and to verify its properties and reliability when being used in palliative cancer patients.
Method: MFI-20 has been used for assessments of fatigue in 229 patients with advanced cancer (palliative), 81 cancer patients during curative radiotherapy, 114 patients attending an outpatient clinic for heart and neurological diseases and a sample of 161 hospital staff, including nurses and nurses' aids. With this data we examined the structure of the dimensions, verified its properties and reliability with a traditional
item analysis method.
Results: Preliminary results showed that palliative cancer patients rated overall highest mean values in all five fatigue-dimensions. Palliative patients reported the highest level of Physical fatigue, all other groups reported highest level of fatigue in General fatigue. The internal consistency, as indicated by Cronbachs alpha ranged from 0.67 to 0.94. The Cronbach alpha reached acceptable levels for all dimension except for Mental fatigue in palliative patients and Reduced motivation in staff.
Conclusion: MFI-20 seemed to be reliable in the new context, although some questions needs further discussions. The scale also display quality aspects of fatigue, which will be further discussed. This work is needed in order to use the MFI-20 in a new group of patients (with advanced cancer) and also in the Swedish cultural context. The results may also contribute to further development of the MFI-20 as a consequence of a deeper understanding of the complexity of fatigue.

Abstract number: 229
Presentation type: Poster
Session: Methodology

Different methods, different findings. Comparing and contrasting research into how patients access community palliative care services

Catherine Walshe, **Ann Caress**, **Carolyn Chew-graham**, **Chris Todd**, The University of Manchester, Manchester, Great Britain

Introduction: Different research strategies have been used to investigate similar topics, producing apparently dissimilar findings. We compare and contrast findings from studies investigating access to community palliative care services (CPCS) which used different approaches.
Quantitative research: Much quantitative work has examined the characteristics of patients accessing CPCS, typically using retrospective record reviews and making comparisons with corresponding data about general palliative care populations. This work reveals inequities: younger, married, higher social class patients, those with carers and diagnosis of a common cancer appear more likely to access care. Such work however struggles to explain why such inequities exist.
Qualitative research: There is little qualitative research investigating referral decisions in CPCS. A current UK study has identified three main areas which appear to affect referrals: the professional's own sense of role (affecting ownership, autonomy, perceived expertise, and job satisfaction); the way professionals interacted (assessing other professionals and they can add to your care); and whether patients chose to receive services. The characteristics of patients appeared less important to professionals in referral decision making.
Conclusions: It appears difficult to reconcile these contrasting findings. Some answers may lie in the consequences of referral decisions and the choices patients make. Complex issues, which may be differentially present in patients, triggered referrals where expertise was lacking. Particular patients may be more able or willing to request or accept care. To address issues of inequity, future policy and research must consider not only service user characteristics, but also the skills, attitudes and beliefs of referring professionals.

Abstract number: 230
Presentation type: Poster
Session: Methodology

Expert Panel Review: Using a consensus method to develop a 'quality of end-of-life care' questionnaire

Catriona R Mayland, **Je Ellershaw**, Marie Curie Palliative Care Institute, Liverpool, Great Britain, **Emi Wiliams**, University of Liverpool, Liverpool, Great Britain, **Jm Addington-hall**, University of Southampton, Southampton, Great Britain

Aim: To develop a 'quality of end-of-life care' questionnaire for bereaved relatives using an expert panel review technique.
Method: An expert panel review was used to gain consensus about which questions to include in the questionnaire. The six-member panel comprised of four healthcare professionals (two clinical nurse specialists, a specialist registrar in palliative medicine and a social worker), a user-representative and a researcher with a background in psychology. Members independently reviewed 121 potential questions based on the Liverpool Care of the Dying Pathway goals, literature on current concepts of a 'good death', and existing questionnaires such as the VOICES questionnaire. Members independently ranked potential questions according to their clarity, sensitivity and appropriateness for use with bereaved relatives and suggested additional questions if appropriate. Responses were collated and summary sheets were circulated. A face-to-face structured panel meeting was held to discuss issues and form consensus regarding the questionnaire's content.
Results: Questions ranked highly included: issues of communication, unnecessary medical interventions, decision making, being treated with respect and dignity, availability of staff, family preparation for patient's death, place of death, and support at the time of death. Modifications were required regarding the symptom control and facilities questions. Disagreements over wording and content were resolved if possible or highlighted for further testing with a pilot group of bereaved relatives.
Conclusion: Expert panel review can form an important part of questionnaire pre-testing, in bringing several different clinical and lay perspectives to the development process. New ideas may be generated and potential problems can be identified and solved earlier, leading to the creation of a more complete draft for testing with the target group.

Abstract number: 231
Presentation type: Poster
Session: Methodology

Using cognitive pre-testing to develop a 'quality of end-of-life care' Questionnaire for use with bereaved relatives

Catriona R Mayland, **Je Ellershaw**, Marie Curie Palliative Care Institute, Liverpool, Great Britain, **Emi Wiliams**, University of Liverpool, Liverpool, Great Britain, **Jm Addington-hall**, University of Southampton, Southampton, Great Britain

Aim: To pre-test a 'quality of end-of-life care' questionnaire for bereaved relatives using cognitive interviewing methods
Method: Cognitive pre-testing interviews are being undertaken with 20 bereaved relatives. Each participant receives the self-completion questionnaire asking about the quality of care their family member received in the last two days of life. In individual face to face interviews, participants are asked about the content and clarity of questions using a 'think aloud' technique. Additionally, participants are being asked about the length of the questionnaire, the sensitivity of the questions, and if other important aspects of care should be included.
Analysis: From interview transcripts, each question is being analysed for: content clarity, sensitivity, ease of information recall and appropriateness of response options. Response patterns are being identified, together with infrequent but important problems with individual questions.
Results: Emerging themes from the interviews about the content of the questionnaire include: the need for more clarity on specific questions e.g. religious and spiritual beliefs; and specific revisions to the questionnaire's lay-out. Although questions are emotive, participants report that they are sensitively worded, easy to understand and answer. Additional themes have arisen about the meaning and context of the interview experience. These include the opportunity for relatives to 'tell their story', to reflect upon and share experiences and to request further information.
Conclusions: Key themes from the interviews are being used to improve the questionnaire, which will seek to compare end-of-life care in a hospice and hospital settings. Cognitive pre-testing forms an important part of the development of questionnaires by identifying potential problems early. In the context of bereavement, the interview may fulfil additional functions for participants.

Abstract number: 232
Presentation type: Poster
Session: Methodology

N-of-1 randomized controlled trials: exploration of its use in pediatric palliative care

Claude Cyr, **Genevieve Legault**, Université de Sherbrooke, Sherbrooke, Canada

Introduction: The Evidence Based Medicine movement has generated attention on the requirement of conducting studies based on established methodological frameworks. Randomized controlled trials (RCT) have not been carried out for most clinical problems in pediatric palliative care. Individual patient trials could inject some methodological rigor into usual clinical decision making. They mimic usual practice in their ability to allow flexibility of dosing, follow-up and individual evaluation of outcome measure. During n-of-1 trials, the unit of randomization is the treatment sequence for an individual, in contrast to classic RCT where the individual is randomized to one group. A treatment cycle includes an exposure to the "new" treatment and the "control" treatment (or placebo).
Objective: We aim to explore the potential of n-of-1 trials in pediatric end-of-life research.
Methods and results: We presented two patient management problems to pediatricians (n =21) caring for children with chronic complex disease. We conducted a semi-structured interview to discuss the potential use of n-of-1 RCT. Nineteen of the 21 physicians would have been interested to use n-of-1 RCT for the child in the vignette. Most of them (20/21) thought of it as useful. Only a few (3/21) respondent felt they had the skills to do an n-of-1 RCT by themselves. The respondents also identified areas of concern: the use of placebo in children, patient safety and the dissonance between the roles of the pediatrician as carer and researcher during emotionally difficult time (for the family and the physicians). They identified potential forces: flexibility in dose and follow-up; the cross-over design allowing children and their family to choose which treatment they prefer.
Conclusion: The n-of-1 RCT research method seems to be possible in pediatric palliative care. This research method offers the possibility of improved clinical care and the appropriate use of medications for individual child.

Abstract number: 233
Presentation type: Poster
Session: Methodology

The power of interdiciplinary collaboration in hospice

Elaine Wittenberg-Lyles, University of Texas, San Antonio, U. States, **Debra Parker oliver**, University of Missouri, Columbia, U. States

Research Aims: To identify collaborative communication among a hospice healthcare team and extend the theoretical framework of interdisciplinary collaboration in a hospice setting.
Methodology: Ethnographic observations of interdisciplinary team (IDT) meetings and the Modified Index of Collaboration (MIIC) were used to identify perceived interdisciplinary collaboration and observed collaborative communication.
Method of analysis: Following a grounded theory approach, the theoretical framework of interdisciplinary collaboration was applied to observation field notes. The unit of analysis was the discussion of a patient's case. Field notes were analyzed through the process of comparison and collaborative communication was coded into one of the four theoretical aspects of collaboration. Participating hospice staff also completed the Modified Index of Interdisciplinary Collaboration. By juxtapositioning observed collaborative communication with team member's perceived collaboration nuances of the theoretical framework and instrument were exposed.
Results: This study supports the proposed theoretical framework for interdisciplinary collaboration among IDT members. Interdisciplinary collaboration among IDT members are sustained through one of four types of collaborative communication. Specifically, this study found that interdisciplinary collaboration also occurs outside of hospice, namely with primary care doctors and nursing home staff. Hospice Case Managers are more active contributors to the collaborative process when compared to their team counterparts. Differences in information sharing in IDT meetings are also noted.
Conclusion: Given the qualitative findings regarding interdisciplinary collaboration, several changes are recommended for the MIIC instrument. It is also noted that future research should explore collaborative communication between hospice interdisciplinary team members and non-hospice staff.

Abstract number: 234
Presentation type: Poster
Session: Methodology

Palliative care for the elderly living in institutional long term care: Methodological reflections on the research process

Elisabeth Reitinger, **Sabine Pleschberger**, IFF Palliative Care and Organizational Ethics, Vienna, Austria

Aim: Implementing Palliative Care in institutional long term care requires basic research on the needs of the elderly as much as their social and organizational context. Research in this field is confronted with several boundaries concerning the fragility of the elderly as much as their social systems and organizations. Revealing these boundaries and challenges is necessary to improve and enhance research in this field. Systems Theory, Grounded Theory, the concept of Palliative Care, needs-management and the concept of dignity serve as theoretical frameworks.
Methods: Metaanalysis of three different types of qualitative research projects in institutions of long term care with the focus on the research process. It should reveal critical factors influencing the adequacy of research methods and processes. We therefore observed different arrangements in data gathering and validation.
Results: Analysis uncovers important boundaries that have to be taken into account to embrace the complexity of the research process in institutions

caring for frail elderly. There are boundaries between individual needs and organizational routines as much as professional boundaries. Furthermore boundaries between the focus on housing and nursing can be observed. Boundaries between long term care institutions and other care services also have an impact. Therefore facing the challenges of research on Palliative Care for the elderly in long term care institutions needs boundary management.
Conclusions: The research process has to be arranged in a way that reflects the needs of the field. Concerning institutions of long term care the challenge then is tuning these needs with the requirements emerging the research questions. Interdisciplinary professional teams demand interdisciplinary research. Looking from an organizational perspective, management has to be taken into account. Arguing within the context of Palliative Care including patient perspectives seems to be vital.

Abstract number: 235
Presentation type: Poster
Session: Methodology

Experience of cognitive interviewing techniques in palliative care research

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Background: In answering questionnaires, research participants use complex cognitive processes. Cognitive interviewing techniques (CIT) are widely used in large surveys, to improve questionnaires by understanding these processes, but their use is less common in other areas of palliative research.
Aim: To identify if CIT can improve refinement of a symptom questionnaire, beyond that achieved in standard piloting.
Sampling frame: The first 10 consecutive patients with chronic kidney disease stage 5, managed without dialysis, in renal outpatients, with capacity to consent.
Method: Patients were cognitively interviewed re completion of a questionnaire comprised of Memorial Symptom Assessment, Geriatric Depression, and Palliative Care Outcomes Scales. 'Think-aloud' and concurrent probing CIT were used. Interviews were recorded and transcribed verbatim.
Analysis: Interviews were analysed using content analysis; content, and themes were attributed to standard piloting or CIT, categorised using Tourangeau's information processing model, and used to refine the questionnaire.
Results: 9 interviews were completed (1 declined). Various questionnaire difficulties were identified-standard piloting identified problems with legibility/format, and word/phrase comprehension, but CIT uncovered more complex difficulties of processing and formulation, and also indicated possible solutions. 'Think-aloud' techniques allowed respondents to determine interview direction and increased range of difficulties identified (e.g. role of self-image, understanding of prognosis, and attitudes towards death, in impeding answer estimation and response formulation). Probing enabled clarification of the nature and consistency of these findings.
Conclusion: Standard piloting identified questionnaire difficulties, but CIT increased the depth and range of understanding of these difficulties, and suggested potential solutions. Wider use of these techniques in palliative research is recommended.

Abstract number: 236
Presentation type: Poster
Session: Methodology

The role of self reported Quality of Life in prediction of survival: A consideration of methodological issues

Gunn Grande, **Chris Todd**, University of Manchester, Manchester, Great Britain, **Morag Farquhar**, Kings College London, London, Great Britain, **Stephen Barclay**, University of Cambridge, Cambridge, Great Britain

Background: Prediction of survival can be an important aid in planning for appropriate patient care. Patients' self reported health related quality of life (HRQoL) is an important predictor alongside clinical variables and clinician estimates. Lack of a consistent approach in past research makes it difficult to assess which HRQoL variables provide best added predictive value, but self reported general well being may be more useful than symptoms and physical function. We will highlight methodological issues surrounding prediction of survival by considering existing literature and examples from a study of survival in palliative cancer patients.
Sample: 46 colorectal and 56 lung cancer patients whose care had switched from curative to palliative as evidenced by hospital discharge summaries and/or outpatient consultation letters.
Method: Patients completed a generic (SF-36) and a cancer specific (EORTC QLQ-C30) HRQoL measure at baseline and were followed up for five years. Deaths were flagged by the UK Office of National Statistics.
Analysis: Univariate and multivariate Cox regression analysis.
Results: Although Appetite Loss for the EORTC QLQ-C30 and Energy/Vitality for the SF-36 emerged as main predictors in the multivariate analysis alongside diagnosis, the high degree of intercorrelation between HRQoL scales made it difficult to reach conclusive results. The clearest and strongest predictor of survival was the composite SF-36 Mental Component Summary scale, designed through factor analysis to be a psychological variable as unrelated to physical components as possible.
Conclusions: High intercorrelations within HRQoL measures and between these measures and clinical variables lead to redundancy of information used to predict survival and inconsistency in findings. To maximize predictive power we need to adopt a more systematic approach to this research area and develop and/or utilise predictor variables that are as independent of each other as possible.

Abstract number: 237
Presentation type: Poster
Session: Methodology

What are the difficulties in recruiting terminally ill cancer patients in primary care

Janneke Goedhart, **BD Onwuteaka-philipsen**, **AJFM Kerkhof**, **G Van der wal**, VUmc, Amsterdam, Netherlands, **CDM Ruijs**, Utrecht, Netherlands

Objective: Recruitment of terminally ill cancer patients has to take place through the general practitioner (GP). Therefore, non response can occur on two moments: the GP can fail to ask patients for cooperation and the patient can refuse to cooperate when asked. Question is how often this occurs, what reasons GPs and patients have for this. Furthermore, it is questioned whether this leads to selective non response.
Method: A convenience sample of 45 GPs in the region of Utrecht was willing to cooperate with a study on unbearable suffering in terminally ill cancer patients in primary care. They were asked to approach patients with incurable cancer, with a life expectancy less than six months, who were competent and with the ability to understand Dutch. Every two months GPs were asked about possible patients that, looking back, should have been included.
Results: Between July 2003 and October 2005, 213 patients were eligible for inclusion. Of these patients 91 (43%) were not asked by the GP. Main reason for this was the deterioration of the patient's condition. Of the 122 patients that were asked, 42 (34%) refused to the GP. Main reasons for this were that the condition of the patient made cooperation too burdensome and that patients did not want to talk about their situation. Of the patients that agreed to cooperate, 14 still had to say no to the interview, mainly because of being too ill for it. No significant differences were found between included and non-included patients for sex (52% and 59% men), age (62% and 61% between 60 and 80 years), having a depression according to the GP (8% and 14%) and having requested for euthanasia in due time (26% and 29%).
Conclusion. Of all eligible patients about only one third was finally included in the study. This was mainly due to the patient's situation not allowing participation anymore. Despite this low response, no signs of selective non response have been found.

Abstract number: 238
Presentation type: Poster
Session: Methodology

Benefits of collaboration in palliative care research even when started after data-collection: pooling of existing datasets

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Collaboration usually commences when developing a research proposal. Collecting data in different sites, institutions, settings, or countries can thus be carefully planned, assuring comparability of the data. In practice, however, similar studies are sometimes carried out simultaneously by different research groups. Nevertheless, pooling collected data after data collection ends can still be rewarding, as we experienced when pooling US and Dutch data from our two prospective studies on treatment (curative and palliative) and outcome of pneumonia in nursing home residents. An obvious benefit of pooling data is increased statistical power for analyses. Further, treatments and end-of-life decisions across different settings can be evaluated for comparable patients. Such cross-cultural comparisons can help identify places where care needs improvement and help understand difficulties in transition from curative to palliative care. Pooling data collected with newly developed instruments can help validate or improve these instruments, which is important for the field to meet standards of high quality research. For prospectively collected data, it may be possible to validate outcome models (e.g., mortality, loss of functional independence) in a different dataset. Finally, increased variability in treatments provided (''natural experiment'') may enhance the ability to detect treatment effects. Although seemingly straightforward, some extra and potentially time-consuming hurdles must be overcome before the efforts can pay off. Before combining data, researchers must consider how to (1) equalize the time of assessment (what is baseline?), (2) match cases (enrolment/selection criteria), and (3) match variables, keeping an eye on possible differences in data quality. Some differences cannot be easily anticipated, e.g., dissimilar interpretations of ''dyspnea'' across cultures. A systematic approach may help, which we will illustrate with pooling existing data from our two studies.

Abstract number: 239
Presentation type: Poster
Session: Methodology

Studying place of death via death certificates. An overview of the Dying Well in Europe Death Certificate Study (DW-DCS) in 7 European countries

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Background: Studying the place of death and the influencing factors is highly relevant for public health policy. Death certificate data provide a unique opportunity in this context, because they make it possible to use large numbers, and therefore provide more statistical power. This study describes the first phase of the DW-DCS study, in which we examined the possibilities and difficulties in obtaining national/regional death certificate data to study the place of death.

Methods: We aimed to collect a database, containing all deaths of one year in the countries participating to the study: BE, DK, IT, NL, NO, SE, UK. Next to the place of death we aimed to include a minimal number of clinical, socio-demographic, residential and health care system factors. All partners of the study negotiated a minimal dataset with their administration of mortality statistics.

Results: Sufficient information about the place of death was available on all databases, except in IT ('home' versus 'other') and SE (certified but not recorded, although 'hospital' vs. 'other' could be deduced from the postcodes of the parish of death). In BE and IT most desired clinical and socio-demographic information was available via the countries' death certificates. In the other countries linkages with other population databases needed to be made. The desired residential and health care system factors were available by linking existing statistics to the municipality of residence of the deceased.

Discussion: Death certificate data provide a unique opportunity to study and monitor the place of death and the associated factors in an international context. However several difficulties arose (e.g. variation between countries in the information on death certificates, and in official rules and procedures to get the data). We suggest modifications of certain aspects of the death certificate registration and the rules of data-protection in order to make an international monitoring of the place of death more feasible.

Abstract number: 240
Presentation type: Poster
Session: Methodology

Information from multiple measurements

Lynn Palmer, **Ying Guo**, M.D. Anderson Cancer Center-Univ. of Texas, Houston, US

The number of times information is collected in a study may be informative in itself. An example is provided based on results of a study of 290 patients on the influence of hyperglycemia and other clinical variables on rehabilitation after neurosurgical procedure in cancer patients. Blood glucose (BG) levels were measured preoperatively, postoperatively, and recorded up to 4 additional times before discharge from the hospital, the number of times depending on the practitioner's preference and patient characteristics. We evaluated BG values by the last available value, by preoperative and postoperative values, and by the number of times BG measurements were made. Our goal was to determine if there was an association between rehabilitation services required (yes or no) and BG values. We also summarize associations of length of stay (LOS) and age. Rehabilitation was significantly and positively associated with the number of BG measurements ($p < 0.003$), but not to the last BG value, preop or postop values ($p = 0.49$, $p = 0.52$, $p = 0.69$). LOS was also significantly and positively correlated with the number of BG measurements ($p < 0.0001$), but not with the last BG value, preop or postop values ($p = 0.46$, $p = 0.86$, $p = 0.99$). LOS was also highly positively associated with rehabilitation ($p < 0.0001$). In contrast, age was significantly correlated with the last BG value, preop, and postop values ($p = 0.03$, $p = 0.04$, 0.008), and associated with rehabilitation ($p = 0.0003$) but was not correlated with the number of BG measurements ($p = 0.52$). Overall the values of BG decreased with an increase in the number of measurements made; however, as stated above the number of BG measurements was more highly associated with rehabilitation than actual BG values. Rehabilitation doctors requesting more BG measurements could in part explain this association. We conclude that it is possible that the number of times information is collected may be of more significance than the actual values collected.

Abstract number: 241
Presentation type: Poster
Session: Methodology

Qualitative analysis of texts sent by relatives of patients to a palliative care unit: A source of information and assessment of palliative care

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Palliative care as a developing speciality needs to show effectiveness and results. In palliative medicine the satisfaction measurement reported through specially designed surveys has been used. Until now it has not been considered that written spontaneous expressions can be an authorized credential. As they are written without previous request and in a completely open context, they can constitute a valid and especially rich source of information about the way of working in palliative care. All the letters (n = 53) sent to the 'Los Montalvos' Palliative Care Unit or published by bereaved relatives were analysed. Two researchers, a palliative care clinician and a nurse, analysed the letters. Only the former was a member of the Unit, which enabled a wide view during the analysis process. A system to analyze the content was developed considering Burnard's (1991) suggestions. The following steps were applied: the letters were thoroughly read to become immersed in the data and read again to write down the headings necessary to describe all aspects of the content; a template was developed to present the analysis by categories and themes; the categories independently identified by the researchers were reviewed jointly to achieve consensus, the results were written including excerpts of the letters to support the findings. The letters provide information about aspects of care for which relatives are particularly grateful. They carry a direct, spontaneous and very original evaluation of the results achieved with palliative care. They allow assessing indirectly, through the analysis of the intensity and quality of the gratitude expressed, the importance of the benefit obtained. They tackle vividly other consequences of the care that are beyond the mere gratitude. The analysis used allowed to identify contents and nuances of the palliative care that the researchers had not even detected in the first reading of the letters.

Abstract number: 242
Presentation type: Poster
Session: Methodology

Systematic review methodology for qualitative studies: Its benefits and challenges

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Background: Systematic review methodology for quantitative studies is well developed but many challenges remain when its principles are applied to qualitative studies in palliative care research.
Aim: To develop systematic review methodology for qualitative studies by applying its principles to the evidence on the experience of breathlessness.
Methods: Relevant literature was identified through four electronic databases and through hand searches. All studies with qualitative enquiry or mixed method designs were included. The methodological quality of studies was assessed with a standard grading scale. Searching of electronic databases required the use of a combination of terms as well as hand searching of several journals The studies were classified according to themes.
Results: Twenty one studies were identified. Tabulating qualitative study data was useful and represented research questions and perspectives in a systematic and comparable way. However, the categories were not always clear-cut and needed qualification due to considerable overlap. The process of making the evidence explicit revealed gaps in the evidence and a possible area for meta-ethnography was identified. Studies did not build on the findings of previous research which led to considerable duplication of findings. A standard tool for the assessment of the studies' quality, which was critically applied, was chosen for pragmatic reasons because of the lack of consensus about what constitutes quality in qualitative research.
Conclusions: The use of systematic review methodology for qualitative studies is possible and worthwhile and its use will lead to its further development. The methodology is useful before embarking on a qualitative study in order to avoid duplication. The systematic review is a powerful vehicle for the communication of users' concerns which complements the statistical results on which policy makers tend to base their decisions.

Abstract number: 243
Presentation type: Poster
Session: Methodology

Betwixt and between: liminality and related ideas as powerful conceptual tools for research in Palliative Care (PC)

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This paper introduces liminality, a term developed by anthropologists to describe a passage from one state to another across a threshold: e.g. seclusion prior to circumcision, or funeral rituals. Related ideas such as boundaries, transitions, and intermediate states are also discussed, and ideas are outlined for new research using these concepts. The term's history, including its use in framing human experience (including health/illness) is delineated. Conceptual domains in which it has been used in the study of dying people and their families are then outlined, including: experiences of those affected by cancer, persistent pain, and bereavement historical development of PC as a discipline. New domains are suggested, including: transition of individuals from mainstream health work to PC, and application of studies of "playful" elements of liminality to investigation of humour in PC. Next, the following related concepts, and their potential application to PC research are explored: Peter Galison's trading zones/ creoles-has PC created a mediating space and "language" between technological medicine and humane caring? ? Michel Foucalt's heterotopias (and the concept of "heterochronia") how does the concept of liminality help to frame the dying person and family's experience of "different place, different time"? ? Folklore's zombies and golems, Jean Baudrillard's simulacra, Donna Haraway's cyborgs, and Victor Turner's liminal monsters-does the use of syringe drivers and other equipment contribute to an experience of being "betwixt and between" human and machine? ? Julia Lawton's body boundedness and dirty dying-do these insights conflict with or complement the idea of liminality? ? Derek Doyle's "platform ticket" does the idea of "perpetual liminality" help inform study of continually delayed yet inevitable dying? Researchers who include liminality in their conceptual repertoire add a powerful tool for understanding their chosen field.

Abstract number: 244
Presentation type: Poster
Session: Methodology

The voice of terminal patients in end-of-life care research: A SWOT-analysis

Reginald Deschepper, **Eva Michiels**, **Jan L Bernheim**, **Luc Deliens**, Vrije Universiteit Brussel, Brussel, Belgium, **Freddy Mortier**, University Ghent, Ghent, Belgium

Background: In end-of-life care, the perspective of the patient is pivotal. Their preferences and opinions should be an important source of information for e.g. health-care policy, guidelines, quality indicators or instruments.
Method: A SWOT-analysis based on literature, comparison of guidelines of ethics committees and personal experiences with interviewing terminal patients.
Results: Strengths: Contrary to curative medicine, where the evidence-based opinion of professionals is decisive, in end-of-life care, the views and preferences of patients are primordial. In most studies so far, the voice of the patient was only a secondary (expert groups) or a tertiary (literature) input. Today, efforts are made to include terminal patients directly by means of interviews or surveys.
Weaknesses: Due to ethical and practical constraints, only a relatively small proportion of terminal patients are able to participate, resulting in possible selection bias. Furthermore, some questions may be too sensitive or confronting to be asked.
Opportunities: Interviewing terminal patients is in line with the shift from 'paternalistic' expert/doctor-centredness to patient-centredness, which calls for more patient-based research. Well-conducted inquiries may actually benefit patients. Threats: To protect vulnerable patients, ethics committees tend to be excessively restrictive. Contrary to e.g. the mass media, which

often exhaustively portray terminal patients without respecting anonymity or privacy, researchers have to heed complex ethical procedures. In practice, patients often perceive the requirement to sign an informed consent as more threatening than the interview itself.
Conclusion: Research in which terminal patients actively participate is necessary, promising and patients can themselves benefit from it. However, there are several practical and ethical obstacles and limitations. Ethical guidelines adapted to this specific kind of non-interventional research may be needed.

Abstract number: 245
Presentation type: Poster
Session: Methodology

Sampling methods in pain and symptom research: Do online and clinic samples differ?

Richard Harding, King's College London, London, Great Britain, **Lorraine Sherr**, Royal Free University College Medical School, London, Great Britain, **Tim Molloy**, GMFA, London, Great Britain

Background: Sample biases in pain and symptom research are common. Behavioural sciences increasingly use web-based recruitment methods, but validity has not been tested in palliative care.
Aim: To test the hypothesis that there will be no difference between web and clinic samples in demographic variables, global, physical and psychological symptom burden.
Methods: 347 gay men with HIV were recruited through an internet-based survey; 427 gay men of a total 627 patients were recruited in 2 clinics with all patients approached. Pain & symptom burden measured using the MSAS-SF. Univariate and multivariate analyses adjusted for age, ARV use and sample source with pain and symptom burden subscales as dependent variables.
Results: Total clinic response rate 92.4%. Web vs clinic samples respectively: mean age 37.4 vs 40.0 ($p = 0.001$); no sig diff on level of education achieved ($p = 0.179$); in paid employment 63.7% vs 58.7% ($p = 0.178$); on antiretroviral therapy (ARV) 57.9% vs 72.2% ($p = 0.001$). Multivariate models: Global Distress Index (GDI), both ARV use ($p = 0.008$, $b = 0.135$) and recruitment from web ($p = 0.035$, $b = 0.079$) associated with increasing score. Being on ARV was associated with increased Physical Distress Index (PHYS), ($p = 0.001$, $b = 0.152$) no association found for sample or age. Psychological Distress Index (PSY), no association found for any variable.
Discussion: This is the first study to explore validity of web-based versus clinic recruitment in pain and symptom research. The regressions showed an association between web recruitment and higher GDI but not with PHYS or PSY symptom burden. Web-based sampling may offer methods that require fewer resources. This method should be validated among other clinic samples of life-limiting incurable disease groupings. Our findings reject the hypothesis that the samples do not differ on demographics or global distress, but find the hypothesis to be true that they do not differ on physical and psychological symptom distress.

Abstract number: 246
Presentation type: Poster
Session: Methodology

The end of care form: An inventive instrument of data recording

Roberta Brugnoli, **Carla Besozzi**, **Carla Malenchini**, **Emanuela Porta**, **Graziana Pozzoni**, VIDAS, Milan, Italy

Introduction: The End of care Form is an instrument conceived and realized in 2000 by a group of palliative care volunteers to detail their home activity. It is filled up by each volunteer as he finishes assisting a patient (for death or service interruption). It is divided into 8 sections, with different topics: a) Patient (health conditions) b) Family (type and frequency of relationship) c) Relationship d) Conversation topics e) Volunteer activity f) Problems remarked g) Opinion on own work h) Free area to write down. It comprises 53 multiple choice questions, objective and subjective answers, plus the free space for notes.
Aim: Validate the form through examination on the performance status analysis, comparing volunteers observations and objective conditions found out by health workers.
Method Sample: 215 forms filled up by volunteers at end of assistance of 150 patients, in the period between 1/6/04 and 31/5/05.
Results: Performance status of the patient verified at first home visit by volunteer and health workers: volunteer health workers. Self-sufficient, the patient can go out 26% 0%. Still self-sufficient ($<50\%$ waking hours in bed) 37% 8%. Passing time in bed ($>50\%$ waking hours in bed) 59% 49%. All the time in bed, apart from seriousness of illness 48% 42%.
Conclusions: Data demonstrate a discrepancy between volunteer and health workers remarks, when Karnosky index is $>60\%$. A deeper data investigation is in phase of analysis. Therefore the End of care Form gives information that suggests how to steer volunteer and workers training along the way, acting on specific topics.

Abstract number: 247
Presentation type: Poster
Session: Methodology

Working through the MRC framework for research in complex interventions: A cluster randomised trial involving dying patients

Andrew Fowell, **Ros Johnstone**, North West Wales NHS Trust, Caernarfon, Great Britain, **Ilora Finlay**, University of Wales Cardiff, Cardiff, Great Britain

The Medical Research Council (MRC) guidelines (2000) for research in complex interventions advocates a five stage approach; theory, modelling, exploratory trial, definitive trial and long-term implementation. This paper reports on the process of working through the guidelines, ultimately running a cluster randomised trial involving dying patients and powered to give definitive answers. Integrated Care Pathway audit data from over 3000 patient deaths indicated that despite using guidelines dying patients had significant symptom burdens. Although guidelines for the management of dying patients exist the underpinning evidence is poor, there was a clear need for research involving this patient group. Problems with existing research methods concern issues surrounding consent, ethics, attrition and vulnerability of patients. This stage represents the 'Pre-Clinical' and Phase 1 of the MRC model. Phase 2 of the MRC model comprised of a literature review identifying two potential research designs, Cluster Randomisation and Zelen. Phase 2 subsequently involved a six-month feasibility study utilising a crossover design, 3 months cluster randomisation and 3 months Zelen and vice versa over 2 palliative care sites, one oncology ward and one Macmillan unit within the North West Wales NHS Trust. Outcomes of the feasibility study indicated that Cluster Randomisation was more favourable for studies involving dying patients. Therefore, phase 3 of the MRC model will be a large scale Cluster Randomised trial looking at Hyoscine Hydrobromide versus Glycopyronium for the management of excess respiratory secretions in the dying patient followed by, dissemination and implementation of the results.

Abstract number: 248
Presentation type: Poster
Session: Methodology

Serial in-depth multi-perspective interviews: A methodological approach to enhanced understanding of the evolving needs of palliative care patients and their carers

Scott Murray, **Marilyn Kendall**, **Kirsty Boyd**, **Liz Grant**, **Aziz Sheikh**, University of Edinburgh, Edinburgh, Great Britain

Background: People with advanced progressive disease have diverse needs which change over time. Qualitative research can yield an in-depth understanding of patients' and carers' experiences and needs, but most such studies have been cross-sectional. Qualitative longitudinal research may

offer advantages in understanding the patient's and carer's dynamic experience of illness and of services.
Aims: To critically reflect on the strengths and limitations of using this methodological approach to studying end of life care needs.
Methods: We searched various medical and social science databases concerning the current usage of this technique, and also our own library of papers. We gained international perspectives of the utility of this approach in comparison with other end-of-life research designs by drawing on interviews with international experts in end-of-life research. We also examined primary data from two studies in which we have used serial in-depth interviews with patients and their informal and professional carers
Results: There is an increasing interest in this method as it more closely captures lived, dynamic experiences than a snapshot approach to data generation. Current under-usage of this approach reflects lack of awareness and specific concerns. Barriers to wider use are concerns about ethics approval, particularly in relation to vulnerable groups; staff gate-keeping; sampling approaches; maintaining consent; timing of re-interviews, patient fatigue; attrition; costs; and analytical techniques. Serial in-depth multi-perspective qualitative interviews (with patient, informal and professional carers) can provide a rich understanding of experiences and evolving needs.
Conclusions: This methodologically powerful technique is currently under-utilised, but offers considerable advantages over snapshot qualitative approaches. A lack of awareness of and concerns about methodological and planning considerations currently limits use of this study design.

Abstract number: 249
Presentation type: Poster
Session: Methodology

Participatory research in palliative care: Two examples in the field of paediatrics

Suzanne Mongeau, **Manon Champagne**, Université du Québec à Montréal (UQAM), Montréal, Canada

Participatory research can be defined as "a process of sequential reflection and action, carried out with and by local people rather than on them [and in which] local knowledge and perspectives are not only acknowledged but form the basis for research and planning." (1: 1667) It is increasingly used in health research, especially in needs assessment and in program development and evaluation. Very few participatory research projects, however, have been conducted in the area of palliative care. Individuals receiving end-of-life care are evidently not expected to get involved in participatory research. We believe, though, that family members, volunteers and professionals accompanying the dying can benefit from participating in this type of research. Among other benefits, it can offer them the opportunity to voice their concerns, and a sense of satisfaction at contributing to the improvement of palliative care. From a researcher point of view, a participatory process can augment the social relevancy and impact of the research. The objectives of this presentation are 1) to briefly describe what participatory research is, 2) to highlight the congruence between the principles linked to this type of research and the ones related to palliative care, and 3) to propose a reflection about the relevancy of using this type of research in palliative care. This reflection will be elaborated through the analysis of two evaluative participatory research projects realized in the area of paediatric palliative care. In order to do so, the objectives and methodology of the research projects will be described, as well as the strategies used to ensure the participatory goal process. The benefits and challenges associated with these projects will be identified. Recommendations for researchers interested in using participatory research in palliative care will conclude the presentation.

Reference

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Abstract number: 250
Presentation type: Poster
Session: Methodology

Suffering and the terminally ill: Confronting patient and caregiver perspectives

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Background: Taking care of patients 'suffering is central to all healthcare providers' interventions, be they from the palliative environment or involved much sooner. Whether both parties perceive suffering in the same way remains unknown. The objective of the present study is to compare patients' and healthcare providers' perceptions of suffering.
Sampling frame-Setting: general and teaching hospitals.-Subjects: Patients (26): 10 men and 16 women, aged 33 to 91, having received a diagnosis of terminal cancer from varied sites. Healthcare providers (93): 43 physicians, 34 nurses, 12 non professional workers, 4 social workers, all involved in full or part-time care with terminally ill patients.
Methodology: Qualitative study using in-depth interviews transcribed for content and conceptual analysis, and focus groups for validation of emerging theory. Coding, comparative analysis and interpretation of data were conducted by several coinvestigators.
Results: Patients and healthcare providers agree on the sources and various dimensions of suffering, though the latter tend to underestimate the shock of initial diagnosis and relapses or the overwhelming aspects of illness. For patients, the suffering caused by healthcare services is equal, if not superior, to the suffering brought on by illness proper. Among healthcare providers, some are aware that interventions are liable to increase suffering, which leaves them feeling frustrated and alienated; others by contrast seem rather oblivious of the harmful impact of some interventions and are therefore more likely to inflict such additional suffering.
Conclusions: In spite of some common ground regarding perceptions of suffering, at times patients and healthcare providers are universes apart on this crucial issue. Acknowledgement of the healthcare environment's influence on the capacity to heal is a first step in implementing the necessary changes towards better care for all terminally ill patients.

Abstract number: 251
Presentation type: Poster
Session: Methodology

A coordinated effort for recruitment and consent to palliative care research

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Background: Recruitment problems make large randomised controlled trials in palliative care difficult. Ethical constraints due to the underlying assumption of the vulnerability of the population, gate-keeping by clinical staff and families, and difficulties in obtaining true informed consent due to the severity of illness all diminish enrolments. In addition, expected patient attrition means the sample size must be increased to ensure adequate power. We have developed a range of strategies to address these concerns.
Setting: A regional community based palliative care service in South Australia, with >1100 referrals yearly, the majority of whom have cancer.
Methods: A focused recruitment plan is developed for each trial. Strategies include: Recruitment nurses with ethics training sensitive to the special needs and risks of burden for palliative patients; A triage process ensuring all eligible patients were screened at referral; Extensive scripting and role-play for both clinical and research staff in introducing the study, recruitment, consent and completion phases; Patient consent prior to development of the condition of interest (for studies in the terminal phase of a life-limiting illness) – Ongoing discussions with clinical staff to reduce gate-keeping, including feedback of positive and negative research findings; Monitoring of Key Performance Indicators; and, Establishment of a Research Committee to monitor all research, it's burden on patients and staff, and interface with the Institutional Ethics Committee.

Results: 2 trials have been successfully completed at this single site (n =461 and n =48), and this site actively participates in >5 other active randomised studies.
Conclusion: We have found patients welcome the opportunity to participate in research despite the potential for no direct benefit. Vulnerability has not hindered recruitment to high quality research and should not be used a reason for exclusion from research.

Abstract number: 252
Presentation type: Poster
Session: Methodology

Hair analysis in cancer patients: A method to analyse opioid pre-treatment

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Lack of patients' compliance is a general problem in therapeutic medicine. Patients submitted to the palliative care units often report earlier medication of 2–4 opioids. To verify opioid pre-treatment hair analysis was performed and results compared to patients' medical history.
Methods: After approval of the local Ethics Committee and patients' informed consent, liquid chromatography coupled with tandem mass spectrometry (LCMS-MS) was introduced to determine opioid concentrations in hair samples of 31 patients suffering from cancer pain. The LC/MS-MS procedure was validated for the simultaneous determination of tilidine, buprenorphine, oxycodone, fentanyl, hydromorphone, morphine, methadone, tramadol and their metabolites.
Results: The method was sensitive with detection limits between 0.8 and 17.4 pg/mg hair matrix and precision ranged between 3.1 and 14.9% by the use of an internal standard technique. The collective, consisted of 15 men and 16 women aged 39 to 84 years (mean 58.7), receiving opioids for the treatment of cancer pain. Fentanyl was detected in a concentration up to 292.4 pg/mg, tramadol in a concentration up to 612.0 pg/mg. Of the opioids stated in the case histories, 67.7% were detected. Intake of 21 (32.3%) further opioids could not be verified by the hair samples, since time of exposure was too short or hair samples were not long enough. Furthermore, in 23 hair samples, 31 additional opioids (mainly tramadol, tilidine and methadone) were detected which had not been recorded by the patient before.
Conclusions: Hair analysis proved to be a non invasive, complementary and useful tool in monitoring opioid pre-treatment. The analysis allows cumulative reflection of long-term opioid medication. Repeated opioid switches are frequent in this population and might be due to adverse events and/or changing physicians' prescription patterns of opioids.

Abstract number: 253
Presentation type: Poster
Session: Methodology

Palliative care (PC) literature as the basis and object of study: A proposed research framework

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Introduction: PC workers are used to thinking of the literature of their field (or more broadly, its knowledge system) as a major *product* of PC research. This presentation, rather than providing empirical data, presents a complementary framework for research which is *based on* the PC knowledge system, and/or *oriented towards* that system. Others are invited to critically discuss this framework, and to contribute towards research within it.
Outline: PC research may be considered to face towards two different "worlds":

- the *existential* world: that of patients, families, societies, informal and formal carers, health systems, life, death and grieving
- the *literature* world: that of journals, books, and conferences.
  Any research effort has both a *basis*: the world in which study is undertaken, and an *orientation*: the world of which understanding is sought.

Much existing PC research is both based in and oriented towards the existential world. Three areas in which the world of the PC knowledge system may provide the basis for research, and/or its orientation are given below, along with examples:

1. Literature-based, existentially-oriented study: literature reviews and meta-analyses.
2. Existentially-based, literature-oriented study: ethnographic research into PC workers' use of knowledge resources.
3. Literature-based, literature-oriented study: empirical studies to:
   a) delineate the *sphere* of PC knowledge
   b) analyse the *system* in which such knowledge is produced, disseminated, and evaluated, and used
   c) identify the *structure* of that knowledge

Studies in area 1 would be assisted by a better understanding of areas 2 and 3, (those of literature-oriented study), which have not received as much attention in PC as they have in other areas of health work.
Conclusion: It is hoped that by providing this framework, others will be stimulated to collaboratively contribute to a better understanding of the ways that PC research can be translated into practice, and the development of tools to do so.

Abstract number: 254
Presentation type: Poster
Session: Methodology

Visual analogue scales for symptom assessment in palliative medicine: A systematic review of validated instruments

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Background: Routine assessment of symptoms and quality of life is important in palliative medicine clinical practice and research. Assessment instruments need to be brief and easy to understand, due to the high prevalence of fatigue and debility. Visual analogue scales (VAS) are sensitive and quick to complete thus potentially useful for recording subjective information in palliative medicine.
Objective: Perform a systematic review of medical literature to identify validated VAS instruments for assessment of symptoms and quality of life in palliative medicine.
Methods: A systematic review of Medline, CINAHL and Psych Info, as well as hand search of reference lists and review articles. Keywords were: (linear analog: .mp or visual analog: .mp) and Neoplasm in Medline and PsycINFO. In CINAHL search strategy combined (Cancer Pain or Cancer Patients) and (pain measurement or symptoms) and (Visual Analogue Scaling or visual analog: .mp or linear analog: .mp) Instrument assessment criteria were: sample size and population, instrument design, validity, reliability, completion rate and time.
Results: 34 validated VAS instruments were identified. These assessed: multiple symptoms (n =2), pain (n =5), quality of life (n =17), depression and emotional distress (n =5), fatigue (n =4), and appetite and food intake (n =1). VAS modifications were also reviewed. Design and applicability of VAS instruments in palliative medicine will be described. Recommendations for the most appropriate VAS instruments for use in palliative medicine will be made.
Conclusions: We conclude: 1. VAS are validated for assessment of pain, symptoms, emotional distress and QOL in palliative medicine, 2. limitations of VAS include poor completion rates. Further research is needed to: 1. standardize techniques for improving completion rates, 2. compare VAS designs for the same symptom, 3. establish

cutoff scores and clinically significant change for VAS in palliative medicine.

Abstract number: 255
Presentation type: Poster
Session: Pain

Pain, depression and fatigue in advanced cancer: A symptom cluster?

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Background: Pain, depression and fatigue are said to cluster in advanced cancer. Direct evidence to support this hypothesis is lacking.
Objectives: To investigate the frequency of co-occurrence of pain, depression and fatigue, and the strengths of associations between these symptoms in advanced cancer. To investigate the factors associated with experiencing pain, depression and fatigue.
Methods: Analysis of a database of symptoms experienced by 1000 patients on referral to a palliative medicine program between 1988 and 1992. Associations between pain, depression and fatigue were tested using the chi-square test and Pearson correlations. Demographic and disease variables, other symptoms, symptom burden, laboratory tests and survival were compared between patients with 0, 1, 2 or all 3 of the symptoms. Multivariate logistic regression analysis was performed to determine factors associated with experiencing all three.
Results: 27% of patients reported pain, depression and fatigue. Only depression and fatigue were significantly associated ($p<0.001$), but the correlation coefficient was low ($r=0.173$). Factors associated with experiencing all three symptoms were: the anorexia-cachexia syndrome, anxiety, confusion, dyspnea, lower creatinine, sleep problems, symptom burden and younger age. Experiencing pain, depression and fatigue together was not associated with adverse performance status or shorter survival. Significant factors on multivariate analysis for experiencing all three symptoms together were anxiety, early satiety sleep problems, and weakness.
Conclusions: Pain, depression and fatigue co-occur in about 1 in 4 palliative medicine patients. Risk factors are the anorexia-cachexia syndrome, total symptom burden, and younger age (but not worse performance status). Those with anorexia-cachexia or high symptom burden should be screened for depression and fatigue. Intensive symptom management may influence the association of pain, depression and fatigue.

Abstract number: 256
Presentation type: Poster
Session: Pain

Symptom clusters and pain in advanced lung cancer

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Purpose: Advanced cancer is associated with a median of 13 symptoms per patient. Symptoms are usually chronic, moderate to severe, and influenced by age and gender. Certain symptoms, anorexia and dyspnea, are prognostic. Symptoms occur in clusters, i.e., non-random associations. We report symptom clusters and pain in advanced lung cancer from a 1,000 patient dataset, 235 had lung cancer.
Methods: 235 lung cancer patients completed a 38-symptom checklist at initial consultation. A cluster analysis was performed on 25 symptoms with $>15\%$ prevalence. An agglomerative hierarchical method was used and linkage was selected, which used the absolute value of the correlation between symptoms as a measure of similarity. A correlation >0.70 was used to define clusters. Pain was graded as none, mild, moderate, severe.
Results: Seven symptom clusters were found. They were: 1) Anorexia Cachexia (anorexia, early satiety) ($R=0.94$); 2) Upper GI (bloating and belching) ($R=0.91$); 3) Aerodigestive (hoarseness and dysphagia) ($R=0.89$); 4) Debility cluster (easy fatigue, lack of energy, weakness, xerostomia) ($R=0.83$); 5) Pulmonary (cough and dyspnea) ($R=0.80$); 6) Dizziness/Dyspepsia cluster ($R=0.77$); 7) Neuropsychiatric (depression, anxiety and sleep problems) ($R=0.73$). Nausea and vomiting (nausea, vomiting, and taste changes) were just below correlation cutoff ($R=0.69$). Pain did not cluster with anxiety or depression nor fatigue with depression. Pain was associated with constipation ($R=0.66$). A close association but not a cluster occurred between anorexia and weight loss ($R=0.62$), bloating and belching, dizziness, and dyspepsia (0.62). Pain was severe in 82 (35%), moderate in 65 (28%), mild in 36 (15%).
Discussion: Moderate to severe pain occurred in 63%. Seven clusters were identified in patients referred to a palliative medicine service.
Conclusions: Seven symptom clusters occur in lung cancer. 2/3 of individuals with lung cancer will have moderate to severe pain.

Abstract number: 257
Presentation type: Poster
Session: Pain

The use of transdermal buprenorphine (Transtec®) for the treatment of cancer pain in clinical practice

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Background: Chronic pain is a common condition requiring a long term treatment with analgesics. The transdermal patch TRANSTEC® meets the demands of the WHO for treating chronic pain. The patch releases a constant dose of Buprenorphine, a semi-synthetic opioid with high affinity for the µ-receptor. The aim of this study was to document the use of TRANSTEC® for chronic pain in daily practice.
Methods: This subanalysis of a non-interventional study took place between October 2002 and December 2003. 10.810 patients were followed over 6 weeks, of which 1339 cancer patients.
Results: Mean age was 68 years (14 to 101) and 56% were females. 78% of the patients already received a chronic pain treatment but in 81% this was unsatisfactory. Previous treatment was mostly tramadol (31%), paracetamol (21%) or paracetamol/codeine (16%). The majority of the patients started with TRANSTEC® 35 µg/h (75%). After 6 weeks the mean dosage was 49 g/h. Mean pain intensity decreased from 6,7 to 2,6 ($p<0,0001$). 88% of the patients reported "Better" to "Much better" pain relief. 91% judged tolerability "Good" to "Very good" and 91% were "Satisfied" to "Very satisfied" with user-friendliness and comfort of the patch.
Discussion: Switching to TRANSTEC® in the earlier stages of cancer pain treatment went without problems and allowed a marked reduction in the pain intensity score. The relatively low doses used to obtain this satisfactory result reflect the high potency of transdermal buprenorphine.
Conclusion: TRANSTEC® is effective in obtaining a good pain control in patients with moderate to severe cancer pain. The mean pain intensity score decreased significantly from 6,7 to 2,6 after 6 weeks of treatment and 88% of the patients judged the pain relief as "Better" to "Much better". Tolerability of TRANSTEC® was considered "Good" to "Very good" in 91% of the patients.

Abstract number: 258
Presentation type: Poster
Session: Pain

Activation of naloxone-sensitive and-insensitive inhibitory systems in humans

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Aim of the study: Endogenous inhibitory systems are of major importance for clinical pain conditions, particularly in the development of chronic pain syndromes. However, there is no reliable clinical sign or symptom that indicates activation or depression of inhibitory antinociceptive systems. Aim of the study was to characterize the impact of the endogenous opioid system on the modulation of pain. We therefore investigated naloxone effects in a

human model of electrically induced pain and hyperalgesia, which is proven to mimic some aspects of chronic pain.
Methods: In a double blind, placebo controlled, cross-over study, fifteen volunteers underwent four 150 minute sessions of high current density electrical stimulation of their forearms. After 60 minutes, naloxone or placebo was given i.v. (increasing plasma concentrations of 0.1, 1 and 10 ng/ml) in three of the four sessions. Pain ratings and areas of mechanical hyperalgesia were assessed at regular intervals during all sessions.
Results: Intrasession effects: pain ratings and areas of hyperalgesia significantly decreased during the sessions to 62% (pain rating), 70% (area of punctuate hyperalgesia) and 82% (area of allodynia) of the initial values. Naloxone (10 ng/ml) reversed these decreases. Between session effects: time course of pain ratings remained constant from session to session. In contrast, the areas of punctate hyperalgesia successively decreased to 60% of initial value at the fourth repetition. The session effect was not reversed by naloxone.
Conclusions: High current density electrical stimulation provokes central sensitization, but in addition inhibitory systems are activated which are only partly naloxone-sensitive. We could show the activation of a naloxone-sensitive short-term and a naloxone-insensitive long-term inhibitory system. Further research is necessary to give a more detailed characterization especially of the long-term inhibitory systems and their relevance for clinical pain states.

Abstract number: 259
Presentation type: Poster
Session: Pain

Coping mechanisms with chronic pain

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Purpose of the study: This study is aiming to explore how do cancer and non cancer patients cope with chronic pain. Psychological strategies used to manage with pain and following difficulties are subject of the research analysis. Meaining of pain in patients subjective perpception was analysied independently.
Research group and methodology: Research group consisted with 50 cancer and non cancer patients (63 women, 37 man, 71 persons lived together with partner, age 20–71 years). In therm to explore coping mechanism, with chronic pain and subjective meaning of it there were used following research tools: Beliefs about Coping Strategies Questionnaire-BPCQ) Pain Coping Strategies Questionnaire-CSQ) Pain Cognitive Assessment Questionnaire Research method were used to measure cognitive, behavioral and so called adaptive and non adaptive strategies. Locus of control in coping with pain context, perception of meaning of pain experience in both groups was explored.
Results: It was found that womens in both groups tend to use pray as a coping with pain mechanism. This do not depend on charakter of the disease. Psychological and demographic factors determined coping strategy selectively. Educational level, age and place of living were important factors correlated with coping strategies. Complete results of the statistical analysis will be presented.
Conclusions: Results show that demographic factors like tender, age, educational level, living condition are factors determining ways of coping in both research groups. In therm of improve care of the patients it is with to consider already existed psychological resources.

Abstract number: 260
Presentation type: Poster
Session: Pain

Can morpine topically applied stimulate the wound healing?

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Opioid receptors located on peripheral sensory nerve are responsible for local analgesic effect of exogenous opioid agonists applied on the inflamed skin and may play a part in modulating the inflammatory process. It is investigated in few medical laboratories to try to find proper forms of preparations for transdermal application of opioids on painful skin and mucosal ulcerations. For the last 4 years, our clinical centre has carried out the research of locally administered preparations containing morphine in the treatment of painful malignant skin. The aim of the research is to evaluate the effectiveness of morphine topically applied in non-malignant skin ulcers.
Materials and methods: The preparations containing morphine were produced at the Department of Applied Pharmacy of the Medical University of Lodz: hydrogels and ointments – 0,2% morphine sulphate. The study comprised 7 patients with non malignant cutaneous ulcers (5 women and 2 men, aged 55–87 years). The morphine was applied twice daily. Preparations are well-tolerated. No side effects observed.
Results: Wound healing and analgesic effect was observed. All patients did not need the special medical support treatment.
Conclusions: Locally administered preparations containing morphine produce significant analgesia and wound healing.

Abstract number: 261
Presentation type: Poster
Session: Pain

An observational study of oncology patients' understanding and utilisation of "breakthrough" medication

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Background: Numerous studies have looked at patient-related factors resulting in poor control of background pain, but there is little data on the patient-related factors leading to poor control of breakthrough pain. The aim of the study is to try to identify such factors.
Methods: The study is a prospective, observational trial. Oncology patients receiving opioids for moderate to severe pain are being asked to complete a questionnaire about breakthrough pain, and in particular their usage of breakthrough medication. The questionnaire has been designed to look at patients understanding of their breakthrough medication, and the factors relating to the utilisation of this breakthrough medication (i.e. factors that make them take their breakthrough medication; factors that make them not take their breakthrough medication).
Results: The study is ongoing. The sample size is 120, and it is anticipated that the study (based on current recruitment levels) will be completed by the middle of December 2005.
Discussion: Anecdotal evidence suggests that patients do not take breakthrough medication as often as they experience breakthrough pain. It is unclear whether this relates to lack of education about the breakthrough medication/breakthrough pain, or to patients unwillingness to use breakthrough medication per se. It is hoped that this study will lead to patient sensitive strategies for improving the management of breakthrough pain.

Abstract number: 262
Presentation type: Poster
Session: Pain

A pilot study investigating the effectiveness of electrophonophoresis in the multimodal treatment of malignant and nonmalignant chronic cancer pain

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In part of the patients with chronic pains the use of non-invasive methods of pain relief plays an important role in the multimodal approach. The effects of applying electrophonophoresis with the use of NSAID's, opioid, and local anesthetic agents were studied. We decided to administer this method to patients with chronic pains located at relatively small and difficult to control areas with systemic or topical farmacotherapy. The aim of the research was to assess the results of electrophonophoresis application alone and with the use diclofenac, ligoncaine, and morphine in the treatment of chronic pains. The research was conducted on a group of 12 patients classified with the chronic and difficult to control pain criteria. Five patients had cancer pains and 7 patients had the nonmalignat ones. The electrophonophoresis was applied using the Sonoter device with the 2.5 cm^2 head and the power of 1 MHz with a dispenser for the medicine in a gel form. All the patients with moderate and severe pains started the treatment with electrophonophoresis alone. For patients with neuropathic pains, who had not responded to this treatment, we used electrophonophorsis with 2% gel with lignocaine. For those with inflammatory pains, 10% gel with diclofenac was applied. If the patients at this stage of treatment, did not feel satisfactory pain relief after 3 days, we continued the pilot by administering 0.5% morphine gel. All patients' pain intensity was recorded before and after the electrophonophoresis procedure. The mild improvement (severe pains converted into moderate ones and moderate pains converted into mild ones) was found in the group of 3 patients with cancer pains and 6 patients with non-cancer pains. In 3 out of 12 patients, the pain remained unchanged at the both stages of the electrophonophoresis therapy. The small group of patients treated with electrophonophoresis with the use of medicines does not allow us to formulate general conclusions.

Abstract number: 263
Presentation type: Poster
Session: Pain

Pain and disability in elderly: An observational study

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The multidimensional impact of chronic pain, optimal pain management requires appropiate assessment to identify the causes, to determine the intensity of pain and its impact on the patient's function and appropiate therapy (pharmacological and non pharmacological management).

Methods: We studied 70 patients (mean age 78 years; M/F 12/58) in a Rehabilitation Unit in Milan (Italy), from 1/8/2005 to 30/9/2005. For each patient, on admission and on dismission, we assessed the type of pain, the intensity with visive analogical scale (VAS), prevalence of depression and disability scale (Barthel Index).

Results: A total of 70 patients were enrolled: 16 patients (group A) affected by neuropathic pain and 54 patients (group B) affected by nociceptive pain. In group A mean age was 79 years, M/F was 6/10, prevalence of depression was 12.5% (2/16), 0/16 patients (0%) were treated only by pharmacological therapy, 6/16 patients (37.5%) were treated only by physical therapy, 10/16 patients (62.5%) were treated by physical therapy associated with drugs, delta Barthel admission-dismission was 6.75, delta VAS admission-dismission 3.63. In group B mean age was 77.2 years, M/F was 6/48, prevalence of depression was 20.37% (11/54), 2/54 patients (3.7%) were treated only by pharmacological therapy, 19/54 patients (35.18%) were treated only by physical therapy, 33/54 patients (61.11%) were treated by physical therapy associated with drugs, delta Barthel admission-dismission was 12.13, delta VAS admission-dismission was 2.92.

Conclusions: We found positive effects in both groups: reduction of intensity of pain and disability. Alleviating pain and improving function and quality of life are both the outcome of rehabilitation program.

Abstract number: 264
Presentation type: Poster
Session: Pain

Patient-controlled analgesia for outpatients with cancer: Morphine consumption during the last week of life

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Introduction: Studies on opioid use in terminally ill cancer patients have shown a prefinal dose increase in the majority of patients (Sykes 2003). Mostly oral opioids were used. Due to the pharmacokinetic pecularities of opioids it is rather difficult to get from those results a reliable estimate of the true opioid need.

Methods: Retrospectively we analysed opioid use during the last week of life of 30 consecutive outpatients with cancer on intravenous morphine patient-controlled analgesia (PCA; background infusion rate and patient controlled bolus). A dose increase (decrease) was defined as an increase (decrease) of the patient's individual daily dose by at least 30% with respect to their prior daily dose.

Results: Thirty patients fulfilled the primary study inclusion criteria. Fulfilling the exclusion criteria, 7 patients had to be excluded from analysis (n = 3, on PCA for less than 7 days; n = 4, PCA was finished before death). Twenty-three patients with a total of 161 treatment days were analysed. The patients' median age was 57 Ys (range, 4 to 72). The median daily intravenous morphine dose during the last week of life was 96 to 115 mg, without significant change (Friedman test). The daily median number of positive bolus requests was between 1 and 5. The corresponding median number of negative bolus requests was 0. During the last day of life, not necessarily comprising 24 hours, there were significantly less positive bolus requests than on the previous day ($p = 0.006$, Wilcoxon test). On 144/161 days (89.2%), morphine dose remained stable. On 9 treatment days (5.6%) the dose increased and on 8 days (5.0%) it decreased.

Conclusion: During their end-of-life phase, cancer patients on iv morphine PCA showed a stable daily opioid need.

Reference

1. Sykes, N et al. Lancet Oncol. 2003 May; 4(5):312–8. Supported by Bayerische Forschungsstiftung.

Abstract number: 265
Presentation type: Poster
Session: Pain

Subcutaneous fentanyl in severely ill patients with renal failure

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Introduction: Fentanyl should be an attractive analgesic in case of renal failure due to its pharmacological properties but data are scarce. The aim of our retrospective study is to collect quantitative/qualitative parameters on the use of subcutaneous fentanyl (SCF) in severely ill patients with renal failure.

Method: Patients followed in our tertiary hospital by our palliative care consultant team from June 2004 to June 2005, with renal failure (calculated GFR <60 ml/min according Cockroft-Gault) and treated by SCF were selected. Data on demographic parameters, diagnoses, renal function, pain, indications, dosage, duration, analgesic and side effects of SCF were obtained.

Results: 53/504 patients (10%) met our criteria. Median age was 79 years (range 46–100); 33 patients (62%) had cancer and 42 (79%) died in hospital. Renal insufficiency was chronic in 37 (70%), acute in 10 (19%) and end-stage in 6 (11%); among these, 4 underwent dialysis. Median GFR was 25 ml/min (4–59). Eighteen (34%) were opioid-naive. Among the 35 patients on opioids, daily median dose (oral morphine equivalent) was 30 mg (10–240). SCF was administered as analgesic in 49 patients (92%) and due to an opioid-related ne urotoxicity suspicion in 26 (49%). The daily initial median dosage was 360 mg (range 60–3600) and the final 720 mg (144–6720). Median treatment duration was 7 days (1–68). Pain control was complete in 31 patients (59%), partial in 14 (26%) (due to too slow titration or ulterior resurgence of pain), not achieved in 1 (2%) and not evaluable in 7 (13%), who died less than 24 h after the introduction of SCF. In the 26 patients presenting with an opioid-related neurotoxicity suspicion, 8 (31%) achieved complete resolution of symptoms and 6 (26%) partial

one. Side effects were painful injection in 3 patients and myoclonia in three.
Conclusion: SCF may be a safe and efficient analgesic in patients with moderate to severe renal dysfunction. Prospective studies are warranted.

Abstract number: 266
Presentation type: Poster
Session: Pain

Incident cancer pain on movement and analgesic consumption decrease after an infusion of Samarium Sm-153 Lexidronam. A pilot study

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Incident pain or movement-related pain is considered a subtype and a more frequent cause of Breakthrough Pain (BP), it is frequently of somatic origin and frequently caused by bone metastases. Pain may be absent or moderate at rest but may be exacerbated by different movements or positions, such as standing, walking, sitting, turning, lifting, deep breathing or crouching. The aim of this pilot study was to observe, in respect to baseline, the variations of pain intensity during movement and and at rest, as well as consumption in analgesic use in patients with prostate cancer and bone metastases four weeks after the treatment with a single dose of 1.0 mCi/Kg of Samarium 153. Ten patients (mean age 64, range 54–77 years) with hormone refractory prostate cancer, painful multiple bone metastases and a positive bone scan, cared for at the Palliative Care out-patient clinic of the NCI of Milan were investigated. All the patients were treated with a single infusion of 1.0 mCi/Kg of Samarium 153, Main outcome measures were: variation of pain intensity during movement and at rest by means of a 6-levels verbal scale and the reduction of analgesic consumption before and 4 weeks after Samarium 153 infusion, and the therapy-related bone marrow toxicity (weekly for 4 weeks). Among the patients in pain, 50% of patients reported a reduction of at least 2 levels of pain intensity during movement, 20% who were not in pain at baseline continued to be free of pain 4 weeks after Sm infusion. Furthermore, 50% of patients with pain at rest had a reduction in pain score in respect to baseline. All 7 patients who were given analgesics reduced them around the clock or as rescue medications. Bone marrow toxicity was mild and readily reversible in 3 patients. Conclusions: In patients with painful bone metastases due to prostate cancer, the infusion of a single dose of 1.0 mCi/Kg of Samarium 153 may be considered an effective and safe treatment both for pain when at rest and during movement.

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Presentation type: Poster
Session: Pain

Clinical evaluation of the pain and mood questionnaire (PMQ) in a day therapy unit in a palliative support centre

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Aims: Patients' pain may include psychological elements as well as physical aspects. This study evaluated an in-house questionnaire as a tool to record patient responses, as an aid to patient/staff discussions, and in training.
Sample: Patients with terminal illness attending for day therapy between 05/2004 and 10/2005 ($n = 38$, 16 males, 22 females). Patients completed the questionnaire once or twice during the 12 week course.
Methods: Responses were gained on the questionnaire (10 visual analogue scales): Worry about pain; Anger; Expression of feelings; Control; Irritation; Anxiety; Depression; Dignity; Frustration; Impact on intimate relationship. Questionnaires were completed with staff. We obtained data at 2 times points if possible and looked at change over time. Results 1 (patient responses at 2 time points $n = 11$): Worry about pain, anxiety, depression, and impact on intimate relationship went down. Feeling in control, and ability to express feelings went up. Worry about losing dignity also went up ($p = 0.048$) perhaps as a function of advancing illness. The greatest change was seen in a decreased worry about pain ($p = 0.022$). Results 2 (PMQ as tool in aiding communication/staff training): The PMQ was accepted as a clinical tool by staff and patients. The process encouraged patients to face and discuss difficult issues. Such discussions had a wider effect by influencing interactions and communications through the unit and facilitated wider discussion of other non-pain symptoms. The medical psychotherapist associated with the unit was able to use the charts as a training tool with staff.
Conclusion: The PMQ was readily accepted in the Unit. After interventions, changes in patient responses were seen which were generally positive. Introducing the PMQ to outpatients in Day Therapy is an appropriate time, enabling communication between patients and staff and between patients in group discussions.

Abstract number: 268
Presentation type: Poster
Session: Pain

Gabapentin and opioid sparing effect on fentanyl tts in oncologic cronic pain

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Introduction: The gabapentin has been used in several studies as an opioid adjuvant in postoperative neuropathic and oncologic pain. The aim of the study was to evaluate the opioid dose reduction for pain control when used in association with an adjuvant.
Methods: 16 outgoing patients with oncologic pain have been studied. Patients have been divided into two randomized groups: 8 patients (group A) treated with fentanyl-TTS and gabapentin; 8 patients (group B) treated only with fentanyl-TTS. Both groups received additional rescue doses of morphine per os when needed. Each patient was asked to fill in the Edmond Symptom Assessment System (ESAS) as recommended by the Italian Society of Anaesthesia Analgesia Resuscitation and Intensive Care (SIAARTI). Data have been analyzed with the Kruskal-Wallis test and the Dunn test ($p < 0.05$).
Results: Results are reported in table 1.

Table 1 Data are expressed as averages ± standard deviations.

	Group A	Group B	p value
VAS	3.44±0.38	6.04±0.53	<0.05
Feeling active	4.50±0.87	5.32±0.84	n.s.
Nausea	3.37±0.45	4.24±1.76	n.s.
Depression	5.14±0.73	4.77±1.72	n.s.
Anxiety	4.07±0.77	5.29±1.25	n.s.
Drowsiness	5.73±0.62	4.11±1.68	n.s.
Appetite	5.12±1.09	4.58±0.74	n.s.
Wellness	6.21±0.8	4.96±0.99	n.s.
Dispnea	0	0	n.s.
Fentanyl-TTS (mcg/h)	32.19±9.92	60.62±4.38	<0.05
Morphin per os (mg/die)	11.21±5.98	26.37±2.7	<0.05
Gabapentin (mg/die)	2260±334.96		

Conclusions: Our data show that gabapentin allows a reduction in VAS values and opiod consumption in patients with stable oncologic chronic pain both in terms of dosage and rescue doses.

Abstract number: 269
Presentation type: Poster
Session: Pain

Treatment of the neuropathic pain with oxycodone and topiramato

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Introduction: According to several studies, the oxycodone appears more active that the oral morphine for the treatment of the neuropathic pain and the topiramate more that the gabapentin.
Objective: To verify the improvement of the neuropathic pain with the association of these two medicaments.
Method: The patients with pain neuropathic, were initiating the treatment with sulfate of morphine and gabapentin. Into the cases that the pain was not controlling they were changed from oral morphine to oxycodone and later of gabapentin to topiramate.
Results: They were studied 25 patients, 16 men and 9 women. The middle ages were 69 years. The distribution of the diagnoses was: 8 neoplasm of bladder, 6 of prostate, 5 of rectum, 4 of lung, 2 of larynx. All these patients were not answering to the previous treatment with morphine and gabapentin. One changed first all, the morphine for oxycodone and answered to the pain 8 patients (32%). To other 17 patients the gabapentin changed for topiramate and answered 13 more patients (76%) and the rest of patients, 4 (16%), did not answer to this association of medicaments.
Conclusions: 1. The oxycodone seems to be more effective in the control of the neuropathic pain, when it is not controlled by oral morphine. 2. The topiramate seems to be more effective than the gabapentin in the neuropathic pain. 3. The association of oxycodone and topiramate is an effective alternative for the control of the neuropathic pain, in the resistant cases.

Abstract number: 270
Presentation type: Poster
Session: Pain

Pain monitoring and treatment in hospitalised patients with metastatic cancer: A pilot study at a Hospital Cancer Centre

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Background: Despite the availability of effective methods of controlling pain, many patients continue to receive inadequate pain relief. An audit was carried out on a 1-year period to identify the prevalence, severity and management of cancer pain in the hospital in-patients referred to the Medical Oncology Unit of the University Hospital of Parma between April 2004 and March 2005.
Patients and methods: A multidisciplinary team of physicians and nurses directly responsible for the patients provided prospective data by reporting both the diagnostic and therapeutic interventions performed and the degree of pain control achieved. Two daily pain assessment, which was based on patients report by a numeric rating scale (NRS), was performed during hospitalisation.
Results: Eight hundred and thirty-four admissions (537 patients) were recorded. Pain was registered in 319 of these (38%) corresponding to 220 patients (106 men and 114 women; median age 66 years, range 21–90 years). The median NRS score (10 = greatest pain severity) was 4.54 (range 1–10) and a NRS score >5 was observed in 137 out of 319 cases (43%). A total of 460 therapeutic interventions were undertaken, including chemotherapy and/or radiotherapy, and analgesic medication was changed in 264 admissions (82%). For admissions with pain level score >5, the quantitative evaluation showed a significant pain reduction between admission and discharge pain levels?mean pain reduction: 4.15 ($p<0.0001$). Seventy-seven percent of patients with pain level score >5 at admission reverted to a pain level <5 after hospitalisation.
Conclusions: These findings show that a highly-motivated hospital palliative team facilitates pain diagnosis and monitoring, is effective at improving pain control, and contributes to the appropriate management of cancer patients hospitalised in medical oncology divisions.

Abstract number: 271
Presentation type: Poster
Session: Pain

The use of topical antidepressants and opioids in neuropathic pain in palliative treatment

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The neuropathic pain characterized by sensation of spontaneous or touch evoked burning with local hypesthesia or allodynia is a common compound of cancer pain. It has a huge influence on quality of life in this group of suffering patients. The aim of the study was to evaluate efficacy of topical antidepressants and opioids in patients with neuropathic pain. The investigations were made in The Department of Pain Treatment and Palliative Care of Jagiellonian University, Krakow, Poland. The patients ($n = 9$) were treated with solution of Doxepin, Morphine or Doxepin and Morphine used together when the neuropathic pain was present. As a method of analysis of the analgesic efficacy were used VAS/visual-analogue scale/score, NRS/numeric-rating scale/ and descriptive scale. We observed better pain control when topical antidepressants as an adjunctive therapy with or without morphine were used. It seams that addition of antidepressants to morphine solution might be an effective way for improving the therapy in neuropathic pain. The low costs of morphine and antidepressants (e.g. Doxepine) solution and lack of side effects if used topically seems to be an alternative for systemic therapy.

Abstract number: 272
Presentation type: Poster
Session: Pain

Patients with cancer or polypathia benefit from sustained-release (SR) hydromorphone as first step III opioid

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Aim of investigation: Evaluation of efficacy and tolerability of SR hydromorphone in pain patients with cancer and/or polypathia who had had no step III opioid prior to investigation.
Methods: Observational, non-interventional study with 755 patients and four visits (initial visit, two control visits at days 3 and 7, final visit after 3 weeks). Study parameters: Demographic and anamnestic data, pain intensity, described by patient self-evaluation (NRS: 0 = no pain, 10 = strongest conceivable pain); quality of life, described by activity, mood, ability to walk, ability to work, social contacts, sleep, cest for life by patient self-evaluation (total score: 0 = no impairment, 70 = maximum impairment). Opioid-typical symptoms (sedation, nausea, vomiting, constipation) were specifically sampled.
Results: 670 patients (mean age 66.3?12.2 years; 56.0% >65 years) of a total of 755 received SR hydro-morphone twice daily as first step III opioid. Pain originated from tumour diseases in 54.2% of patients. In 71,7% of cancer patients tumour disease or status of patients was advanced or moribund. 49,1% were patients with polypathia (59.5% of the >65 years old patients). Prior to therapy with hydromorphone no patient had got a step III analgesic, 48.9% step II and 51.1% no analgesic or concomitant analgesic or NSAID. Mean dose of hydromorphone was $12.7 \pm 9{,}6$ mg/d. Pain intensity decreased by 64.8% from 7.1 ± 1.4 at start of treatment to 2.5 ± 1.6 at final examination. Quality of life increased by 54.7%. The sum score was reduced from 45.3 ± 11.9 to 20.5 ± 12.6.
Conclusions: SR hydromorphone can be used even at the beginning of step III in the therapy of cancer pain as well as for pain treatment in patients with polypathia or those with severe pain and polymedication.

Acknowledgements: Supported by grants from Mundipharma (HDM4407).

Key words: Hydromorphone, severe pain, cancer pain, polypathia.

Abstract number: 273
Presentation type: Poster
Session: Pain

The study of patients' preferences, efficacy and improvement of the performance status with the transdermal fentanyl and sustained release oral morphine in patients who have pain in their advanced stage of cancer

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Objective: A randomized, unblinded, open labeled crossover study was conducted to compare the efficacy, patient preference and the performance status between transdermal fentanyl and sustained release oral morphine in patients with cancer related pain.
Methods: Patients who required strong opioid analgesia (based on stage II and III WHO analgesic ladder) were recruited from October 2004 till April 2005. Patients received one treatment for 4 weeks followed immediately by the other for 4 weeks.
Results: A total of 22 patients with mean age 56.4 years and 54.5% female entered the trial but only 17 completed both treatment arms. Patients recorded their daily VAS, amount of rescue medication used (an intermediate release morphine), and side effects (vomiting, diarrhea, constipation and daytime somnolence). The results showed that both treatments were equally effective in pain control, as assessed by the patient and investigator rated VAS ($p = 0.047$ and $p = 0.019$ respectively). There was no significant difference in the performance status score as measured by Karnofsky performance status between treatment groups ($p = 0.907$). The overall incidence of treatments related side effects were similar in both treatments. More patients preferred transdermal fentanyl compared to sustained release oral morphine (52.9% vs. 29.4%) but this was not statistically significant ($p = 0.193$). In conclusion, transdermal fentanyl and sustained release oral morphine were equally effective in providing pain relief with no significant difference in the side effects. Patients' preference toward a treatment should be considered in individualizing patient assessment for pain control.

Abstract number: 274
Presentation type: Poster
Session: Pain

Survey of the practise of opioid switching in a Regional Cancer Centre

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Objectives: To determine frequency and clinical indications for opioid switching. To assess the opioids used, frequency of dose reduction, use of alternative measures for opioid toxicity and prevalence of renal dysfunction.
Method: This was a prospective audit of episodes of opioid switching. Information obtained included demographic data, indications for switching, details of opioids used, other measures taken and presence of renal dysfunction. Where possible, creatinine clearance was calculated using the Cockroft-Gault formula.
Results: 676 inpatients taking regular opioids were reviewed. 46 (6.8%) had at least one opioid switch. 67% involved a switch from morphine to oxycodone; 27% oxycodone to hydromorphone. 17% of episodes involved a route change. 75% switches were made on the advice of the palliative care team. 23% had their initial opioid dose reduced but subsequently required a switch and 29% had a dose reduction at the time of switching. Inadequate analgesia was the indication in 31% and side effects in 94% (cognitive impairment, drowsiness, myoclonus and hallucinations were commonest). Renal impairment was present in 46% (91% pre-renal & 18% post-renal) and corrective measures taken in 86%. Creatinine clearance was calculated in 71% patients. Despite renal dysfunction in 46%, only 15% of patients had mild renal impairment as defined by a Creatinine clearance of 20–50 ml/min and 56% had clearance over 50 ml/min.
Conclusions: Approximately 1 in 15 inpatients required 1 or more opioid substitutions. Morphine remains the drug of first choice; oxycodone second and hydromorphone third line. Most episodes involved a switch to an equianalgesic opioid dose without any dose reduction. Neuropsychiatric side effects are the commonest indications for switching. Renal impairment is a significant factor in opioid switching but creatinine clearance is probably unhelpful in patients with pre-renal impairment.

Abstract number: 275
Presentation type: Poster
Session: Pain

Pain experience of cancer patients at oncology institutions in Lithuania

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Background: Our aim is to explore the experience of pain among cancer patients who are being administered different oncological treatments and stages (primarily among chemotherapy and radiotherapy patients).
Methods: An anonymous questionnaire survey was performed in 5 oncological hospitals in all regions in Lithuania during January 2005. The questionare requested information concerning: 1) Amount of pain experienced, 2) The source of the pain experienced, 3) The time duration of the pain experienced, 4) The intensity of pain (VAS), 5) The awareness of the pain by the oncologist, 6) The pain relief medication received.
Results: 473 patients that filled the questionnaire. 60% experienced pain, 36% did not and remaining 4% did not experience pain due to effective administration of pain relief medication. Cancer was the source of pain indicated among 41% of pain experiencing patients and 30% indicated that cancer treatment as the main source of pain. The source of pain had a direct correlation to pain duration and intensity. Among the 48% of the patients that experienced pain due to cancer treatment, had pain duration of less than one month with a weak to moderate pain intensity. Among 76% of patients experiencing pain indicated they were using pain relief medication of which 64% of medication was prescribed by the oncologist. "Strong opioids were being used" were indicated by 49% of patients experiencing pain from cancer and 21% of patients experiencing pain from cancer treatment.
Conclusions: More that half of oncology patients experience pain, of which moderate pain dominated. Only 4% of patients that experience pain receive full pain relief. After the survey, recommendations to include active pain monitoring and pain relief medication in daily clinical oncology practice were introduced. A follow up survey will be performed January 2006 and preliminary results will be available during the poster presentation.

Abstract number: 276
Presentation type: Poster
Session: Pain

Study on opioid instauration and rotation (ROP) in patients with cancer pain

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Aim: To know the natural history of the use of opioids in far advanced cancer patients, the effectiveness of opioids rotation (OR) and the causes to do it.
Material and method: Observational, epidemiologic, longitudinal, prospective and multicentre study (30 centres on the national level). We enrolled patients with cancer pain from their first visit in a Palliative Care, Medical Oncology or Radio-Oncology Services, and we followed them up during 6 months. We recorded both instauration and switch of opioid, causes of OR, and its effectiveness using Visual Rate Scale (0–10).
Results: 257 patients were enrolled (68,9% were men). The most frequent tumours were lung tumour (23,7%) and head-neck tumour (20,6%). Somatic

pain (40,9%) and constant pain (72,4%) predominated. Initial pain was only observed in 14,8% and irruptive pain in 9,3%. 380 cases were analysed (155 are instaurations and 225 rotations). The drugs more used in the instauration of the opioid treatment were fentanyl (45,8%) and buprenorphine (25,2%). The average of ROP/patient is 1,50, being morphine the drug more used (45,8%). The main cause of rotation was no pain control (50,4%). Average VAS reduction on the 7th day in instaurations of 2,77 (SD 2,31) for baseline pain and 2,40 (SD 2,98) for irruptive pain Average VAS reduction in is 2,27 (SD 2,54) and 2,01 (SD 2,92) respectively. 72,5% of the instaurations and 59,4% of the rotations were effective. All of the potent opioids achieve effective rotations (ENV average: buprenorphine = 2,64, fentanyl = 2,04, morphine = 2,28). 573 adverse events (AE) were registered. The most frequent AE were constipation (162), nauseas (101), somnolence (71). 90% of them were classified as mild or moderate.

Conclusions: Both processes are effective to reduce pain. We observe differences between the different drugs, but comparative studies are not needed to confirm this fact.

Abstract number: 277
Presentation type: Poster
Session: Pain

Ketamine in complex cancer pain

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Limited evidence exists for the use of Ketamine in treating refractory cancer pain. This retrospective review examines data on 52 patients (63 episodes) with complex cancer pain treated with Ketamine, by the Palliative Care Team in a regional cancer centre over a four year period. All 63 prescriptions initiated by a single consultant were available for analysis. Data on indications, pain syndrome and efficacy were analysed. Most patients had advanced cancer (94%) with metastatic disease occurring in 82%. Treatment received concurrently with Ketamine included simple analgesics, NSAIDs, neuropathic adjuvants, steroids, radiotherapy, chemotherapy, bisphosphonates and samarium. A large spectrum of opioids was used concurrently with morphine equivalent doses ranging from 2.5–2400 mg. Ten patients had rotated to alternative opioids before Ketamine use. In 87% of patients, Ketamine was introduced for opioid-resistant neuropathic pain identified as burning (20.6%), radiating (36.5%), numbness (11.1%), allodynia (12.7%), neuropathic (6.3%). Oral Ketamine (63.4%) was used to a maximum of 70 mg qid while subcutaneous (30%) administration was to a maximum 400 mg/24 hrs by syringe driver. Psycho-mimetic side-effects occurred in 27%, cardiovascular occurred rarely (3.2%); Ketamine was discontinued in four cases only due to intolerability. Effectiveness was documented as stated improvement in 62%, improved pain scores in 28%, opioid-sparing in 49% and improved mobility in 11%. After 4 weeks, 12/20 patients concurrently receiving radiotherapy and 10/15 patients receiving chemotherapy remained on Ketamine. The discussion will include data re other clinical pain syndromes and the challenges of retrospective review. In conclusion, these retrospective data indicate that Ketamine is well tolerated in this patient population. In our experience Ketamine has a role to play in the treatment of refractory cancer pain where therapeutic options are limited.

Abstract number: 278
Presentation type: Poster
Session: Pain

The increasing use of hydromorphone in palliative care patients: A retrospective analysis 2000–2004 (Poster)

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Introduction: Hydromorphone (HM) is a semi-synthetic opioid that has been used widely and has become a, increasingly important option for the treatment of acute pain, chronic cancer pain and to a lesser extent, of chronic non-malignant pain. Its pharmacokinetics and pharmacodynamics has been well studied. We investigated the use of hydromorphone compared with other WHO III opioids in patients suffering from terminal cancer in our palliative care (PCU) unit in Bonn from 2000 to 2004.

Methods: A retrospective analysis of 1001 patients admitted to our PCU from 2000–2004 was performed. Of these patients, 81% were treated with WHO III opioids during the hospital stay. Demographic and cancer-related data (diagnosis, symptoms) were documented. Statistic: mean?SD, ANOVA, significance $p < 0.05$.

Results: A total number of 807 inpatient data were analysed (Age 66.3 ± 12.5, 47.3% men). The most common carcinoma were lung cancer (16.3%), breast cancer (15.1%), colorectal cancer (12.3%) and prostatic cancer (11.1%). In 2000, 17.7% of these patients were treated with hydromorphone and 63.1% with morphine (M); 2001: 10.1% HM/60.1% M; 2002: 19.3% HM/55.0% M; 2003: 20.0% HM/68.7% M and 2004: 39.2% HM/53.8% M. The use of fentanyl decreased from 20.6% in 2001 to 2.1% in 2004, whereas HM became the second frequently used opioid after M on our palliative care unit. The most common reasons for switching to HM treatment were nausea, emesis, hallucinations and renal impairment.

Conclusions: We conclude that hydromorphone is a well accepted alternative to other WHO III opioids. Particularly, if patients suffer from opioid-induced side-effects, hydromorphone has become increasingly important in the treatment of cancer pain. (Acknowledgements: R. Sackler Research Foundation).

Abstract number: 279
Presentation type: Poster
Session: Pain

The added value of the 4-in-1® pain scale and the Pain Impact Score® during Palladone® SR treatment

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Introduction: As shown in the Pain in Europe Survey, 1 out of 5 Belgians is suffering from chronic pain (www.painineurope.com) and the lack of communication between patient and physician. The 4-in-1® pain scale and the Pain Impact Score® were recently developed to measure pain and the impact of pain during Palladone® SR (hydromorfone) treatment. The 4-in-1® pain scale consists of 4 scales; expressing pain in words, VAS, faces or bar. The Pain Impact Score® is measuring and visualising the pain and the impact of pain on daily activities, work and quality of life.

Objective: The objective of this survey was to evaluate whether both scales could improve the communication between the patient and the physician during Palladone® SR treatment. Methods A questionnaire regarding both tools was sent to 200 physicians in Belgium.

Results: 87 physicians (44%) returned the questionnaire and treated in total 435 patients. The majority of the physicians (>95%) used the 4-in-1® pain scale to evaluate the pain on a regular basis. Of the 4 pain scales the 'word' (34%) and the VAS scale (35%) were used most frequently. The 'faces' and 'bar' were used less frequently (23% for both). The Pain Impact Score® was mainly used in adults (61%) and elderly (31%) and less in children (7%), reflecting the main patient population with pain. 70% and 75% of the respondents indicated that this tool was useful in the communication about pain between physician and patient for the 4-in-1® pain score and Pain Impact Score® respectively. The reported advantages were an objective measurement (both tools) and visualization (Pain Impact Score® only) of pain and treatment effects.

Conclusion: Both the 4-in-1® pain scale and the Pain Impact Score® were very effective and appreciated tools for the measurement of pain and the effect of the Palladone® SR treatment. Moreover, they have an added value in the communication between patient and physician.

Abstract number: 280
Presentation type: Poster
Session: Pain

Reliability of PACSLAC, A pain assessment tool in seniors with dementia

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Context: Assessing and relieving chronic pain represent one of the main priority aspects in palliative and end of life care for patients with chronic diseases.
Objectives: To develop and validate a French version of an existing pain observational tool, the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC).
Design: Instrument validation study in long term care institutions.
Participants: One hundred twelve patients with a diagnosis of dementia and limited ability to communicate.
Main outcome measures: Internal consistency, test–retest and interobserver reliability, discriminant validity of the PACSLAC completed by nurses after different observations of their patients and nurses' acceptability of the instrument in their daily practice.
Results: The PACSLAC is a 60-item instrument which assesses facial expressions, activity/body movement, social, personality/mood and physiological/eating/sleeping changes/vocal behaviors. The sum of items allows calculation of a global score. PACSLAC internal consistency was good with Cronbach Alpha of 0.74 for the global score. PACSLAC mean global score was 8.6 in pain situations, 4.1 in calm situations and 10.8 in distress situations ($p < 0.0001$). Good test-retest reliability was found in pain situations, with a correlation coefficient (CC) of 0.83, and in calm situations ($CC = 0.86$). The interobserver reliability was excellent in pain situations (intraclass correlation coefficient-$ICC = 0.94$) and in calm situations ($ICC = 0.93$). Nurses perceived the PACSLAC as a very useful tool which took them less than 5 minutes to complete and it helped them to systematize their observation of the patients to identify pain.
Conclusions: Validation of the French version of the PACSLAC shows good reliability. Further testing of the PACSLAC is needed to establish a threshold for the relevance of intervening on pain and to verify if it can be used to assess the effectiveness of pain interventions.

Abstract number: 281
Presentation type: Poster
Session: Pain

Evaluation of pain control in patients with bone metastases or multiple myeloma in Zoledronic acid therapy. Observational clinical study

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Background: Pain associated with metastatic bone disease is present in 70% of oncologic advanced patients, reduced quality of life and performance status of patients. Zoledronic acid, is a new bifhosfhonates recommended in treatment of skeletal complication, reduced calcemia and pathologic fractures.
Objectives: Primary endpoint: evaluation of pain control and analgesic use. Secondaries endpoints: Evaluation of quality of life, tolerance and patients satisfation. Patients and Methods: eligible patients with histologic diagnosys of Carcinoma or Multiple Myeloma, at least one bone matastasys with radiological diagnosys, bone pain, prevision survival at least 6 month, written informed consent. Not eligible patients: concomitant radiotherapy for bone pain control, radiometabolic therapy, not therapy with Pamidronate in the last month, not therapy with Zoledronic acic in the past. Treatment: Zoledronic acid 4 mg administred as a 15 minutes infusion in 100 cc of normal saline every 4 weeks. Pain assessment with Brief Pain Inventory (B.P.I.) and Analgesic Score. Evaluation of Quality of Life with questionnarie FACT-G. The study started in 2005 January. Centres partecipantes are the Institution of Medical Oncology and Palliative Care of Oncological Institute of Romagna (I.O.R.): Forlì, Lugo, Rimini, Faenza, Ravenna, Cesena.
Results: Actually 55 patients are enrolled in this study (age range 37–84 years, median 69 years), 92% with multiple bone metastases, 30% with lythic metastases. At baseline 42% of patients required opioids to control pain, median BPI 13 and median Analgesic score 2. Final accrual about 100–150 patients in 3 years.

Abstract number: 282
Presentation type: Poster
Session: Pain

Intra-operative analgesia does not cause acute opioid tolerance or hyperalgesia in prostatectomy for prostate cancer

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The aim of this prospective study was to seek clinical evidence in support of acute opioid tolerance and/or hyperalgesia in patients undergoing radical prostatectomy for prostate cancer. Sixty-five consecutive opioid-naïve patients undergoing uncomplicated radical prostatectomy performed by the same surgeon were included in the study. During standard general anesthesia patients received intraoperative fentanyl and morphine administered as deemed clinically indicated by the discretion of the anesthesiologist. Postoperative morphine use was self-administered by the patients using intravenous morphine via PCA. Patients were stratified according to the intraoperative opioid use in 4 groups: A1) intraoperative opioid use of or below 20 mg morphine equivalents, A2) between 21 and 30 mg, A3) between 31 and 40 mg, and A4) over 41 mg morphine equivalent. One day after the surgery, postoperative morphine consumption to intraoperative morphine equivalent ratio was 5.4 in Group 1, 7.7 in Group 2, 3.1 in Group 3, and 2.1 in Group 4. Thus, the patients who received the lowest dose of intraoperative opioids required relatively high doses of morphine postoperatively, and the patients who received the highest morphine doses required relatively low postoperative morphine within the first post-operative day. Postoperative morphine use was independent of intraoperative fentanyl dose. Cumulative and post-operative morphine use did not differ significantly among groups. Average cumulative intravenous morphine use in these patients after prostatectomy was 100.5. Administration of higher doses of intra-operative opioids did not lead to the development of tolerance during the first 24 hours postoperatively. On the contrary, it was associated with lower postoperative opioid consumption and compatible analgesia. This pain model is an attractive model to study analgesic medication and the mechanisms of pain other than hyperalgesia and acute opioid tolerance.

Abstract number: 283
Presentation type: Poster
Session: Pain

Local administration of Morphine or Ketamine as a mouth rinse for treatment of breakthrough pain in patients with cancer of the mouth

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7 patients suffering from cancer of the tongue, gingival and salivary glands were treated either with Morphine or Ketamine solution as mouth rinse for control of the breakthrough pain in the dept. of Palliative Care for 2004–2005. All the patients had underwent definitive radiotherapy and complained from sore mouth, altered taste and severe pain while talking or eating,. The patients were treated on regular basis with Morphine SR and adjuvant drugs and at rest their pain intensity was VAS 0–1/10. The patients were given to use for treatment of their breakthrough pain prepared in advance 50 ml solution containing either Morphine 1 mg/ml or Ketamine 5 mg/ml for the next 24 h. When the patients felt pain they were asked to take

3 to 5 ml of the solution and to rinse their mouth as long as possible. They were told to spit after use but the patients prefer to swallow. The patients were asked to measure the intensity of their pain on the 1st, 5th, 10th and 15th min. They were also asked to compare the efficacy of the treatment that day with the efficacy of the treatment the day before and to measure their satisfaction and their preferences.
Results: 1. Both drugs Morphine HCl 1 mg/ml and Ketamine 5 mg/ml as mouth rinse were active in treatment of breakthrough pain in patients with oral cancer. 2. The effect of the Morphine sol was faster than Ketamine sol. 3. There were no troublesome side effects. 4. The patients' preferences were Morphine/Ketamine sol = 38/19. 5. When we tried to increase the daily dose of Morphine SR with 50 mg 6/7of the patients experience almost the same number of breakthrough pains so they preferred to have their usual daily dose and to use for breakthrough pain Morphine sol.

Abstract number: 284
Presentation type: Poster
Session: Pain

Ketamine use in Palliative Care Department – Interregional Cancer hospital – Vratsa

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Abstract: 18 patients with poor pain control because of dose connected intolerable opioide and other co-analgesic drugs side effects were treated by CSCI of Ketamine as an adjuvant analgesic. All patients had more than one pain: neuropathic pain 18 patients, 12/66%/ of them had more than one neuropathic pain, somatic pain experienced 13/72%/ of 18 patients, visceral pain 10/18 patients or 55%. All patients had pain score VAS > 80 mm and BRS-6 > 5 and performance score PPSv2 > 40%. All patients were converted from oral to CSCI of morphine = 3:1/the dose of the CSCI was fixed and remained the same through the time of treatment/+sc rescue doses/fixed mg/+CSCI of Ketamine 1 mg/kg/24 h. The pain intensity, patients' satisfaction, the number of rescue doses, the daily amount of morphine and the side effects were followed and evaluated. The dose of Ketamine was raised with no more than 75 mg/24 h up to 500 mg/24 h. The Results: There is significant reduction of pain score VAS 8.93 before treatment to VAS-2.11 after treatment BRS-6 from −5.55 to 1.55. Satisfaction was = 1.5/0 (completely) 3 (not at all)/. The mean opioide consumption reduced from 282.22 mg/24 h before treatment with Ketamine to 226.11/24 h-21.5%. The numbers of rescue doses per person reduced from 7.3 the first day to 1.7 in the last day. The side effects observed in 7/18/38%/ patients were: bad sleep-4/7, hallucinations-5/7 confusion-2/7 delirium-2/7, redness of the injection site 4/7, infiltrate-2/7 patients and sterile abscess-1/7 patient 4/7 patients had more than one side effect and 3/7 patients had only one. 1/18 patient /5.5%/ get no pain reduction. The severity of the side effects was 1.96 /0-no -5 max/. 1/18 patient stopped treatment because of the side effects. 1/18 patient PPSv2 = 40% deteriorated so the whole treatment was stopped, she died after 40 hours. 1/18 patient suffering from lung cancer died on the seventh day from massive hemorrhage.

Abstract number: 285
Presentation type: Poster
Session: Pain

Analgesic efficacy and safety of transdermal buprenorphine 70 μg/h in patients with severe chronic cancer pain. A randomised, multicentre, placebo-controlled, double-blind study

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Background: Create new data on transdermal buprenorphine in severe cancer pain.
Aim: To examine the analgesic efficacy and safety of transdermal buprenorphine 70 μg/h in patients with severe chronic cancer related pain.
Methods: Multicentre study with randomised, parallel group, double-blind (db) design. Patients, who had been pre-treated with opioids and requiring a dose range equivalent to 90–150 mg/d oral morphine and who successfully finished a run-in period, were randomised to receive placebo or active patch (70 μg/h) as well as buprenorphine sublingual tablets (0.2 mg) for breakthrough pain episodes. Primary endpoint was the proportion of responders, defined as those patients, who completed at least 12 days of the db-period, had an average pain intensity of < 5.0 on an 11-point NRS-scale during the last 6 treatment days and did not use more than 2 sublingual tablets during the db-phase. Secondary endpoints were pain intensity, patients' global assessment of the treatment, amount of rescue medication, and incidence and nature of adverse events.
Results: 189 patients were randomised into the two treatment arms of the 15 days-db-period. 74.5% of buprenorphine-patients were classified as responders compared to 50% of the placebo-patients ($p = 0.0003$), indicating a significantly higher response rate for buprenorphine 70 g/h. Pain intensity was on average 1.8 (active patch) vs 3.0 (placebo), but placebo-patients had a 50% higher consumption of sublingual tablets per day than buprenorphine-patients. The incidence of adverse events was 30.9% in the buprenorphine- and 25.3% in the placebo-patients. Most frequently (> 5%), constipation (9.6% vs 2.1%), nausea (3.2% vs 7.4%) and vomiting (5.3% vs 6.3%) were reported.
Conclusion: Transdermal buprenorphine 70 μg/h showed a high efficacy in severe cancer-related pain and was well tolerated. Transdermal buprenorphine 70 μg/h is thus an efficient option for the treatment of severe chronic cancer-related pain.

Abstract number: 286
Presentation type: Poster
Session: Pain

Rapid escalation of diamorphine dose in the last days of life-fact or fallacy?

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Aims: A common misconception exists that there is a crescendo pain in the last days of life, leading to an exponential increase in analgesia. There is paucity in the literature on this subject. We therefore examined trends in dose escalation and whether dose increments were based on breakthrough analgesic requirements. The information will inform current practice, and will be used for teaching purposes. It can also be used to compare with similar existing data on other strong opioid analgesics.
Methods: A retrospective analysis was done of 100 case notes of patients who died whilst on diamorphine via syringe driver during the year 2004. Documented evidence of renal or liver impairment, previous opioid requirements, starting dose of diamorphine, rate of dose escalation and whether the increments were based on breakthrough analgesic requirements, were noted, as well as the total number of days on Diamorphine.
Results: The median age of patients was 70 years, 21% has liver dysfunction and 8% documented renal impairment. The average duration on Diamorphine was 5.2 days and starting doses ranged form 5 to 160 mg. The study showed gradual escalation of the diamorphine dose in 56% of patients; the dose remained stable in 44%. In all patients, the dose increments were based on actual breakthrough analgesic requirements in the previous 24 hours. In all patients that were on oral strong opioids, diamorphine via syringe driver replaced the oral opioid. Patients on fentanyl patches remained on them until death.
Conclusions: Diamorphine dose escalation in the last days of life is only needed in 56% of patients, and is gradual (mean escalation 11.3% per day). Increases are based on breakthrough analgesic requirements. One would anticipate that, if there were increased analgesic requirements in the last days of life, the trend showed in our study would most likely be similar in other strong opioid analgesics.

Abstract number: 287
Presentation type: Poster
Session: Pain

A randomized double-blind crossover comparison of continuous and intermittent subcutaneous administration of opioid for cancer pain

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Background: Although the preferred route of opioid administration is oral, cancer patients (PTS) often require an alternate route. Options include continuous subcutaneous infusion (CSCI) or regularly scheduled intermittent subcutaneous injections (ISCI). CSCI maintains steady drug levels, theoretically avoiding the "bolus effect" of nausea and sedation post-dose, and breakthrough pain prior to the next dose. However, portable infusion pumps can be costly to use. The Edmonton Injector (EI) is an inexpensive portable device for ISCI. The two modes of subcutaneous opioid administration have not been directly compared.
Objective: To compare CSCI and ISCI of opioid for treatment of cancer pain.
Design: Randomized, double-blind, crossover trial.
Patients and methods: PTS were recruited from two Palliative Care Units.
Eligibility: stable cancer pain requiring opioids; need for parenteral route; normal cognition. PTS were randomized to receive opioid by CSCI (portable pump) or ISCI (EI) for 48 hours, followed by crossover to the alternate mode for 48 hours. Total daily and breakthrough opioid doses were the same during both phases. During each phase, placebo was administered by the alternate mode. Evaluations: intensity of pain, drowsiness, nausea by visual analogue scale (VAS); side effect checklist; global assessment of treatment effectiveness; overall treatment preference.
Planned sample size: 24 PTS.
Results: The study was closed after 12 PTS were entered, due to slow accrual. Eleven PTS completed the study.
Baseline characteristics: Edmonton Staging System for pain prognosis-good(7), poor(4); opioids-hydromorphone(9), morphine(1), oxycodone(1); median daily opioid dose – 60 mg (parenteral morphine equivalents); median pain VAS-21 mm. Median rating of effectiveness was 2(moderate) for CSCI and 3(very) for ISCI. In all cases, PTS and investigators expressed no preference for one treatment mode over another. Analysis of pain intensity and side effects is pending.

Abstract number: 288
Presentation type: Poster
Session: Pain

Place of interventional pain therapies in palliative care

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Introduction: the appropriate use of the WHO ladder allows to relieve pain in most cancer patients. The development of interventional pain therapies offers new alternatives in complex situations. Their place in palliative care however is yet to be defined. The aim of this study was to determine in which patients a spinal catheter was placed and what was the outcome.
Methods: retrospective review of charts of all patients hospitalised in the Geneva University Hospitals taken in charge by a mobile palliative care team and the interventional pain team and had either an epidural or an intrathecal catheter.
Results: 12 patients (7M/5W) were included. Median age was 58–10 years. All patients had advanced cancer. Pain was related to bone metastasis (thoracic or pelvis) ($n=8$), peritoneal carcinomatosis ($n=3$), and Pancoast syndrome ($n=1$). Before interventional pain management, all the patients had systemic opioids (mean oral daily morphine dose 933 mg (120–4200 mg)), 8 patients received anticonvulsant drugs for neuropathic pain, 6 patients had corticosteroids or NSAIDS. The reason for placing a spinal catheter was uncontrolled pain in 10 patients and unacceptable side effects in 2. All patients had better pain control afterwards but ten of them experienced major anxiety. They all died during the hospital stay, a median of 25–26 days after catheter implementation. At the time of death 10 patients had systemic opioids (mean oral daily morphine dose 1180 mg (20–3900 mg)), 7 patients received anticonvulsant drugs, and most had corticosteroids ($n=9$) or NSAIDS ($n=1$).
Conclusion: a spinal catheter was placed in cancer patients in the terminal phase of their illness. Although all experienced relief from pain, most of them still received high doses systemic opioids when they died. After catheter implementation, nearly all patients reported high levels of anxiety. Prospective studies to better evaluate the role of interventional pain management in palliative care are needed.

Abstract number: 289
Presentation type: Poster
Session: Pain

Managing cancer pain and symptoms of outpatients by rotation to sustained-release hydromorphone: A prospective clinical trial

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Purpose: In this prospective clinical trial we examined the technique of opioid rotation to oral sustained-release hydromorphone for controlling pain and symptoms in ambulatory cancer pain patients.
Methods: Before and after rotation variables of 50 patients were assessed by Numerical Analogue Scales (NRS), or as categorical parameters, and analyzed by descriptive and confirmatory statistics (Wilcoxon; Chi2).
Results: Rotation was successful in 64% of patients experiencing pain (60%), central (46%), and gastrointestinal symptoms (32%) under oral morphine, tramadol, or transdermal fentanyl. NRS of pain (4.1 to 3.2; $p=0.015$) differed significantly, but not mean morphine equivalent doses (108.9 to 137.6 mg/d; $p>0.05$). Insomnias and gastrointestinal symptoms improved, especially defecation rates ($p=0.04$). Although not all patients were rotated because of insomnias, their incidences reduced significantly in the entire population.
Conclusion: Rotation to oral hydromorphone is a helpful technique for alleviation of pain and several symptoms.

Abstract number: 290
Presentation type: Poster
Session: Pain

Controlled-release hydromorphone under practice conditions: Good pain reduction and tolerability, marked improvement in quality of life in cases of severe pain of different aetiology

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Aim of investigation: To document the treatment of severe pain with controlled-release hydromorphone under practice conditions.
Methods: A total of 1,895 patients (mean age 63.5 years) with severe pain of different aetiology received a regular dose of 4 mg or 8 mg hydromorphone twice daily after an initial examination in a multicentre observational study. Follow-up was performed on days 3 and 7, with a final examination after about 21 days. Efficacy (NRS 0 = no pain to 10 = severe pain), tolerability, compliance and quality of life, assessed by the patients themselves, were studied based on the parameters of general activity, mood, ability to walk, normal work, relationships with other people, sleep, enjoyment of life (total score: 0 = no impairment to 70 = most severe impairment).
Results: Pain intensity fell by 64.3% from 7.0 at the start of treatment to 2.5 at the final examination on controlled-release hydromorphone. Quality of life improved by 51.3% compared with the initial visit. The total quality of life score was reduced from 46.4 to 22.7. Typical opioid side effects were present in a large proportion of patients at the start of treatment and

subsided markedly during the course of therapy with controlled-release hydromorphone when treatment was adequate: fatigue from 29.9% to 4.2%, nausea from 30.8% to 3.3%, constipation from 30.3% to 4.0% and vomiting from 13.1% to 1.8%. Both efficacy and tolerability as well as patient compliance were rated as "very good" and "good" by the doctors in over 80% of cases.
Conclusions: Controlled-release hydromorphone alleviates severe pain, is well-tolerated and markedly improves the quality of life.

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Key words: Hydromorphone, severe pain, cancer pain, quality of life, compliance.

Abstract number: 291
Presentation type: Poster
Session: Pain

Do long term opioids affect performance in long term use in cancer and non-cancer pain? A systematic review

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Aim: To systematically examine the literature regarding performance on long term opioids to find out which parameters of performance are affected and in what way.
Method: Papers were located using literature searches in Medline and Embase, reference lists of papers, conference proceedings, and communication with authors. Inclusion criteria were chronic cancer or non-cancer pain, established opioid use, and objective methods of assessment of performance through neurophysiological and neuropsychological tests.
Method of analysis: Metanalysis of results was impossible because of heterogeneity of material. Papers were graded according to strength of methodology using a scale allowing assessment of non-randomised as well as randomised trials and deemed to be suitable for use in systematic reviews. Results were tabulated according to the different aspects of performance examined in each paper, to detect differential effects of opioids.
Results: 34 papers published since 1980 were included in the analysis. These addressed cancer, non-cancer or mixed pains, and employed a number of study designs. Overall, chronic opioid use in chronic cancer or non-cancer pain produced no impairment in any of the various parameters of psychomotor performance. In general, studies which showed performance to be impaired had serious methodological weaknesses. However, there was a minority of patients in whom impairment was clearly present, and there is much individual variation in the effects of opioids on performance. Some tentative conclusions regarding possible risk factors are drawn, and the interaction between pain and attention is briefly examined. Recommendations for future studies are made.
Conclusion: Overall, long term opioid use in patients with chronic cancer and non-cancer pain does not impair performance on any parameter, but there is wide individual variation. Future studies should concentrate on factors which can predict individual response.

Abstract number: 292
Presentation type: Poster
Session: Pain

Long-term administration of intravenous lidocaine for the treatment of cancer pain

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Background: Intravenous(IV) lidocaine has been reported to relieve neuropathic pain of varying origins. Traditionally it has been administered as a short-term infusion (30–60 minutes) resulting in pain relief of varying duration. There are a few reports of the continuous administration of IV lidocaine for the relief of refractory neuropathic cancer pain and even less for continued treatment in the home setting.
Purpose: To assess the effectiveness of a continuous intravenous infusion of lidocaine for the treatment of neuropathic cancer pain.
Study: A retrospective study for all patients treated with continuous infusion of IV Lidocaine.
Results: Six patients were treated during 2004 to 2005: 3 were female. Age range: 27–61 years. Primary cancer sites: lung, breast, colon. All patients had neuropathic pain syndromes: 3 brachial plexopathies, 1 sacral plexopathy, 1 sternal lesions. All patients had severe pain and toxicities prior to the initiation of lidocaine. Lidocaine infusion rates: 65 to110 mgs per hour.Serum lidocaine level range: 6.0 to 20.1 umol/l. Length of infusion: 2 hours to 8 months. Five patients had excellent pain relief. Pain scores were reduced on average by 8 points (0 to10 scale). One patient did not respond. Four patients were discharged home with infusional lidocaine. Two were later admitted to hospice for terminal care. Reported side effects were infrequent but included brief hallucinations and tremors.
Conclusion: For this group of patients IV lidocaine was an effective, well tolerated treatment for intractable neuropathic cancer pain. Problems cited were administrative and related to staff discomfort in caring for patients with IV lidocaine without continuous cardiac montitoring. Problem solving included education and policy development.

Abstract number: 293
Presentation type: Poster
Session: Pain

Transdermal Buprenorphine in cancer-related pain treatment

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Introduction: Buprenorphine is a third step treatment in cancer related pain, recently introduced in Italy with transdermal patches, favoured by patients and physicians.
Objective: valuate the use of this new drug in patients with severe cancer pain (VAS = 7), with or without metastasis, where previous step drugs were no more effective. Tested: pain intensity; tolerance; period of treatment; average doses of starting, final and intermediate times; associated pain treatments; reason of drop-outs. Sublingual buprenorphine rescue medication.
Research design, methods: Open, observational study; 10 patients recruited at our Operative Unit of Palliative Care, at 'G. Salvini' hospital, Garbagnate Milanese, Italy. Buprenorphine transdermal patches (35, 52.5 or 70 microg/h) were given. Patients assessed their pain relief. Total observation time: 9 months; average individual documented treatment time: 30 days.
Results: 10 patients with cancer pain evaluated. Most frequent diagnoses: prostatic cancer (30%), stomach cancer (20%), then lung cancer, myeloma, sarcomas; bone metastasis: 50% of patients. 70% of cases the patients affected by somatic pain, 20% neuropatic pain and 10% mixed. 80% treatments started with 35 microg/h patch. Initial dose increased subsequently only in 50% of subjects. This drug provided effective, sustained and dose-dependent analgesia in patients with cancer, good or very good pain relief documented for 70% of the patients with the initial assessment; percentage increased to 90% at the first follow-up and 100% at the final assessment. 10% of subjects discontinued treatment owing to unsatisfactory pain relief. Adverse events documented for 3 patients (30%); relationship with transdermal buprenorphine assumed for 40%. Tolerability profile: very good. No any previously unknown side effect.
Conclusions: Buprenorphine transdermal patches are well tolerated and effective in the treatment of chronic cancer pain. No clinically relevant development of tolerance.

Abstract number: 294
Presentation type: Poster
Session: Pain

Methadone in cancer pain treatment – Polish experience

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Aim of the study: Assessment of analgesia, side effects of methadone and own method of calculation equianalgesic doses of oral morphine and methadone.
Patients and methods: 16 opioid tolerant patients (9 men 7 women) age 20–74 (mean 50.72?13.52 median 51.5) with severe cancer pain-open prospective study.
Pain: neuropathic 15 patients, bone 11, somatic from soft tissues 3, visceral 3. Methadone given because of pain (NRS >6) on morphine (4 patients), TF (transdermal fentanyl) (3), morphine and TF (2), morphine, ketamine and TF (1), tramadol (1), pain with drowsiness on morphine with ketamine (3), pain on morphine with nausea (1) and confusion (1). Dose ratios equivalent daily dose of oral morphine (eddom) to starting daily dose of oral methadone (sddomet): 4:1 (up to 100 mg eddom), 6:1 (100–300 mg), 12:1 (over 300 mg). In 4 patients ratio 25:1 instead 12:1 because high eddom (3–1500 mg, 1–600 mg). Single methadone dose not exceeded 30 mg regardless eddom. 14 patients stopped previous opioid, 2 on methadone with other opioids. Mean eddom before switch 736.43 ± 495.42 (median 700) mg. Methadone administered 3 times a day, 15 patients oral water solution or syrup, 1 suppositories. Breakthrough pain: oral methadone (6 patients), oral methadone with other analgesics (6), other analgesics (4).
Results: Mean treatment time 36.79 ± 25.37 (range 7–92 median 29.5) days, starting doses increased in 14 patients. Mean daily doses: start 45.93 ± 19.26 mg, maximal 138.14 ± 104.43 mg, end of therapy 121.14 ± 105.19 mg. Good analgesia (NRS <4) 8 patients, partial (NRS 4–6) 7, unsatisfactory (NRS $>$ 6) 1 stopped methadone after 7 days. Side effects: drowsiness (7 patients), constipation (6), nausea and vomiting (2) and sweating (2), no serious adverse reactions especially respiratory depression.
Conclusions: Results confirmed good analgesia and acceptable side effects methadone. The applied method of dose calculation was safe and effective.

Abstract number: 295
Presentation type: Poster
Session: Pain

The comparison of controlled release dihydrocodeine and tramadol in cancer pain treatment – experience from Poland

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Aim of the study: Assessment of analgesic efficacy, side effects, quality of life (QL) of dihydrocodeine (DHC Continus® 60 90 120 mg) and tramadol (Tramundin® 100, Tramal Retard® 100 150 200 mg) controlled release tablets in cancer pain treatment and CYP2D6 activity.
Patients and methods: 20 opioid naive patients with nociceptive moderate to severe cancer pain intensity (VAS >4) in prospective open randomised cross over study 7 days each analgesic without wash out. Visceral pain 10 patients, bone 6, mixed 4. Analgesia by Brief Pain Inventory, side effects by verbal scale and ESAS, QL by EORTC QLQ C 30, CYP2D6 by PCR. DHC doses 2×60, 2×90, 2×120, 3×120 mg, tramadol 2×100, 2×150, 2×200, 3×200 mg. Antiemetics (metoclopramide) or laxatives (lactulose and senna) used only when nausea/vomiting or constipation appeared. Moderate pain (VAS 4–5.5) in 15, severe (VAS >5.5) in 5 patients.
Results: Time of treatment 3–68 (mean 31) days, daily doses DHC 120–360 (mean 185) mg. Good analgesia (VAS <4) 16 (80%), partial (VAS 4–5) 2 (10%), 2 (10%) ineffective (VAS >5). Side effects: constipation 8 (40%), drowsiness 3 (15%), nausea 1 (5%). Tramadol group: good analgesia 15 (75%), partial 2 (10%), ineffective 3 (15%). Side effects: constipation 4 (20%), nausea 3 (15%), sweating 2 (10%). In both groups side effects did not cause treatment termination, respiratory depression not observed. In 6 (30%) patients on DHC and 8 (40%) on tramadol during follow up after mean 31 and 28 days respectively substitution with strong opioids due to ineffective analgesia. QL was similar in both groups.
Conclusions: 1. Dihydrocodeine and tramadol controlled release tablets are effective in cancer pain treatment of moderate intensity. 2. In majority of patients treatment is well tolerated with no serious side effects. 3. In 30% DHC and 40% tramadol patients after mean 31 and 28 days respectively analgesics were substituted with strong opioids due to poor analgesia.

Abstract number: 296
Presentation type: Poster
Session: Pain

Reliability and validity of the Korean Cancer Pain Assessment Tool (KCPAT)

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The Korean Cancer Pain Assessment Tool (KCPAT), which was developed in 2003, consists of questions concerning the location of pain, the nature of pain, the present pain intensity, the symptoms associated with the pain, and psychosocial/spiritual pain assessments. This study was carried out to evaluate the reliability and validity of the KCPAT. A stratified, proportional-quota, clustered, systematic sampling procedure was used. The study population (903 cancer patients) was 1% of the target population (90,252 cancer patients). A total of 314 (34.8%) questionnaires were collected. The results showed that the average pain score (5 point on Likert scale) according to the cancer type and the at-present average pain score (VAS, 0~10) were correlated ($r = 0.56$, $p < 0.0001$), and showed moderate agreement ($kappa = 0.364$). The mean satisfaction score was 3.8 (1~5). The average time to complete the questionnaire was 8.9 minutes. In conclusion, the KCPAT is a reliable and valid instrument for assessing cancer pain in Koreans.

Abstract number: 297
Presentation type: Poster
Session: Pain

An audit on the use of strong opioids for pain management in an Irish regional hospital

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Introduction: Despite publication of international and local guidelines, cancer pain is often inadequately managed and presents a challenge in everyday practice. The WHO analgesic ladder recommends the use of strong opioids for severe cancer pain (Step 3).
Objectives: We wished to assess the quality of strong opioid prescribing in a regional hospital, following educational input from the palliative care team.
Methods: A retrospective review of the charts of twenty patients at point of referral to the palliative care service was undertaken. A questionnaire concerning quantities of opioids prescribed; charting of breakthrough analgesia and concurrent use of laxatives was completed. Medical and nursing staff were invited to attend an educational session on opioid prescribing. The updated departmental guidelines on this topic were circulated. A further chart review was undertaken following the educational input.
Results: 45% patients were on a regular strong opioid at time of referral. Of these: 66% had breakthrough analgesia prescribed but only 33% had breakthrough analgesia appropriately prescribed. 77% continued on a weak opioid preparation 77% had regular laxative cover. In the second chart review, it was found that 35% of patients were on a regular strong opioid at time of referral. Of these, 70% had breakthrough analgesia prescribed and in 90% of these patients it was correctly prescribed 40% of patients were concurrently prescribed a weak opioid 100% had regular laxative cover.
Conclusions: Quality of strong opioid prescribing for pain management can be improved by simple measures such as specific educational sessions to medical and nursing staff and raising awareness of departmental guidelines. Ongoing education must be a priority.

Abstract number: 298
Presentation type: Poster
Session: Pain

Opioid rotation in palliative care patients

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Aim of investigation: Availability of different WHO-step 3 opioids has encouraged the discussion on criteria for the best opioid primarily indicated in specific situations. While a change of application route is quite often performed in advanced palliative care true switches from one long act to another long act opioid are performed less often. Aim of this study was to analyse frequency, indication and dose ratio of opioid rotation (OR) in a two-years observation period of stationary palliative care patients.

Methods: The clinical records of 550 palliative care patients consecutively treated between 2004 and 2005 with strong opioids (WHO step 3) were retrospectively analysed in relation to the kind of opioid, doses, documented problems of opioid therapy and reasons for opioid switch. On the base of these data a critical evaluation for the OR decisions was made.

Results: OR included morphine, fentanyl, buprenorphine, oxycodone, hydromorphone and l-methadone. OR was found in over 30% of the documented cases but the frequency of true switches was much lower. True switches were performed more because of adverse effects, Efficacy problems were more frequently recorded in patients with compliance problems by the route of application leading to OR. Considering interindividual variability in response to various opioids no sound evidence of the superiority of the first line opioid over another was found.

Conclusions: Even when it is difficult to relate adverse symptoms to the opioid therapy in palliative care the specific properties or indications of different opiods should be considererd more consequently. More prospective studies on the specific features of the different opioids must be made before recommendations can be given on a evidenced base.

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Abstract number: 299
Presentation type: Poster
Session: Service Organisation and Place of Care

The impact of palliative care on the places of death of cancer patients in Berlin

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Aim of investigation: Since 1995 an annually increasing number of cancer patients in Berlin has been treated during the last period of life by ambulatory nursing and medical services specialized in palliative care. Aim of this study was to evaluate the role of the Palliative Care Network Berlin, especially the ambulatory Home-Care-Berlin project for the places of death of terminal cancer patients.

Methods: The data of more then 10 000 palliative care patients treated by Home-Care-Berlin since 1995 were analysed with relation to diagnoses, medical problems, days of hospitalisation and locations of death. On the base of these data a calculation of costs and a demand analysis was made and criteria for the structure, educational needs and improvement in the quality of palliative and social care were developed.

Results: About 60% of the patients with advanced cancer under specialised palliative care died at home. Only 19% of the patients where transferred to a hospital for the dying phase. The average duration of stay of these patients was 9 days. With increasing facilities for hospice care in the last years the number of patients dying at home decreased again. Now 32% of the cancer patients in the home care program spend their last days in a stationary hospice (26%) or in a nursing home (6%) while only 12% were admitted to hospitals for the dying phase. Average costs of care/patient could be calculated with 6750 ?. totally. Lacking social support and nursing care was the main reason, that patients with advanced cancer could not remain at home during their final phase of life.

Conclusions: Specialised palliative care can increase the number of patients to spend their final days at home. A Palliative Care Network with "three columns" Palliative Care Units, Stationary Hospices and ambulatory Home-Care contributes to a better quality in end of life care that allows dying at home or at the preferred place and also to a reduction of costs in the final year of life.

Abstract number: 300
Presentation type: Poster
Session: Service Organisation and Place of Care

Place of death of cancer patients referred to a palliative care service

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Introduction: Little is known in the Irish context of where terminally-ill patients die. The single study published to date, concerned only patients referred to a hospice home care team (Tiernan et al. IMJ 95(8)2002).

Objectives: We wished to determine: i) what percentage of total cancer deaths in a defined region, were known to palliative care services ii) the place of death of cancer patients referred to those specialist services.

Methodology: The total number of cancer deaths for the region, in a specified year, was sourced from the Central Statistics Office. Deaths of patients known to all elements of the palliative care service (hospital-support teams, hospice, home-care team) were examined over the same period. The area of residence; diagnosis and place of death of these patients was determined.

Results: There were a total number of 391 cancer deaths. 297 (76%) patients were known to some component of the palliative care service. Of these, 77 (26%) died at home; 89 (30%) died in a hospice in-patient unit; 125 (42%) died in hospital; 6 (2%) died in a nursing home.

Conclusions: 76% of all patients who died from cancer, in the defined region, over a one year period, were known to palliative care services. The majority of cancer deaths occurred in either a hospital or hospice setting with just over a quarter of all deaths of palliative care patients taking place at home. Further research is needed into factors that influence patients' preferences for place of death and actual place of death, as well as related quality of life and satisfaction with care issues. This will form the basis of future work.

Abstract number: 301
Presentation type: Poster
Session: Service Organisation and Place of Care

Evaluating "Partnerships in Care": A 2 day shadowing programme for nurses across community, hospital and hospice sectors

Maureen Gambles, **Kate Matthews**, **Lynne Jones**, **Philip Saltmarsh**, **John Ellershaw**, Marie Curie Palliative Care Institute Liverpool, Liverpool, Great Britain

Background: Communication between different sectors of the NHS is not always optimal (Hanlon 1996, Beyea 2004), and Baileff (2000) suggests that few health care professions "have a clear understanding of the nature of the others roles". The first phase of an initiative-"Partnerships in Care" involved 9 nurses of various grades from three sectors (Community, Hospital and Hospice) in a nurse shadowing programme. Each nurse 'shadowed' the work of a colleague in a different sector for 2 days. The broad aim of the programme was to enhance understanding of the roles of colleagues in different sectors and to encourage and improve cross site communication.

Aim of the present study: To explore the perspectives of participants in the Partnerships in Care programme to assess its impact and usefulness, and to pinpoint important elements to improve future planned phases.

Method: A focus group evaluation of the shadowing programme was conducted by 2 researchers external to the shadowing programme. A topic guide based loosely around the stated aims of the initiative was used to guide discussions, though participants were encouraged to talk about all aspects of their experience that they felt were significant.

Results: The sample consisted of 2 males and 3 females, with a range of 8–26 years post qualification and 2 weeks to 16 years in their current post. Following thematic analysis of the verbatim transcript independently by both researchers, three major themes emerged: 1) Communication and Insight; 2) Planning and Organisation; and 3) Personal Development.
Conclusion: There was considerable evidence to suggest that all participants felt they had increased knowledge and understanding of others roles after participating in the programme. Many also highlighted opportunities for improved cross-site communication. Recommendations for future phases of the shadowing programme are discussed.

Abstract number: 302
Presentation type: Poster
Session: Service Organisation and Place of care

The challenge of communication in the dying phase: Evidence from a recent cancer network benchmarking exercise using the Liverpool care pathway (LCP).

Maureen Gambles, **Deborah Murphy John Ellershaw**, Marie Curie Palliative Care Institute Liverpool, Liverpool, Great Britain.

Background: A benchmarking exercise using the LCP to assess the delivery of care in the dying phase was undertaken recently in a cancer network in the north-west of England. A total of 315 patients from 16 organisations (5/9 hospitals (96 patients), 6/8 Hospices (119 patients) and 5/7 Community Teams (100 patients) whose care in the dying phase was delivered via the LCP were included in the sample. LCP goals focus on encouraging optimum symptom control, appropriate and timely communication about prognosis and religious/spiritual and emotional support. Evidence from the communication skills literature illustrates the challenges for healthcare professionals in entering into communication with patients and carers around such sensitive topics.
Aim: To evaluate performance on goals concerned with the communication with patients to highlight areas requiring future educational input.
Results: The percentage ‘achieved’ for goals concerned with explaining the deteriorating condition of the patient and the change in the emphasis of care to relatives was high across all sectors (85% achieved – hospital; 93% achieved – Hospice; 90% achieved – Community). However, percentage ‘achieved’ recorded for conversations of a similar nature with patients was much lower, particularly in the hospital sector (48% achieved – Hospital; 66% achieved – Hospice; 75% achieved – Community). Percentage ‘achieved’ for goals relating to religious and spiritual assessment for patients and relatives was also lower in the Hospital sector (65% achieved).
Conclusion: Though communication with relatives appears to be taking place routinely across sectors, relatively high levels of missing data suggest that communication with patients in the dying phase appears to be a challenging area for health professionals. Future research should address health professionals’ perceptions of the particular challenges inherent in such communication, so that appropriate education can be specifically targeted.

Abstract number: 303
Presentation type: Poster
Session: Basic and Translational Research

Valuing variance: An in-depth exploration of how variance is reported on the liverpool care pathway (LCP) for the dying

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Background: The LCP is a multi-professional document providing an evidence-based framework for the delivery of care in the dying phase. Goals focus on comfort measures, anticipatory prescribing, discontinuation of inappropriate interventions, psychological and spiritual care for patients and families, and care provided after the death of the patient. An important element of the pathway is variance reporting, which facilitates explanation of the clinical rationale and/or issues underpinning variations from planned care.
Aim: To assess the quality of variance recording on the LCP in one cancer network in the north-west of England.
Method: Phase 1b of a recent benchmarking project extended its focus to include the analysis of the variance sheets of 394 patients who had died on an LCP across a cancer network. The sample comprised up to 20 sets of data from each of 5 PCTs, 6 hospices and 11 hospitals. An audit proforma was developed to identify the number and nature of the variances recorded, how often a corresponding entry was made on the variance sheets when a variance had been ticked against a goal, and whether the variance reported comprehensive and useful information.
Results: Preliminary analysis revealed that 1150 entries were made on the variance sheets which, particularly where variance sheets were well structured, included useful descriptive information and appropriately outlined any action taken. The majority of entries were recorded against goals on the ongoing assessment section, and were primarily for pain, agitation and respiratory tract secretions. In just under one third of cases, goals ticked ‘no’ on the Initial Assessment and Care After Death sections had a corresponding explanation on the variance sheets.
Conclusion: The results indicate the need for further education to stress the positive role of variance reporting and have led directly to the refinement of variance sheets to further improve reporting.

Abstract number: 304
Presentation type: Poster
Session: Service Organisation and Place of Care

Mapping palliative care in the six member countries of the Middle East Cancer Consortium (MECC): Reviewing historic development and current service provision

Amanda Bingley, Institute for Health Research, Lancaster, Great Britain, **David Clark**, Lancaster University, Lancaster, Great Britain

Aim: To assess the current state of palliative care in Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey, exploring the perspectives and experiences of health professionals involved, with a view to stimulating professional networks and future development.
Methods and analysis: Multi-method review involving a synthesis of evidence from published and grey documentary literature; ethnographic field visits to 4 countries; qualitative group or individual interviews with 48 individuals, emailed information from 12 individuals in all 6 countries; collation of existing public health data. Participants were hospice and palliative care professionals including clinicians and managers, and also interested academic researchers.
Results: The 6 MECC member countries report a total of 37 palliative care services, 18 specialist pain units with some emerging palliative care and 4 services in early stages of development. In 3 countries, at least 1 non-government organisation (NGO) for cancer patients offers support at the end of life. Service provision is highly variable: only 2 countries have widespread, specialist services, 3 have fewer than 3 active services but are promoting development; 1 has no active specialist service but support is offered where possible in oncology units or via an NGO. Good opioid availability in 4 countries contrasts with difficulties in 2 others.
Conclusion: Flexible, efficient models for services exist in the region, but long term military and political conflicts pose challenges for training, service development and provision. Other difficulties include opioid phobia and lack of financial resources. Despite these problems the majority of countries are experiencing improvements in provision and training, and in professional and public awareness.

Abstract number: 305
Presentation type: Poster
Session: Service Organisation and Place of Care

Quality of out-of-hours palliative care in general practice

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Background: Dutch general practitioners (GPs) provide twenty-four hour palliative care to (cancer) patients at home. In the last decade large-scale GP centres have taken over GP care outside ordinary business hours. Each centre covers a population of about 100,000 people. Many GPs worry about the quality of palliative care provided by the GP centres.
Research aim: Improving out-of-hours palliative care provided by GPs. This study addresses two research questions. 1. Which problems do GPs report about out-of-hours palliative care provided by GP centres? 2. Which measures do GPs propose to improve the quality of out-of-hours palliative care?
Method: Three focus group interviews were held with eight to ten GPs each. Audiotapes of the meetings were transcribed, items concerning 'problems' and 'measures' were extracted by two researchers, and checked by the focus group members. Results: GPs reported as main problems: 1. GPs on duty have no access to patient records, and a summary of relevant medical information is often lacking. 2. GP centres often deal with palliative patients by telephone whereas a home visit would be required. The following measures were proposed: 1. Development of a palliative care form to transfer relevant medical information. Information on expected complications was considered essential, as was information on agreements with the patient and family on end-of-life decisions. 2. Implementation of the palliative care form with a training session on using the form, on anticipation in palliative care, and on the importance of home visits followed by evaluation and audit.
Conclusions: GPs are in need of a palliative care form to inform their colleagues on duty about the medical condition, anticipated medical decisions and agreements with palliative patients and their families. Currently the effectiveness of the palliative form is being evaluated in a controlled trial.

Abstract number: 306
Presentation type: Poster
Session: Service Organisation and Place of Care

Preferred place of death in terminal illness

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It is frequently asserted that 65% or more of patients with cancer would prefer to die at home. However, research in this area has often asked questions of a well population or patients and families early in the illness history and has not focussed on patients without cancer despite the recognised need to extend services to this group. These estimates have led to many initiatives to organise home based palliative services to achieve death at home for those who desire it.
Method: A short postal questionnaire was designed to explore whether GPs routinely ask preferred place of death in adult patients in receipt of palliative care (both cancer and non-cancer), how comfortable GPs feel asking about preferred place of death and the documentation and communication of this information to others. This was sent to 112 Scottish GPs working in two geographical areas and 52 replies received (46%).
Discussion: Discussing a preferred place of death with any particular patient requires great sensitivity but it is essential if an otherwise unspoken desire to die at home is to be realised. The recording and communication of this information when known is important and needs to be improved if inappropriate admission is to be avoided. GPs ask this question more frequently in cancer patients (56%) than non- cancer patients (30%). There is further work to be done around the issues of communication in non- malignant disease 94% of GPs find it easier to discuss the preferred place of death in patients who raise it themselves and 50% of GPs still feel it is easier to discuss with a carer or family member who raises it rather than the patient. It is important to note that if only 56% of the 25% deaths due to cancer have their preference known (14% of all deaths) and only 30% of the rest (22.5% of all deaths) the preference is only known for less than 40% of all deaths. Much needs to change if we want to get close to 65% dying at home.

Abstract number: 307
Presentation type: Poster
Session: Service Organisation and Place of Care

Providing home palliative care for oncological children: A hospital-territory integrated experience

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Preference: The management of home palliative care for oncological terminal children is one of the best choice to guarantee quality of life to the patients and families. From 1991 in Veneto region is activated a multiprofessional, interdisciplinary team of Palliative care, until 2004 mostly voluntary. In 2004, after a Regional law disposition, this group became the referent for the planning, the coordination and the evaluation of the interventions for palliative care and antalgic therapy both in hospital and in home care. The palliative care team organizes for every child the specific palliative home care program, in closely contact and integration with the territorial services and the local hospitals. It permanently supports the territorial services being available for consultations, programmed home visits to patients, call service for patients, families and operators 24 hours a day, 365 days a year, and availability for emergency evalutations made both from the team operators and other specific specialists activated according to the child's specific needs. All the personal that follows the child and his family in home care program is involved in periodic meetings to evaluate the efficiency of programmed interventions, and to reconfirm or change the approach modalities, depending on the situation's changes. After a child's death, there are meetings between the equipe and parents (individually or in group) to help the whole family in dealing and to go over the mourning and evaluate the intervention's quality. During these 14 years, the team took care of over 180 children with terminal oncological disease. 70% died at home, with acceptable quality of life, respecting child's and family's wishes, preferences and needs, and good social retrieval. Among the barriers for provision of palliative care we meet difficulties to integrate hospital with home care approach, and cultural impediments in sanitary and social contests.

Abstract number: 308
Presentation type: Poster
Session: Service Organisation and Place of Care

Palliative Care Directories in the WHO European Region

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A Directory is a database of useful resources for people that use it as a communication tool. In Palliative Care context, several Directories have been developed in different geographic areas. They provide information for professionals, patients and careers, and general public. We studied the Palliative Care Directories that have been published in WHO European Region in order to know their main features. This work is included in the study about the reality of Palliative Care in Europe performed by the "Development Palliative Care in Europe" Task Force of the EAPC. The work has been split in two studies: the first one exclusively directed to the Directories that have been appeared as a printed edition and the second one to those that are available on-line. We carried out a systematic review of the literature including NLM catalogue, Network of Spanish University

Libraries (REBIUN), Internet search and meta-search engines. In addition we asked the EAPC Secretary and National Associations on Palliative Care. We completed our strategy with a round of talks with experts in Palliative Care. Our search strategy was: 1# "palliative care" OR hospice; 2# directory OR resource OR list; 3# 1 AND 2. In the first study we founded six printed Directories: Spain, France, Germany, Italy, Ireland and UK. All of them presented data about location and Services available. Only the Spanish one gives information about activity and all team members. In the second one, 12 on-line Directories were registered: Spain, Austria, France (3), Germany, Israel (IAHPC), Italy (2), Scotland, Ireland and UK. All of them give information on location; 9/12 shows an interactive map for a geographic search; only 4/12 can be updated on-line. Only nine countries from the WHO European Region have available Directories on Palliative Care, six of them have both printed and on-line versions. All of them give information on location and most of them also on structure. Only one gives information about activity.

Abstract number: 309
Presentation type: Poster
Session: Service Organisation and Place of Care

Dying at home or in an institution: evaluation of symptom burden and medical care

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For most people dying at home is preferable to dying in a health care institution. However, this preference seems to become less obvious when death is nearing, possibly due to the awareness that dying sometimes involves problems and symptoms that are best treated by professional caregivers in an institutional setting. We investigated to what extent cancer patients die at the place they prefer and whether the care that is provided in various settings is differently appreciated. We followed 103 patients with incurable cancer until their passing away. Attending physicians filled out a written questionnaire on patient and care characteristics. For 63 patients, a bereaved relative was willing to be interviewed after the patient's passing away. Of all patients, 49 died in an institution (mostly a hospital) and 54 died elsewhere (mostly at home). Place of death was not related to the personal characteristics of patients. According to the bereaved relatives, 26 out of 63 patients had expressed a wish to die at home: 20 were able to do so. Five patients had preferred to die in an institution and all 5 were able to do so. The remaining 32 patients had no or occasionally other preferences. Fatigue, loss of appetite and pain were the most common problems during the last 3 days of life in all settings. Anxiety was the only problem that was significantly more common among patients dying in an institution. According to the relatives, most symptoms were medically treated in both settings. Fatigue and psychological problems were typically ignored. Most relatives were quite satisfied about the provision of medical and nursing care during the last 3 days of life. We conclude that many Dutch cancer patients do not seem to have a clear preference concerning their place of dying. The place of dying does not seem to involve clear differences in symptom burden, level of symptom treatment and satisfaction of bereaved relatives.

Abstract number: 310
Presentation type: Poster
Session: Service Organisation and Place of Care

Hospital admissions and place of death in lung cancer patients

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Background: Lung cancer is the main cause of cancer death in Denmark. A large proportion of the patients has a short survival and a substantial palliative care need. Studies have indicated that 50–80% of cancer patients want to die at home. In Aarhus County a specialist palliative care team and hospice were established in 1999, in Funen County these services began in 2003 and 2004 respectively. The Counties have about 500.000 inhabitants each, representing 20% of the Danish population.
Aim: In lung cancer patients in Aarhus and Funen Counties for two periods (1998 and 2001) to describe: 1) Place of death 2) Extent and cause of hospital admissions in the last month of life Method & material: Descriptive, retrospective register study. Data on time, place of death and hospital admissions were retrieved from three national databases. Data were obtained on a total of 1425 lung cancer patients.
Results: In Funen County in 1998 ($N = 307$) 61% died in hospital, 28% in home, 10% in nursing home and 0% in other places, in 2001 ($N = 311$) the figures were 59%, 32%, 9% and 1% respectively. In Aarhus County in 1998 ($N = 400$) 56% died in hospital, 29% in home, 15% in nursing home, and 1% in other places, in 2001 ($N = 407$) the figures were 52%, 30%, 13% and 5% respectively. In Funen County there was no difference in place of death in the two periods. In Aarhus County significant more deaths were in other places (mainly hospice) in 2001 compared to 1998 ($p < 0,01$). In 1998 89% (mean 11 days) of the patients in Funen County were admitted to hospital in the last month of life, in 2001 it was 78% (mean 11 days). In Aarhus County 73% (mean 13 days) were admitted in 1998, and also 73% (mean 12 days) in 2001.
Conclusion: A large proportion of the patients were admitted to hospital in the last month of life, and on average the patients spent nearly two weeks of this period in hospital.

Abstract number: 311
Presentation type: Poster
Session: Service Organisation and Place of Care

Hospital doctors' and nurses' educational needs in palliative care-A questionnaire survey before starting a palliative care service

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Background and aim: In most counties in Denmark a palliative care team has been established or is planned. There are six hospices with a total of 69 beds. Nearly sixty percent of Danish cancer patients die in hospital. In Vejle County with 350.000 inhabitants a specialist palliative care team started clinical work in June 2005. A questionnaire study was carried out in June-Aug. 2005 to assess the attitudes to and educational level of palliative care in hospital staff. The intention was to uncover the educational needs and use this information in planning the educational effort of the team.
Method and material: Cross-sectional questionnaire study. 1032 doctors (31%) and nurses (69%) in departments expected to take care of palliative patients were asked to participate. 576 responded (response rate 56%), 178 (31%) doctors and 398 (69%) nurses.
Results: 85% of responders agreed that palliative care should be an integrated part of the treatment in their department. 56% thought patients' need for pain-treatment was well met, but other needs as e.g. spiritual support and attention to cultural determined needs was met to a much lesser degree. 79% of responders have felt the need for emotional/psychological support in their work with dying patients, 24% had access to supervision or the like. More than 80% of responders have had no or less than 5 hours of training in treatment of pain and other symptoms and bereavement. Only 9% did not think they needed further training in palliative care.
Conclusion: The hospital staff reports a need for optimizing palliative care in the hospital setting and there is a substantial need for education in most subjects on palliative care.

Abstract number: 312
Presentation type: Poster
Session: Service Organisation and Place of Care

Evaluation of one year hospice home team work in Zagreb, Croatia

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According to recent data 76% of healthy population in Croatia prefere to die at home. Palliative care(PC) provided a good symptom control and a better quality of life, but is not available in Croatia to all dying patient. The interdisciplinary home care teams provided PC in Zagreb from 2000. Home care visites(doctor, nurse, social worker) from 1st september 2004–30th september 2005 were evaluated. There were 50 patients with advanced cancer, 30 female and 20 male, age 34–80. 47 patients died and 3 are still in care 37 (80%) died at home and 10(20%) died at hospital or private nursing home. We analyzed who were main caregivers, daughters 19 (40%), wifes11 (20%), sons 7 (12%), housband, mothers 5 (10%) and 3 patients were alone and they are looking for hospice. Our work were valueted by caregivers or other family mambers 30 (60%) were satisfied, wrote a thanks letter or participated in our activites 10 (20%) asked for eqiupment or volunteers, 5 were looking for hospital or 24 hours home care, 2 were angry on whole health care system, but they accept our help 40% of our patient were in care 2 weeks or less and they had good pain control mostly by fentanyl patches. Conclusion PC must be available to all dying patients so they had a better quality of life and good simptom controll, and hellp the caregivers in their holly mission. Hospice home care visites can not be sufficient for patient who lives alone so the hospice or palliative unit is necessary.

Abstract number: 313
Presentation type: Poster
Session: Service Organisation and Place of Care

Young Adults with Cancer: Implications of the palliative care setting

Anne Grinyer, Lancaster University Lancaster, Great Britain

Earlier research amongst the parents of young adults with cancer suggested that the being on a ward with children or with much older adults was experienced as inappropriate and sometimes distressing. Thus the aim of this study was to understand the impact of place of care for this age group. The qualitative methods used included individual in depth interviews with outpatients who had been treated on adult and children's wards, interviews with inpatients on a specialist adolescent oncology ward and observational research in the specialist ward. The thematic analysis of the data was achieved through the use of data reduction techniques. The results suggest that the setting of care can have a far reaching effect on feelings of well-being. Even good quality care in an environment experienced as inappropriate led to feelings of isolation while the culture of a specialist facility was perceived to be supportive and empathetic. The visits of day patients from general wards to the specialist unit to lessen isolation emphasised the difference in culture and demonstrated the value of meeting others in the age group undergoing a similar experience. Young people facing changes in their appearance, disrupted life trajectories, separation from peers and threats to the 'normality' of young adulthood, found support and reassurance when introduced to a similar cohort. Nevertheless, the bonds formed between patients on a teenage ward coupled with the possible death of peers resulted in feelings of loss and survivor guilt that may not have been the case in a non-specialist facility. Conclusions are that the emotional well being of young adults with cancer was enhanced when care took place in an adolescent unit. Despite the potential loss of newly made friends the benefits of the atmosphere, environment and culture mitigated feelings of isolation and the loss or 'normality' so acutely felt at this life stage.

Abstract number: 314
Presentation type: Poster
Session: Service Organisation and Place of Care

An action research project to modernise the Minimum Data Set (MDS) for Specialist Palliative Care Services in the United Kingdom

Claire Littlewood, **Deborah Murphy**, **John Ellershaw**, **Barbara Jack**, Marie Curie Palliative Care Institute Liverpool, Liverpool, Great Britain, **Ann Eve**, **Erica Young**, **A Khatri**, The National Council for Palliative Care, London, Great Britain

Background: The Minimum Data Set (MDS) for specialist palliative care services was developed in 1995 to provide annual data on palliative care services. The development of payment by results and health resource groups together with identified limitations of the current MDS including missing data, the potential for double counting and a 68% return rate, resulted in a current collaborative project between the National Council for Palliative Care and the Marie Curie Palliative Care Institute Liverpool to revise and update the MDS.

Method: A modified action research approach was selected for the project. A purposive sampling was used to invite key stakeholders including the multidisciplinary specialist palliative care services involved in the completion of the MDS from across England and Wales. 28 respondents attended 2 workshops, where each section of the MDS were discussed and revised. Revised sections were then returned to the participants for review and comments.

Results: There was a consensus that the MDS did not completely reflect the current patient workload, the extent of services provided or the development of integrated palliative care services. Additionally with the development of regional Cancer Network Groups (CNG) some data was more appropriately collected regionally by the CNG.

Conclusion: A modified action research approach enabled a national consultation process to be completed effectively. The involvement of a wide sample of stakeholders ensured the revisions were made based upon a national consensus of opinion and met the changing provision of specialist palliative care services. Further information regarding the action research process, the changes made to the MDS and forthcoming pilot will be presented.

Abstract number: 315
Presentation type: Poster
Session: Service Organisation and Place of Care

Focus on patient safety in palliative home care

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Background and aim: An important issue of the advanced home healthcare service (ASIH) is the palliative care of patients. ASIH cares for around 75 patients at home. As a result of an organisational change at ASIH during the spring 2004, most of the patients no longer receive their drugs on prescription, but instead dispensed from the ward stock by nurses for one-week consumption. Practical reasons with, e.g., all nurses involved in the drug handling process have however increased the risk of incidents. Thus, addressing an improved patient safety, the aim of the present study was to decrease the drug-related problems (DRPs) with 50%.

Method: A quasi-experimental strategy, the time-series design, was used for the PDSA (Plan, Do, Study and Act) study. A baseline period is followed by the introduction of interventions.

Results: Drug-related incidents include problems related to the drug handling process as well as the use of drugs per se, e.g., lack of an indication for a drug. During two pre-intervention observation periods of two weeks each, a total number of 54 and 41 DRPs, respectively, were identified. The majority of the problems concerned the drug charts and the drug dispensing process. From the last period the projected annual cost was estimated to 6000 EUR for the physicians and 9000 EUR for the nurses. From the survey of incidents, knowledge has been gained about possible functional and causal relationship between changes in behavior and impact on the outcome. This understanding has resulted in different multifaceted interventions for improvement, e.g., technical solutions and pharmacists involved in the drug handling process. In addition, the interprofessional collaboration, including pharmacists, has enlightened the different professional competence for their optimal use that may favourably affect the outcome.

Conclusion: A high potential for improvement in patient safety can be expected in the interprofessional drug handling process.

Abstract number: 316
Presentation type: Poster
Session: Service Organisation and Place of Care

Home maintenance failure and admission of 32 palliative outpatients at emergency department

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The purpose of the study is to understand the reasons that lead to the admission of palliative outpatients at the emergency department of a public hospital. The study discusses the organisation implemented by GP's at their patient's home in order to provide daily care and cater for palliative emergencies, as well as the circumstances of home maintenance failure. Two surveys were conducted: (i) a prospective survey covering outpatients admitted to the emergency department of the Saint-André hospital (Bordeaux, France); and (ii) a retrospective survey with outpatients' GP's. All 32 patients in the sample suffered from cancer. In each case, palliative emergencies occurred in the three months prior to hospitalization, most being treated at home. In 18 cases, we found a traditional home care team comprising the GP, a nurse and the patient's family. However, there should be no care continuity unless the family is involved in the provision of care. We found that communication inside the home care teams was poor. There was a lack of on-site psychological support for both family members and caregivers; this led to a rising feeling of insecurity within the teams. We further found that the eventual admission at the emergency department was explained neither by an extraordinary clinical situation, nor by any specific lethal risk for the outpatient. Rather, it was the result of a progressive mismatch between the home care team capabilities and the deteriorating clinical status of the outpatient. A psychological exhaustion of the caregiver in the team was also found to be a relevant cause. We conclude that the traditional home care team involving the GP, a nurse and family members cannot provide on its own the full support needed by a palliative outpatients in a long-term perspective. However, it can be possible to develop home palliative medicine with the help of a care network involving a local hospital, the GP and professional caregivers trained in palliative care.

Abstract number: 317
Presentation type: Poster
Session: Service Organisation and Place of Care

The map of specific resources of palliative care in Europe

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The EAPC Task Force on the Development of Palliative Care (PC) in Europe started its work in 2003. In 2005, after carefully defining the work method and gathering the necessary personnel and material resources, four studies were carried out, two about published scientific literature and two international surveys focussed on the understanding and evaluation of the development of PC in Europe. We report here on one of these surveys

The 'FACTS' Questionnaire is specifically designed to collect data about the state of PC in each Euroepan country. It is addressed to a 'Key Person' chosen for his or her knowledge and/or publications about the development of PC in that country. The questionnaire gathers data on the number and specific kinds of PC resources, as well as data on workforce capacity and qualifications, the target population, the financing of services. By October 30th, 2005, replies from 36/52 countries had been received (69% of the population studied). Further replies are anticipated up to the closing date of 31st December 2005.

The FACTS Questionnaire provides data that allow for a preliminary comparison of different features of the development of PC. A graphic representation of the results will be shown and a first Map PC Resources in Europe will be presented: The Map includes the total number of services per million inhabitants in each country, as well as the proportion of existing services of each type (Domiciliary Palliative Care Teams, Support or Mobile Teams in Hospitals, Hospices, and Day Care).

Abstract number: 318
Presentation type: Poster
Session: Service Organisation and Place of Care

Transference and Counter Transference as an Agent in Care

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Uncovering the nature and importance of the effect of transference and counter-transference, a central feature of all relationships, is an important but rarely undertaken task, especially within complementary therapies (CTs) that may be used for those with life-limiting illness and palliative care.

Aim: To explore the nature of the transference/counter transference relationship for those receiving aromatherapy massage within a palliative care setting.

Methods: A qualitative longitudinal study was undertaken centred on 10 theoretically sampled clients and their CT practitioners, with clients interviewed on three occasions (before, during and after the CT treatments), observation of the practitioner/client relationship and practitioner interviews. The taped, transcribed data was analysed using thematic analysis and language use, supported by the N-Vivo software package.

Results: Identifying features of transference/counter-transference is feasible and identifiable from the language which clients use, intonations, pauses and emotional responses. Key associations include memories of smells, colour, people, taste and colour, and of critical events surrounding the diagnosis and cancer itself. Features of transference and counter transference are also linked to perceptions of a satisfactory outcome and feelings of client well-being, and provide important and positive feedback to the providing practitioner.

Conclusion: Recognising and studying the importance of transference and counter transference in client-practitioner relationships within CT and palliative care is both important and feasible. This element of the client-practitioner relationship also forms a further specific effect to explore in uncovering the outcomes of CT.

Abstract number: 319
Presentation type: Poster
Session: Service Organisation and Place of Care

Palliative Care: Perceptions and referral practices of Australian specialists and general practitioners

Claire Johnson, **Afaf Girgis**, **Chris Paul**, The Cancer Council NSW/ University of Newcastle, Wallsend, Australia, **David Currow**, Flinders University, Adelaide, Australia

Introduction: Late or non-referral of patients to specialist palliative care services (SPCSs) impacts on quality-of-life for patients and their caregivers. General practitioners (GPs) and specialists are the main gatekeepers to SPCSs.

Aim: To investigate perceptions, barriers, triggers and practices relating to GPs' and specialists' referral of patients with advanced cancer to SPC; and to identify differences in practice between GPs practising in the city compared to other GPs and specialists.

Method: A self-report survey was mailed to a stratified random sample of 1523 Australian GPs and 1723 specialists.

Analysis: Frequencies, proportions and means were reported. Between group comparisons were made using Chi-Square analysis and T-Tests. Referral predictors were identified using multiple logistic regression.

Results: 31% (469) of GPs and 45% (699) of specialists returned surveys. City GPs saw fewer patients with advanced cancer than Other GPs or specialists, but referred to SPCSs at a higher rate. City GPs and specialists were more likely to report availability of comprehensive SPCSs

than other GPs. The most frequent reasons for referral by all doctors were: the presence of a terminal illness; future need for symptom control and uncontrolled physical symptoms. Psychosocial issues triggered referral less frequently. Main reasons for not referring were: the doctor's ability to manage the symptoms and the absence of symptoms. Apart from agreement that all patients should be referred to SPCSs, items associated with higher referral differed between GPs and specialists. Both groups included demographic, attitudinal and service related items as predictors of higher referral.
Conclusions: Doctors report readily referring to SPC for disease-related characteristics. Education is needed to improve referral where psychological, emotional, cultural and spiritual concerns are evident. Measures are needed to encourage more systematic and objective needs-based referrals.

Abstract number: 320
Presentation type: Poster
Session: Service Organisation and Place of Care

Dying in the emergency unit: A study on the caregivers' practices

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Introduction: The goals of emergency ward hospitalization units (EWHU) are to take care of severely-ill patients before their admission into a hospital department and to provide immediate intensive care. The number of deaths (1–2 per week) is one of the highest in comparison to other hospital units. However, death remains a relatively "surprising" event in such units. Our hypothesis is that the gap between the objectives of acute care and the frequent confrontation with death may induce breaks along the care practices leading to psychological suffering of the caregivers.
Methods: Both the approaches and the methodological aspects of our research, performed in two different EWHU, are clearly multidisciplinary.
Approaches, Objectives, Methods: 1-Epidemiology. To characterize the clinical care and the trajectories of the deceased patients. Restropective analysis of 300 patient files. 2-Sociology. To formalize the various aspects of care. Direct observation. 3-Psychology of work. To unveil the subjective relations to the work and analyse the representations of palliative care. Group discussions.
Results: The results obtained are both corrobatory and complementary. They show that, although there is no explicit palliative approach, informed palliative care giving does however exist, the goal of which being to improve the quality of the patient's life and the accompanying of the family. They also highlight some specific representations of palliative care : one is related to the care of very terminally-ill patients whereas another is linked to its non-professional content. Finally, our results lead to an increased knowledge of the causes of work-induced suffering.
Conclusion: The investigation of death in EWHU, still poorly developed, may however reveal changes in the dominant medical paradigm and raise the issue of the incorporation of palliative care in EWHU.

Abstract number: 321
Presentation type: Poster
Session: Service Organisation and Place of Care

Needs based utilisation of palliative care services in Australia: Overview of a program of work 2003–2009

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Background: Late or crisis referral and in some instances non-referral of patients to specialist palliative care (SPC) services impacts significantly on patients' and carers' quality of life. Ensuring those who need SPC are offered these services in a timely way remains a challenge.
Aim: To undertake a comprehensive program of work that will result in palliative care (PC) resources being allocated in a more systematic, objective and transparent needs basis.
Methods: Phase 1: A national qualitative study (n = 40) exploring perceptions of PC and issues surrounding referral in the Australian health care system. COMPLETED Phase 2: A national survey of doctors' (n = 1173) current referral practices, predictors of different referral patterns and the prevalence of triggers used to precipitate referral to PC. COMPLETED Phase 3: Development of national patient-centred consensus SPC Referral Guidelines and a Palliative Care Needs Assessment Tool (PC-NAT), to enhance SPC resource utilisation and increase equitable access to SPC. UNDERWAY Phase 4: Evaluation of the impact of the Guidelines and PC-NAT on patterns of PC (referral, utilisation and complexity of care) and on patient and carer outcomes. 2006–2008 Phase 5: National dissemination of the Guidelines and PC-NAT, with relevant training of referrers and PC services. 2008–2009 Phase 6: Generalising the resources to non-cancer palliative populations. 2008–2009 The presentation will describe the program of work and focus on early results of Phase 3 pilot testing.
Significance: Use of the Guidelines and PC-NAT is expected to reduce the incidence of late and crisis referral and improve referral where psychological, social, physical and spiritual problems are evident. Improved outcomes for patients and families are expected to include improved symptom control, quality of life and satisfaction with care.

Abstract number: 322
Presentation type: Poster
Session: Service Organisation and Place of Care

Making research in palliative care happen: attributes of our success

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Evidence-based practice in palliative care relies on the existence of good quality research. We know that there are well-recognised barriers to research in palliative care. Our research unit aimed to address them systematically from the outset. Specific strategies included: Appointing of a research manager to coordinate and facilitate the development of research within the organisation-Working with the institutional ethics committee to develop ethically sound research protocols and separately monitor research burden – Linking with the University to ensure health services students are exposed to palliative care and the associated research conducted by our organisation – Strengthening links with the clinical team to: reducing gate-keeping-ensuring research was clinically relevant and incorporated into routine practice-involving clinical staff in the research process to evolve the team culture to better enhance research-Incorporating research screening into routine clinical practice – Developing a diverse and highly qualified research team with a service commitment to facilitate career development – Strategic research direction geared to the needs of patients, caregivers, health professionals and health planners – Links with stakeholders and peak bodies in Australia in order to target research to areas of need – Strong commitment to multi-site research in recognition of the limitations of single site research – Close links with other clinical teams to facilitate translation into practice.
Conclusions: Research has become a core component of the work conducted by this palliative service and issupported by all clinicians. Our research organisation has produced innovative studies that are being recognised worldwide. Our ability to attract competitive funding is increasing providing a secure and long-term career structure for researchers in Southern Adelaide.

Abstract number: 323
Presentation type: Poster
Session: Service Organisation and Place of Care

Home zoledronic acid (HZA) in patients with bone metastases admitted to an home care program of assistance. Preliminary data of feasibility and safety

Davide Tassinari, Supportive and Palliative Care Unit, City Hospital, Rimini, Italy, **Barbara Poggi**, Hospice, Rimini, Italy, **Alina Fabbri**, Home Care Unit, Rimini, Italy, **Stefania Nicoletti**, **Emiliano Tamburini**, Department of Oncology, Rimini, Italy

Introduction: Bisphosphonates represent an effective and safe treatment in patients with bone metastases. The most part of bisphosphonate have to be administered EV, needing hospital accesses that can be difficult for patients with bone pain or low performance status, while oral formulations are often unpleased for side effects or difficulties in the assumption.
Methods: From January 2005 we have commenced treating patients with bone metastases and low Performance Status with HZA. All the patients with documented bone metastases, low performance status or difficulties in accessing to the oncologic department, are considered eligible and enrolled into the program. A clinical evaluation and a laboratoristic assessment of serum creatinina and calcium are performed in all the patients before every administration of HZA. An oral supplementation of calcium is prescribed in all the patients before commencing the treatment. Outcome analysis is performed recording the number of the administrations of HZA, the reasons of the interruption of the treatment, the number and severity of side effects, the number and the reasons of medical and nursing accesses at home, the sanitary costs of the treatment at home. Preliminary results (work in progress). Until now, 56 patients have been enrolled in the program. Neither major side affects occurred, nor any treatment had to be interrupted for toxicity. The median number of the administration/patient was 3 (range 1–8), and our preliminary results of activity/safety seem to be comparable with those obtained in hospitalized patients. The definitive analysis of the costs, activity and safety will be performed at the end of 2005.
Conclusion. Although our data are preliminary, HZA seems to be safe and easily administered to outpatients with bone metastases at home. The datum could be of interest, supporting the use of parenteral bisphosphonates at home when clinical conditions do not permit periodical accesses to the hospital.

Abstract number: 324
Presentation type: Poster
Session: Service Organisation and Place of Care

Palliative care network (PCN) as a model for an integration between clinical oncology and palliative care

Davide Tassinari, Supportive and Palliative Care Unit, City Hospital, Rimini, Italy, **Barbara Poggi**, **William Raffaeli**, Hospice, Rimini, Italy, **Adriana Pecci**[c], **Mirco Tamagnini**, Home Care Unit, Rimini, Italy

Introduction: Although medical oncology and palliative care are often distant dimensions in the treatment of patients with cancer, it is a common notion that an integration could improve the outcome in a comprehensive assistance to the patient.
Methods: To create a PCN in our Department, we promote the creation of a multidisciplinary team (MT) with oncologists (2), palliativists (1), psychologists (1), and nurses (2) with the aim of favouring the continuity of care along all the phases of the disease. The MT gathers the competences of the oncologic and palliative care units, and is coordinated by the responsible of the supportive and palliative care unit of the district. A personalized project is elaborated for every enrolled patient, assembling his history and needs. All the patients admitted to the PCN can continue to be followed by the oncologist that treated the patient before the admission, and the palliative care project are weekly updated by the MT. The outcomes of the PCN are evaluated every six months for activity and annually for efficacy.
Results: 1841 patients have been admitted in 2003–2004 period (265 in Hospice), and 670 (115 in Hospice) from January to September 2005. All the patients were evaluated before entering into the project, and more than 90% before changing the assistance setting. Preliminary data seem to suggest a positive impact of the shared approach against the symptoms of advanced or terminal disease, and satisfaction assessment is ongoing (work in progress).
Conclusions: The continuity of care is considered an index of the quality of care and an integrated model of palliative care should be elaborated in every oncologic district; oncologic departments seem to represent the ideal dimension where favouring an integration between medical oncology and palliative care and every effort should be made to realize this kind of integration.

Abstract number: 325
Presentation type: Poster
Session: Service Organisation and Place of Care

“Barriers” for Palliative Care in Hospitals: Perceptions of Doctors and Nurses

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Presently, the majority of people die in hospitals. Meanwhile, palliative care has been developing in the last years, but the “state of the art” points to the lack of quality in care given to people at the end of life in those institutions. The principal “barriers” are related with: the knowledge of health professionals, “medicalization” of death and a culture of healing associated to hospitals, and with difficulties in communication. However, in Portugal, there aren’t studies about this subject.
Objectives: Analyse the perceptions of doctors and nurses about the principal “barriers” for palliative care in hospitals. Analyse if there are significant differences between the perceptions of the two groups of professionals. Developed in Hospital Pulido Valente, in Lisbon. 222 health professionals participated in the study by filling a questionary with questions in the format of the Likert scale. The data were treated statistically with the help of the informatic programme SPSS.
Results: 83,4% of the respondents refer to have necessities of formation in palliative care. About half the answers indicate the use of invasive techniques and an ineffective control of pain in terminally ill patients. The majority of the respondents recognize that the quality of care can be neglected in hospitals. There are also detected difficulties of communication between health professionals and patients/families (due to lack of time or difficulty in taking care of people at the end of life). Comparing the two professional groups, nurses have more negative perceptions of the reality that they observe in their services and in the institution.
Conclusions: The obtained results reinforce the importance of develloping investigation in palliative care. In order to adopt measures to answer to questions like the persistence of “barriers” for a better quality of care given to people at the end of life, in hospitals, better results will be obtained if they are based on scientific evidence.

Abstract number: 326
Presentation type: Poster
Session: Service Organisation and Place of Care

Hospice and palliative care development in India: A review of services and experiences

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Aim: To assess the current state of palliative care in India, mapping the existence of services state by state and exploring the perspectives and experiences of those involved, with a view to stimulating new development.
Methods and analysis: multi-method review involving a synthesis of evidence from published and grey documentary literature; ethnographic field visits across India; qualitative interviews with 87 individuals from 12

states; collation of existing public health data. Participants were hospice and palliative care activists in India, including physicians, nurses, patients, patient family members, managers, volunteers and policy makers.
Results: 135 hospice and palliative care services in 16 states were identified. These are usually concentrated in large cities, with the exception of Kerala, where they are much more widespread. Non-government organisations and public and private hospitals and hospices are the predominant sources of provision. There are 19 states or union territories in which we were unable to identify palliative care provision. Development of services is uneven, with greater provision evident in the south than the north. For the majority of states coverage is poor. Barriers to the development of palliative care include: poverty; population density; geographic distances; opioid availability; workforce development and limited national palliative care policy.
Conclusions: Successful models exist in Kerala for the development of affordable, sustainable community-based hospice and palliative care services. These have arisen from adapting western models of hospice and palliative care for implementation in the India cultural context. Further work is required to ensure that the growing interest in hospice and palliative care in India is utilised to increase the momentum of progress.

Abstract number: 327
Presentation type: Poster
Session: Service Organisation and Place of Care

Palliative Care Needs Assessment in the Special (High Security Mental Health) Hospitals of England and Wales – Background Demographic Data

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Background: Current evidence indicates an ongoing need for a residual group of psychiatric patients to be cared for in high security units. At one such hospital difficulties have arisen relating to the delivery of palliative care to several patients. Though the numbers involved are small, the impact on hospital staff and patients is significant. Little is known of the level of need for palliative care services within UK High Security Mental Health.
Aims: To describe the inpatient population of the special hospitals of England and Wales to inform an investigation of the level of need for palliative care within these hospitals.
Method: A retrospective study of data held on hospital databases regarding 1440 patients admitted to Ashworth, Broadmoor or Rampton Special Hospitals from January 1995 to December 2004.
Results: 84.2% of patients were male. Median age at admission was 31 yrs (16–68). 81% were single and 15% separated, divorced or widowed. 65.3% were admitted from prison/police custody and 28.4% from a high or medium security hospital. 20% had a previous admission. 71.7% were white, 17.9% black and 10.4% from other ethnic groups. 82.4% were British and 97.2% understood English. 57.8% were Christian, 7.5% Muslim and 18.8% had no religious beliefs. In 59% of patients, either the next of kin was not known (23%) or there was no contact with those identified (36%). 60.4% were classed as having a mental illness and 21% a psychopathic disorder. 55% were discharged or transferred out of the hospital and 42.6% remain as inpatients. During the study period 34 patients died in the three hospitals.
Conclusions: UK clinical guidance directs that all patients should have equal access to palliative care. Providing care to this isolated group of National Health Service patients is a significant challenge. Further work including case reviews and seeking stakeholder opinion to investigate palliative care need more fully is currently being undertaken.

Abstract number: 328
Presentation type: Poster
Session: Service Organisation and Place of Care

Enhancing Primary Care Physician Capacity: PE-ace Model of Integrated Palliative Care Service Delivery

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Primary care physicians play a critical role in care of the dying but may lack the knowledge, skills, and confidence to deliver effective palliative care. More importantly, given the multiple domains of EOL support of an interdisciplinary palliative care team is needed to deliver comprehensive care that enables home death.
Purpose: The PE-ace project integrated interdisciplinary palliative care into family physician practices and evaluated its impact on outcomes of symptom severity, patient/family psychological distress, and patient/family/provider satisfaction with quality of care.
Aims: The principal aim of the project was to build primary care physician capacity to deliver quality palliative home care using multifaceted approaches such as academic detailing.
Study Design: A longitudinal cohort research design with repeated measures was used to evaluate the impact of the project.
Sample: An inception cohort of all eligible palliative patients/families (N = 100) in 3 group practices in a rural region (21 family physicians) were recruited to the project and followed until death.
Analysis: Descriptive statistics (means, medians, SD) were used to summarize sample characteristics. Repeated measures ANOVA and correlations were used to examine relationships between independent patient-related and illness variables on outcomes.
Results: Statistically significant changes in symptom severity and distress were noted for the sample, congruence between preferences and place of death, and patient/family satisfaction with care quality.
Conclusion: Integrated models of home care delivery should be considered in health care policy setting and future research should evaluate effectiveness in controlled trials.

Abstract number: 329
Presentation type: Poster
Session: Service Organisation and Place of Care

Comparison of the organisation of palliative care in Austria and the Netherlands: is there anything we can learn from each other?

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Austria and the Netherlands are developing different systems to provide palliative care. The organisation of palliative care was studied in the context of the country characteristics and the health care system. The data were obtained by literature research and semi-structured interviews. Austria has a structured system of palliative care that covers the hospital and social domain of health care. In the Netherlands there are different institutions, but there are no discerning definitions available. The policy of the government is to integrate palliative care into basic care. The Austrian strengths are: a plan in which palliative care is clearly classified with recommendations for future developments. The Austrian weaknesses are: financing structures outside the hospital domain are unclear, palliative care isn't available anywhere in Austria and the government has no influence in planning for palliative care structures outside the domains, it controls financially. The Dutch strengths are: the regional coordination authorities and the availability of palliative care in the whole country. The Dutch weaknesses are: unclear distinction between different palliative care institutions, financing comes from many different sources and the gap between professionals and volunteers. In Austria in contrast to the Netherlands there exist plans to solve most weaknesses in the future. The differences in the organisation of palliative care between Austria and the Netherlands and the connected strengths and weaknesses originate partly from country characteristics, health care system and the genesis of palliative care. This hampers the possibilities for transfer of strengths. Nevertheless it seems justified to conclude that the determination of definitions of the different institutions of palliative care can be recommended to the Netherlands, were the establishment of regional coordination authorities in Austria can be suggested.

Abstract number: 330
Presentation type: Poster
Session: Service Organisation and Place of Care

Variability of palliative care management in extremadura

Javier Rocafort Gil, **Emilio Herrera Molina**, **Mercedes Blanco Guerrero**, Servicio Extremeño de Salud, Mérida, Spain, **Laura Blanco Toro**, Asociación Española Contra el Cáncer, Mérida, Spain, **Silvia Librada Flores**, Asociación Española Contra el Cáncer, Badajoz, Spain

Introduction: One of the goals of the Regional Palliative Care Program of Extremadura (Spain) (PRCPEx), is to guarantee full coverage of palliative care (PC), and this is obtained increasing primary care provision of PC, and mantaining 8 PC teams, one in each health district. These teams must care for the most complex cases. All the PC professionals together realized in 2002 the same 400 hours training course. The aim of this survey is to compare different attitudes on the management of patients, measuring the variability between them.
Methods: In September 2005, a questionary was send to all the doctors and nurses working in the PC teams. The questions talked about the management of different problems. There were 5 common questions, and there were another 5 specific questions for doctors and for nurses. Each professional had to choose one of the 5 possible answers for each question. A template with the answers was made and the variability was measured by the cathegoric disperssion index (CDI) (100% = maximum variability).
Results: 17 physicians and 16 nurses answered the questionary (100% response rate). The common questions and their respective variability (CDI) were: Bereavement: 79,9%; Itch: 63,3%; Ethics: 58,5%; Interdisciplinay team: 80,1%; Evaluation: 54,2%. The specific physician questions and their respective variability (CDI) were: Sedation: 75,3%; Levels of care and relations: 14,6%; Bowel obstruction: 41,0%; Last days management: 36,3%; Administration: 96,0%. The specific nurse questions and their respective variability (CDI) were: Infusors: 77,1%; Relatives: 86,9%; Nurse rols: 14,6%; Management of crises without a physician: 49,8%; Family education: 27,3%.
Discussion: We have got a first apprximation of variability in our teams, but we need to know another similar surveys, in different regions, o in a different time. Then, it will be possible to compare the results.

Abstract number: 331
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Session: Service Organisation and Place of Care

Relative value units (RVUs) estimation in the practice of the palliative care teams of the servicio extremeño de salud

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Introduction: Relative value units (RVUs) are factors which allow the transformation of consumed resources by means of a procedure financially associated with those resources. The most common components are material and time. The objective of this study is to define the RVUs for the different services carried out by the Palliative Care Teams (PCT) in Extremadura.
Materials and Methods: Following the RVU estimation method, we have defined 6 services rendered by the PCT to estimate the cost, they are: Hospital consultation charged to other people (Hc), Home visits (Hv), Advising (A), Coordination (C), Teaching Sessions (Ts) and External Consultations (Ec). First of all, the PCTs conducted a survey for the first six months of 2005, in which we could define the% of time dedicated to each service by each one of the teams. The activities carried out for each service by the teams were determined and the first RVUs were defined dividing the average time for service values by the activity data and multiplying by 10 this result. The personal payment expenses were assigned to services and the warehouse and pharmacy materials and transportation expenses were assigned to the different services related to those expenses. Finally, and after ruling out the 2 extreme values, (superior and inferior) the averages were calculated, thus reaching the second and definitive RVU. Outcome 100% of the PCT (8/8) answered the questions related to the average time devoted to each activity. The percentage values were: Hc = 17.75%, Hv = 41.5%, A = 10.37%, C = 10.12%, Tsd = 10.12% and Ec = 10.12%. 100% of the management assigned expenses to each team, the total PCT expenses were: ?780,841.12. The calculated RVUs were: Hc = 1.1, Hv = 1.68, A = 0.14, C = 0.17, Ts = 2.9 and Ec = 1.28. There are large differences between them due to the difference in time devoted to each one.

Abstract number: 332
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Session: Service Organisation and Place of Care

A Retrospective Study of Deaths Occurring in a Tertiary Cancer Centre

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Background: In this Canadian Tertiary Cancer Centre (TCC), care is provided on an outpatient basis, while inpatient beds are available for purposes of active cancer treatment, investigation, and management of complications of treatment. One goal of the Regional Palliative Care Program, implemented in 1995, was to decrease the number of deaths from cancer occurring in acute care settings by creating hospice beds and increasing palliative care (PC) services in the community. The TCC PC Program has a role in facilitating access to hospice beds and community-based PC services.
Objective: To document the characteristics of deaths that occurred at the TCC over a 12 month period.
Materials/Methods: In this retrospective study, the charts of all inpatients who died at the TCC from March 2004 to February 2005 were reviewed.
Results: One hundred and nineteen patients died. The most common cancer diagnoses were haematological (28%) and lung (25%). Seventy-five% were receiving active cancer treatment at the time of admission. Eighty-eight% were palliative. Cancer treatment was the most common reason for admission (46%). Median time between last cancer treatment and death was 13 days. Median length of stay was 9 days. The TCC PC Program was involved with 57%. Thirty% died while awaiting hospice transfer. DNR had been established in 77%. For the 8 patients who had an advance directive, DNR status had been documented a median of 560 days prior to death. For the remaining patients, DNR status had been documented a median of 7 days prior to death.
Conclusions: A significant number of patients died while admitted to the TCC. The majority appeared to have been appropriate for care in a cancer centre. Therefore, it is important for cancer centres to have resources to support these patients and their families. Clinical outcomes of patients who died, and the issues of referral to PC, transfer to hospice, and relatively late establishment of DNR status, deserve further examination.

Abstract number: 333
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Session: Service Organisation and Place of Care

The Home Deaths Project

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Many people continue to die in hospital despite the fact that most people state their preference is to die at home.
Aim: The aim of this project is to better understand factors influencing the place of death of cancer patients by interviewing former carers (next-of-kin).
Sample: A population-based sample of bereaved carers of deceased cancer patients from Sydney, Australia was recruited.

Methodology: Data collection was by means of face-to-face semi-structured interviews, and a questionnaire based on literature review and validated by an expert committee.
Analysis: Interviews were tape recorded, transcribed verbatim, and subsequently analysed. Content analysis involved open coding, sorting, collation of coded excerpts and category development based on questions from the interview. Initial coding was undertaken by one researcher and verified by at least two other members of the research team.
Results: Twenty interviews have been conducted. Thematic analyses suggest that: being present at the death may be more important for the carer than the place of death, however, this may be more easily achieved at home; early in the disease trajectory, information regarding available resources-even just a contact number-would be helpful; and information on prognosis-balanced with hope-would help with carer decision making.
Conclusion: Findings from this population-based study may aid health care professionals in clinical decision making and service planning to better support people to achieve their final wish regarding place of death, whether or not they are referred to a specialist palliative care service. In this presentation we will further explore the emergent themes.

Abstract number: 334
Presentation type: Poster
Session: Service Organisation and Place of Care

Clinical profile of Patients referred to a Hospital Specialist Palliative Care Team in a General Hospital with a new diagnosis of malignancy

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Specialist palliative care referral may be appropriate from point of diagnosis but is more commonly perceived as occurring later in the disease trajectory. Hospital Specialist Palliative Care Teams provide an integrated acute service in hospitals where the diagnoses of malignany is commonly made We have reviewed the clinical profile of patients with a diagnosis of malignancy made during the HSPCT referral episode. Method 1 year retrospective review of HSPCT charts Data: demographics, diagnosis, referring specialty, symptomatology, patient priorities, ECOG, outcomes, Palliative Outcome Score Results 60 patients, 13.4% of total referrals.
Diagnosis: Bronchial 18; GI:19; Urogenital 11; Unknown 2; Breast:2; Sarcoma:1. Source of referral: Acute Surgery; 20; Urology:6; General Medicine:27; Oncology:5; Elderly Care:2; OP: 1 Reason for referral: 91% symptom control; 81% psychosocial support; 16% Hospice Transfer; 13% Homecare 17 Symptoms documented on initial assessment Priorities per patient range 1 to 6. Patient priority themes: Information and practical requirements (support at home, financial); Place of Care; future management (treatment plans, rehabilitation) psychosocial support (uncertainty, family support, shock). 17 Symptoms documented. Symptom prevalence Pain 65%. Nausea/Vomiting 20%, Dyspnoea 10%, Delirium 10%. 25 (42%) patients completed POS.
Outcome: 22% died, 52% discharged with palliative care follow up 7% Hospice transfer; 10% hospital transfer 8% no follow up. Mean length of contact with HSPCT:10.5 days (50% of patients 3.4 days).
Conclusion: Referral for Specialist Palliative Care is not traditionally considered at point of diagnosis. Supporting patients at this time is a predictable role of the HSPCT in a General Hospital. Symptom control is the most common reason for referral Symptom scores and prevalences documented are lower than for patients with advanced disease. Appropriate early referral facilitates further Specialist palliative care input.

Abstract number: 335
Presentation type: Poster
Session: Service Organisation and Place of Care

Pilot Development of a Specialist Palliative Care Service to a Community Hospital

Kathleen Sherry, **Maire O'riordan**, **Miriam Tadjali**, **John Bass**, The Ayrshire Hospice, Ayr, Great Britain

A joint Hospices and Specialist Palliative Care Services report has been produced in Scotland recommending. that there is increased input form specialist palliative care services (SPCS) into community hospitals. We describe a pilot study of the development of a specialist palliative care service to a local community hospital.
Method: Seven month retrospective review.
Data collected: Questionnaire survey assessing pre-service provision and knowledge of specialist palliative care; patient clinical profile and activity statistics.
Results:148 questionnaires, 63% response rate. GP's: 33% had a special interest in palliative care 10% had previous palliative care training, 90% were confident/fairly confident in the use of syringe drivers, 100% were fairly/very confident in the management of pain, nausea and vomiting. Delirium, psychological and spiritual distress were areas where all professionals were less confident 33% of GPs thought that all patients with palliative care needs should be seen by the SPCT. All staff requested further palliative care training.
Activity: 35 patients, age range 64 to 92 years, mean 78 years. 95% malignant disease. Reason for referral: 80% symptom control, 6% Hospice homecare.
Symptom prevalence: pain 60%, nausea and vomiting 31%, dyspnoea 17% delirium 11%. Outcome (available for 71%), 44% died, 32% discharged with hospice home care, 6% transferred to acute hospital, 12% still inpatient. POS: Patient derived symptoms: pain 64%, dyspnoea 77%, fatigue 82%, eating problems 60%, nausea 50%, constipation 50%, depression 36% anxiety 41%.
Conclusion: Palliative care is an integral part of Community Hospital care where patients may have a significant symptom burden and may benefit from Specialist Palliative Care advice/intervention. Further evaluation is essential and service development will impact on resources in terms of staffing education and training.

Abstract number: 336
Presentation type: Poster
Session: Service Organisation and Place of Care

Health care consumption and place of death among old people with public home care or residential care in their last year in life

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When developing care for older people in the last phase of life knowledge about type and extent of care as well as factors associated with place of death is needed. The aim was to investigate age, living conditions, dependency, formal and informal care and service among old people receiving public care and service during the last year in life, but also clarify place of death. The sample was drawn from the care and services part of in the Swedish National study on Ageing and Care (SNAC). Criteria for inclusion were being 75 years and older, had died 2001–2004 and having public care and services from the municipality during the last year in life. Data about care and service from the municipalities' were collected through municipal staff that filled out a form. Data concerning hospital care and outpatient care were received from the county council register. The material were analysed with a quantitative approach. Statistical comparisons were performed concerning age, housing and number of hospitals stays. Regressions analyses were performed to detect factors associated with place of death. The results showed that those living in their ordinary home were younger, had less dependency in IADL and PADL, and had more consumption of formal and informal care than those living in special accommodation. Furthermore, those living in their ordinary home and those having several hospital stays did more often die at hospital. More visits to physicians in outpatient care were associated with dying in hospital while living in special accommodation and high dependency in PADL was associated with death outside hospital. The conclusion of the study is that old people in their last year in life consume a considerable amount of both municipal care and service as well as care from the county council in terms of out patient care and hospital care. The last year in life seemed to be accompanied by a high number of hospital stays, which also in several cases ended with death in hospital.

Abstract number: 337
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Session: Service Organisation and Place of Care

Say what you mean-using discourse analysis to examine the mission statements of palliative care services

Margaret O'Connor, Monash University Peninsula Campus, Frankston, Australia

The language used in descriptions of palliative care has become the subject of increasing discussion within the literature and in local services. Because all language is highly symbolic and rarely neutral, palliative care services need to ensure that public statements are readily understood by those who require care and are consistent with the intent of the care offered.

Discourse analysis is a research method utilised to assist understanding of the commonly held views of a community. Because language in any group is socially and culturally situated; it gives construction to community identity; provides shared patterns of meaning and may indicate agreed values. There may also be a political connection between a discourse, the use of power and social change.

Discourse analysis was utilised in a study of published mission statements from 38 palliative care services in Australia. The study aimed to gain a picture of what statements were utilised in the public domain, in order to highlight language as a potential barrier to community understandings about palliative care. The statements were analysed, to examine the words and phrases used, the values expounded and other symbolic aspects of the language. Key words, themes, differences and commonalities were highlighted. Subtleties, like missing words and phrases and differing emphases between statements were also sought, drawing out the taken for granted notions that often lie beneath language. Little continuity was found between the statements, which may contribute to community uncertainty about what palliative care actually is. Euphemistic and inaccessible language was also noted as being a difficulty for the community as the intended audience.

This paper discusses these findings, with comment on the important symbolism of language. While palliative care services possess a certain pride in being distinctive, there is a risk in using "exclusive" language, that those who need care may have difficulty understanding.

Abstract number: 338
Presentation type: Poster
Session: Service Organisation and Place of Care

Linking the parts: Articulating the role of Consultant Palliavtive Care Nurses in Acute Hospitals

Margaret O'Connor, Monash University Peninsula Campus, Frankston, Australia, **Ysanne Chapman**, Research Fellow, School of Nursing & Midwifery, Monash University, Australia

The role of consultant palliative care nurses in acute hospitals has developed over the last ten years as an integral part of service delivery. Despite this, there is little evidence or literature that describes what contributes to the success of this role. Anecdotal reports indicate that the role has become pivotal to both staff and patients-in connecting services, in liaison and advocacy, both within the hospital and to other services that may be required at home.

A three phase study was undertaken to explore aspects of these roles; to ascertain strengths and limitations and thus provide direction for further development. The study, involved 12 consultant nurses, from 12 acute hospitals; the design incorporated included interviews with the palliative care nurse consultants, data collection to measure the extent and type of activities undertaken; and interviews with the nurse consultants managers

The aims of this study were:

- to describe and document aspects of the role of consultant palliative care nurses in acute hospitals;
- to evaluate the role from the nurses themselves;
- to utilise this information to write a position paper and to make recommendations for best practice in the future development of this role.

The first phase revealed very little commonality in terms of job description, title or pay rates. Four distinct themes emerged from the interviews – institutional "responsiveness within the role"; community-"making the links outside"; positive aspects " breaking new ground"; and challenges in the role-"balancing a double-edged sword".

The roles displayed local idiosyncrasies, responding to local need, but all of the roles were regarded as pivotal in being a tangible contact for families and staff to receive additional support and assistance with dying This paper reports on the above results and makes recommendations for further work that will assist in the more uniform development of the nurse consultant role.

Abstract number: 339
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Session: Service Organisation and Place of Care

Working with cancer patients and carers to develop effective models for the delivery of primary palliative cancer care

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Aim: To develop, with cancer patients and carers, feasible models for primary palliative care.

Methods: Participatory action research. Two groups of cancer patients and carers met monthly for ten months to identify challenges in providing primary palliative care and suggest interventions. Findings from interviews with 16 key professionals and policy documents, were integrated to develop a care framework. This was piloted in five General Practices. The delivery models were evaluated, jointly with the groups, via interviews with staff, patients and carers, fieldnotes from researchers, and document analysis.

Results: The group members resisted attempts to fragment their experience of cancer. They wished a palliative care approach from diagnosis of a life threatening disease. Their framework started with interventions at diagnosis, covering information, communication, equity, and holistic, patient-centred care. It highlighted four other key times, during treatment, after discharge, at recurrence, and final weeks, when support from a known member of the primary care team was valued. The pilot practices developed different models for delivering the framework, including a web-based register, a cancer care protocol, and the use of monthly cancer care meetings.

Conclusions: The framework identified a key role for primary care in offering all patients continuity of care and information that is patient-centred and holistic, throughout the cancer trajectory, with proactive and ongoing contact as its central tenet. The framework differed from professionally developed ones in its focus on the processes, and relational aspects of care. The approach successfully integrated patient and carer perspectives, central to the "quality and outcomes" framework being developed for the care of people with cancer in the community, and is transferable to other progressive illnesses. The range of models developed enshrine the framework's principles and offer flexibility to adapt to local contexts.

Abstract number: 340
Presentation type: Poster
Session: Service Organisation and Place of Care

Primary palliation? – Taking care of cancer patients in the primary sector

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Background: Palliative care for cancer patients is an important part of a GP's work. Although every GP is frequently involved in care for terminally ill cancer patients, only little is known about how these palliative efforts are perceived by the patients and their families, a knowledge that is vital to further improve palliative care in the primary sector.

Aim: The aim of the study was to analyse the quality of palliative home care with focus on the GP's role based on evaluations by relatives of recently deceased cancer patients and professionals from both the primary and secondary health care sectors.

Method: A number of focus group interviews were conducted with three types of subgroups: 1) Bereaved relatives, 2) GPs and 3) Various health-care-professionals, namely community nurses, hospital physicians and GPs. The interviews were transcribed and analysed according to a phenomenological approach.

Results: The analyses revealed several key areas, e.g.: 1) How to take, give and maintain professional responsibility for palliative home care. 2) A need for transparent communication both among primary care professionals and among professionals across the primary/secondary interface. 3) The primary sector needs easy access to specialist advise, supervision and empowerment. 4) Better and easier communication pathways are important, both within the primary sector and across the sectors to improve accessibility.

Conclusion: Our study shows a need for improvements in palliative home care and provides important knowledge about how these improvements are achieved. The GPs want closer supervision and improved shared care. They want to be key persons in palliative home care, but to fill this role it is vital that they take or are given the responsibility in a very transparent way, i.e.: A way that is transparent, both to themselves, the patients and the relatives and to the other healthcare professionals involved.

Abstract number: 341
Presentation type: Poster
Session: Service Organisation and Place of Care

Perceived obstacles in palliative care in general practice

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Background: Knowledge of obstacles that hinder palliative care in general practice is important in facilitating GPs in their work with palliative care patients and increasing opportunities for patients to remain at home for as long as they wish. Our previous research has enabled us to identify levels on which obstacles occur.

Objectives: In this survey, we have concentrated on the prevalence of obstacles and how they vary among GPs.

Methods: We developed a questionnaire rigorously and used it to conduct a survey. The perceived obstacles were grouped as follows: communication; organization and co-ordination of care; knowledge and expertise; integrated care; time for relatives. The survey was carried out according to demographic and expertise development determinants in order to determine the variation associated with obstacles.

Results: We found that GPs experienced considerable obstacles in all aspects of palliative care. Problems with bureaucratic procedures, the time necessary to arrange homecare technology, and the difficulties brought about by the wish or necessity to obtain extra care were particularly common. The variables 'number of years of experience', 'specific educational meetings', 'region', 'practice setting' and '(multi-disciplinary) case discussions' were significant contributors to two or more scale or item scores.

Conclusion: Roughly, more years of GP experience and participation in educational activities resulted in fewer perceived obstacles. These results are capable of forming a basis enabling policymakers and practitioners to plan and set priorities in handling the obstacles encountered, choosing the (additional) expertise needed in the future, and putting in place the preferred expertise advancement activities.

Abstract number: 342
Presentation type: Poster
Session: Service Organisation and Place of Care

Quality of primary palliative care: Experiences of patients and their informal care providers

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Aims: Generally, palliative care patients prefer to stay and die in their own homes. In order to support patients in primary care and their informal care providers, it is important that their professional care providers gain insight in both their physical and emotional situation and in their experiences with the care they have received. Therefore, in this study we aimed to assess the quality of primary palliative care from the perspective of the patient and his/her informal care provider.

Methods: This crossectional observational study is part of a larger study on health care status and quality of life. Patients were initially informed about the study by their GP, only if the patiënt sent back a reply card, the researchteam was able to contact him for further information. Patients and, if present, an important informal care provider were visited at home by a researcher. Both quantitative- as well as qualitative data were gathered by means of questionnaires and interview. To assess the quality of primary palliative care, we have rigorously developed the Quality of Palliative Care-Questionnaire (QPC-Q).

Main results: 96 GPs participated. Together they announced 54 patients, data of 32 of them could be used. Both patients and informal care providers were quite positive about their experiences with concrete aspects of care. Both ranked the GP the highest; he/she can always be called upon. Both groups criticized the delay in acquiring care or material/equipment for care due to rules and procedures of organisations. Generally, the informal care providers were more critical in their opinions.

Conclusions: This study shows that patients in primary palliative care and their informal care providers are of the opinion that palliative care in primary practice is of a fairly good level. The critical comments as well as the positive findings are important input for improvements. This is relevant in the light of the increase of palliative care in primary practice.

Abstract number: 343
Presentation type: Poster
Session: Service Organisation and Place of Care

An interpretative phenomenological study of the meaning of resource allocation experienced by nurses working on a palliative care unit in Switzerland

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Purpose: To reveal the unarticulated skills and knowledge embedded in the clinical nursing practice of resource allocation (=ra).

Background: Most often ra is discussed at the macro-level of politics and budgets. No evidence was found regarding the clinical base of ra. Although ra decisions are made daily by nurses, they are rarely articulated.

Method: The research process followed the recommendation of van Manen (1990). Data were collected from six palliative care nurses by means of open ended unstructured interviews. Participants were asked to reflect on practices that would allow an understanding of ra. I facilitated and transcribed verbatim all interviews from Swiss-G. in German. After acceptance of the transcript I analysed the data.

Results: Each participant demonstrated another perspective of the phenomenon. The essence seemed to be the close association of ra and person. The nurses experienced resources as part of them, flowing through them and being marked by them. Their ability to allocate resources was bound to structures and ra decisions of the greater system. The opportunities and limitations were experienced indiv. and had effects on the nurses' condition, perception and readiness to meet needs, resulting again in effects on the team, the quality of care and the patients. These correlations are not always obvious and known.

Conclusion: Discussing ra highlights the complexity of the phenomenon, uncovers the skilled know-how, the clinical knowledge and the everyday ethical component. To learn from skilled nurses helps other nurses, especially trainees. Reflecting and discussing, deciding and carrying the consequences together supports individual nurses and prevents burnout. My study showed the danger of burning out in attempt to compensate for a lack of resources. More investigation helps to clarify situations and responsibilities. Discussion enhances conscious decision-making at the micro-level as well as at the macro-level of policy making.

Abstract number: 344
Presentation type: Poster
Session: Service Organisation and Place of Care

Telephone Advisory Services – who are they for and when should they operate?

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Analysis of 1132 telephone advice calls received over almost 3 years by a Specialist Palliative Care service covering a population of 200,000 provides information on who requests advice and their concerns. It also provides commissioners with information as to when advice is requested and may help in the prioritisation in use of limited resources.

In the period April 2003 to December 2005 there was an increase in the percentage of advice calls received out of hours. In 2003 thirty percent of calls were received out of hours whilst in 2005 it was fifty percent. Influencing factors will require discussion.

The information suggests that health professionals and users and carers alike require an advice line available 24/7. Health care workers from both primary and secondary care predominantly requested advice on symptom control, drug related issues and management of continuous subcutaneous infusions through a syringe driver. This information could impact on the development of education and training packages.

District Nurse advice calls also included a request for general support in relation to dealing with complex cases in the community. This information may inform the way reflective practice is developed within the service. Patients were infrequent direct users of the service but relatives and friends regularly requested advice in relation to symptom control and general support. They tended to use the service as often during normal hours as out of hours. General practitioners tended to use the service during normal hours. Hospital consultants did not use the out of hours service at all. The reasons for this are discussed.

Abstract number: 345
Presentation type: Poster
Session: Service Organisation and Place of Care

Providing palliative care at home: Does age or non-cancer diagnosis affect time spent in the care of the service?

Philippa Hughes, **Dr Bill Noble**, University of Sheffield, Sheffield, Great Britain

Specialist palliative care has become more widely available, but older patients and those with non-malignant conditions are less likely to access services. However, concern exists that extending access may overburden resources. In 2004 the Intensive Home Nursing Service in Sheffield UK, an end of life service using support workers in patients' homes, managed by qualified nurses, extended its service.

Research Aims: As part of a service evaluation we aimed to identify characteristics of patients that were associated with time in the service and death at home.

Method and analysis: We undertook a documentary review of patient referral data and compared time in care and death at home with patient characteristics.

Results: Of 603 patients referred to the service, 425 patients received palliative care. Half were aged over 75. Non-cancer diagnoses were found in 21%, and 53% were female. Fifty-nine percent died at home. The median number of days spent in the care of the service was 5 (quartiles 2, 12). No statistical difference in length of stay was identified in patients under or over 75 (median 5 days), or with non-cancer diagnoses (median 4 days) or cancer diagnoses (median 5 days). Men spent a median of 4 days receiving care, compared to 5 days for women ($p = 0.01$). Sixty percent of cancer patients died at home, compared to 58% of non-cancer patients, and 64% of those under 75 died at home compared to 60% of those over 75. Neither finding was statistically significant. More men than women died at home (65% and 54%) and this was statistically significant: $p = 0.021$.

Conclusion: Older patients and those with non-cancer diagnoses did not spend longer in care. Women spent longer in care, but were less likely to die at home. Concern that increasing access to palliative care to the elderly and those with non-cancer diagnoses would unduly overburden resources appears unfounded.

Abstract number: 346
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Session: Service Organisation and Place of Care

Who cares for those with no carers: Palliative care needs of "Home Alones"

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The aims of this national scoping study were to explore the issues of palliative care clients living alone without a primary carer, from a client and service provider perspective, and to provide evidence-based information to assist with service planning for this growing population, as community and home-based palliative care services are facing increasing challenges in service provision. The project methodology consisted of: 1. Analysis of services' records from three services in three Australian states (721 records). 2. (a) In-depth qualitative telephone interviews with 9 key health professionals (b) Face-to-face qualitative interviews with 11 clients from both metropolitan and rural settings, (c) Postal survey to a sample of health professionals from metropolitan and rural ($n = 47$). People living alone with a terminal illness had more hospital admissions and were less likely to die at home than those who have a carer, and more so if they lived in rural areas. However, the group with a carer appeared to have required twice as many visits and slightly more hours of service than the group with no carer. In terms of support services provided, clients with no carer needed considerably more assistance with hygiene, more home help, and management of their care required more liaisons with other health professionals. However, clients with a carer required more equipment, more oxygen and more counselling. Four main themes emerged from the interviews with health professionals: care challenges, differences in care provision, appropriate approaches to care, and essentials for an effective service. Clients talked about their support needs, physically, socially and emotionally. The study made recommendations to the Australian Department of Health and Ageing about services considered important in developing support structures for this growing population.

Abstract number: 347
Presentation type: Poster
Session: Service Organisation and Place of Care

Cooperation in primary palliative care: Results from the Dutch National Survey of General Practice

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Aim: Palliative care is considered to be a multidisciplinary approach. The ability to cooperate is an essential part of the competence of the general

practitioner (GP). The aim of this study is to investigate cooperation regarding palliative care between GPs and other carers and determinants of this cooperation.
Methods: For each patient that died during the one-year registration (2000–2001) of the Second Dutch National Survey of General Practice (DNSGP-2), the GP received a palliative care questionnaire to identify patients who received palliative care and to describe the patient characteristics, care characteristics (perceived importance of symptom treatment, psychosocial care and spiritual care) and cooperation with other carers. Frequency tables were used to express cooperation and chi-square tests were applied for differences. We modeled potential determinants of cooperation using logistic regression.
Results: Of the 375.899 patients, 2194 (0,58%) patients died during the study-year. GPs returned 1771 (73,3%) of the palliative care questionnaires. In total 743 (46,2%) patients received palliative care. Cooperation with informal carers (82,6%) was most prevalent, followed by cooperation with other GPs (70,8%), district nurses (63,0%), specialists (55,3%), the home care team (42,0%), pharmacist (25,4%), homes for the elderly (14,0), physiotherapist (9,8), volunteer (7,5%), spiritual carer (7,3%) and other carers (6,6%). Almost all GPs (97,7%) cooperated with at least one other carer. The best determinants for cooperation with other carers were lower age, cancer as underlying disease and psychosocial care as perceived important aspect of care.
Conclusion: Cooperation in primary care between GPs and other care providers is highly prevalent, with informal carers and other primary care givers as most frequent collaborators. Cooperation is more prevalent in younger patients, patients with cancer as underlying disease and psychosocial care as a focus.

Abstract number: 348
Presentation type: Poster
Session: Service Organisation and Place of Care

Specialist Palliative Care Nursing Service Model of care provision

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Aim: The aim of this paper is to highlight the benefits and burdens of an integrated Specialist Nursing Service within Primary and Secondary care as apposed to working within dedicated areas.
Background: Historically The Specialist Palliative Care Nursing Service was divided into four different areas, General Hospital, Community, Inpatient Specialist unit and Day Hospital. Specialist Nurses worked in isolation as a consequence this involved lone working and poor quality of effective communication. A waiting list was held for patients within the community to access a Specialist Nurse. During periods of individual Nurses leave there was no service provision. Stress levels for the individual and the service were at their utmost. A combination of personnel changes and team commitment promoted service development. This allowed the nursing team to explore service models of delivering high quality seamless care to patients and their families. An integrated model of nursing care was adopted within the four parts of the service New methods of working have not only benefited the Specialist Nursing Service but have had a positive impact on the whole Specialist Team, Primary Care, Secondary care and the patients and families experience. There is no longer a waiting list; new referrals are all seen within 48 hours (Monday-Friday). There is no break in service provision when team members are on leave. Communication is more effective within the whole service and team members are less stressed.

Abstract number: 349
Presentation type: Poster
Session: Service Organisation and Place of Care

An Audit of Hospital Consultants' Awareness of a Palliative Care Service: Do they know what we do?

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Background: There is little written on perception of hospital Consultants about the role, remit and effectiveness of hospital palliative care teams.
Aims of audit: 1. To assess Consultants' perception of the effectiveness of York Hospital Palliative Care Team (YHPCT) – preference on referral to YHPCT and mode of communication post assessment-knowledge of services available through the YHPCT 2. To highlight areas of practice that may need to change.
Method: A questionnaire was circulated to clinical Consultants. Most questions asked them to rank answers from a given list in order of importance. Results were analysed using the statistical package SPSS to identify whether there were any differences in referral preferences and knowledge between medical and surgical specialists.
Findings: 1. In general, the YHPCT are well thought of by Consultant colleagues. 2. Consultants would prefer to decide to refer themselves and ideally would like us to feed back to them or their Registrar. 3. Clinical Nurse Specialists and ward nurses are more highly ranked than junior doctors (pre-registration house officers and Senior house officers) regarding feedback and referral 4. YHPCT input is sometimes felt to be unnecessary, therefore we need to check consent before agreeing to assess 5. The majority of teams would be happy for us to alter medication directly 6. The majority would find an assessment measure to indicate referral criteria helpful 7. The majority of Consultants were unaware of the "out of hours" specialist palliative care advice service 8. The Integrated Care Pathway for the Dying has generally been found useful where it has been implemented 9. Palliative care as a Specialist Service is still contentious.
Discussion: This audit highlights areas for improvement in service, dissemination of information and changes in practice.

Abstract number: 350
Presentation type: Poster
Session: Service Organisation and Place of Care

Success criteria for multiprofessional cooperation in palliative care teams

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Introduction: According to relevant associations' definitions, team work is considered as a central component of palliative care. The emergence of new institutions (e.g., palliative care units) within this comparatively young field of medicine is mostly associated with the challenge of establishing a completely new team.
Methods: This study focuses on factors enhancing success as well as outcome criteria of team work in the perception of team members of a palliative care unit. The palliative care team at the University Hospital of Aachen (n = 19) has been interviewed 1 year after the unit's startup by the means of semi-structured interviews. The text material has been analysed using qualitative content analysis.
Results: Factors crucial to cooperation in the team members' views are: close communication, team philosophy, good interpersonal relationships and high team commitment, autonomy and the ability to deal with death and dying. Herein, a close communication was by far the most frequently mentioned criterium for cooperation. Team performance, good coordination of workflow and mutual trust are mainly used for the evaluation of efficient team work. Inefficient team work in the first instance is associated with the absence of clarity of goals, tasks and roles, as well as a lack of team commitment.
Conclusion: In a new team close communication evidently has a special significance due to the need for orientation in the midst of a new peer group. The results confirm the outstanding importance of clarity, commitment and close, positive exchange among colleagues for succesful team work.

Abstract number: 351
Presentation type: Poster
Session: Service Organisation and Place of Care

Guidleines for the development of psychological support services

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Background: Although psychological distress is commonly experienced by patients, studies suggest that identification and assessment of distress is far from optimal. Lack of rigor in the assessment of psychological distress is further compounded by disparity in access to appropriate support services. Aims To review psychological support service provision and provide guidelines for the development of services.
Method: As part of the Mersey & North Cheshire regional audit programme, a survey questionnaire was developed to assess knowledge of, and access to, psychological support services in the South Liverpool Clinical Network. Additionally, an overview of services across the region was provided by each Network Chair. Parameters assessed corresponded with those identified in the National Institute for Clinical Excellence (NICE) guidance on Cancer Services.
Results: Variances in the availability of support services were recorded. Although access to social work services is available in all 5 networks, access to clinical psychology and psychiatric services were limited; only 2 Networks had identified psychiatric support services; 4 networks had no referral criteria for psychiatric services. Further, of the 36 staff surveyed in South Liverpool, a majority felt confident in being able to identify psychological issues such as 'Well Being' (n =30) and 'Low Mood' (n =34). However, less felt confident in their ability to identify Depression (n =21) and Psychosexual Difficulties (n =10). In addition, staff were unsure whether specialist psychological (n =19) and psychiatric services (n =16) were available.
Conclusions: Regardless of severity, patients with psychological distress benefit from appropriate professional support. However, in order to access support, appropriate identification of distress and referral is required. In light of findings from this survey, and in line with NICE recommendations, guidelines for the development of psychological services are presented.

Abstract number: 352
Presentation type: Poster
Session: Service Organisation and Place of Care

Palliative Care Consultation: Overview and Analysis of Over 1300 patients

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Aim: In 2002 a palliative care consult service consisting of a physician, nurse practitioner, social worker, chaplain and pharmacist was established in this 645 bed tertiary care teaching hospital. The service is intended to: support to patients and families facing advanced illness; support staff caring for these patients; enhance clinical decision making during crisis; and improve pain and symptom management. The aim of this research is to describe the services provided to date by this consult service.
Methods: Retrospective study using descriptive analysis of the Palliative Care Consult Service administrative data base.
Results: During the first 34 months, 1303 patients and their families have been served, with an average of 55 patients currently seen monthly. The most frequent primary diagnoses for patients referred to the consult service were for: respiratory failure (12%), Carcinoma of the Lung (9%), Cerebral Vascular Accidents (8%), End Stage Heart Disease (8%), and End Stage Renal Disease on dialysis (4%). Breast cancer was the only other malignancy among the top ten diagnoses. Consult requests have been received from more than 200 physicians and resident physicians in training. The majority of the consult requests came from Intensive Care and Pulmonary/Critical Care specialists (40%) and Internal Medicine Physicians (28%). A cluster of reasons labeled "End of Life Issues" prompted use of the service for 70% of patients and their families. Other consult reasons included: symptom management (15%); pain management (8%); and family support (23%).
Conclusions: Tracking of patient outcomes shows that 38% died while in the hospital, 27% were formally admitted to hospice, 14% transferred to extended care facilities, and 12% went home. It is estimated that nearly 2300 unnecessary patient days were saved for the Intensive Care Units and the general medical floors. Patient, family and clinician satisfaction levels have been high.

Abstract number: 353
Presentation type: Poster
Session: Service Organisation and Place of Care

Can access to a hospice in-patient service influence the place of death of terminally ill patients receiving home care?

Tomasz Gradalski, St. Lazarus Hospice, Krakow, Poland

The majority of severely ill patients expect to die within their home environment. Choosing home as the place of death depends mostly on the family's ability to cope with the complex problems of dying and on constant support from competent carers. The continuity of care can be a measure of its efficiency. Patients who cannot stay at home are usually admitted to a local hospital (where the quality of care is often insufficient) or to a hospice. In Krakow the St Lazarus Hospice has provided professional palliative home care for terminally ill patients (mostly with cancer) since 1993. Starting in 1998, when the 30 bed hospice was opened, patients who were not able to stay longer at home could be cared for in the hospice. The aim of this paper was to assess the influence of expanding hospice care to include in-patient care on the place of death of our patients. The numbers of patients, their place of death with percentage of hospital deaths in the years 1993–2004 are shown in Table: YEARS: (HOME HOSPICE HOSPITAL% HOSPITAL) 1993: 25–6 24,0; 1994: 120–32 26,7; 1995: 139–26 18,7; 1996: 209–49 23,4; 1997: 219–51 23,3; 1998: 189 53 42 17,4; 1999: 210 67 55 19,9; 2000: 244 68 67 21,5; 2001: 251 88 68 20,1; 2002: 275 91 83 22,7; 2003: 312 83 80 20,3; 2004: 339 79 73 17,5; Total: 2532 529 632 20,6. The results indicate that access to hospice care was associated with lowering the risk of hospital death from a mean of 23,2% in the years 1993–1997 (SD 2,8) to 19,8% in the years 1998–2004 (SD 1,9) (t-test, p =0,036) although some patients and/or families still preferred hospital deaths. Hospice care appears to be a valuable supplement for home care, which may guarantee a broader access to palliative care.

Abstract number: 354
Presentation type: Poster
Session: Terminal Care

Palliative sedation: has the practice changed? A Palliative Care Unit five years experience

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Introduction: numerous controversies surround the use of palliative sedation. The reported prevalence rates vary from 1 to 52%, depending on the definition used, the study design and setting. The most frequent indication is restlessness, followed by pain and delirium. Palliative sedation is performed in our Palliative Care Unit (PCU) under strict criteria and with close monitoring, using midazolam. Our study aims to obtain the incidence rate and quantitative/qualitative parameters of the sedations performed in our PCU in a five years period and to follow their evolution throughout the study period. Method: a retrospective charts review of the patients who died in our PCU from 2000 to 2004. Data on demographic parameters, diagnosis at the moment of sedation, indication and duration of sedation, duration of the hospitalization, midazolam dosage, way of administration and concomitant treatments were obtained.
Results: 579 charts were reviewed. Palliative sedation was used in 13.3% of the patients. 92% had an oncological diagnosis. Indication for sedation was pain (30 patients), dyspnea (24), restlessness (16), anxiety (14), g-i symptoms (3), confusion (2) and others (5). In 31.2% of the patients, more than one symptom led to sedation. Mean

duration of sedation was 44,8 hours (range 1 to 294); s-cut midazolam was used in 51%, iv in 39% and 10% had to switch from s-cut to iv. Mean midazolam dosage was 3 mg/h (range 0.5–10). All patients received adapted antalgia. Mean hospitalisation duration was 28.32 (sedated) versus 29 days (non sedated).

Conclusions: pain and dyspnea are the most frequent indications for sedation in our PCU, in opposition to the majority of literature reports, in which restlessness and delirium are prominent. We postulate that increased knowledge on opioids-related neurotoxicity through recent medical literature, leading to a better control of its manifestations until the last hours of life, may be the cause of this difference.

Abstract number: 355
Presentation type: Poster
Session: Terminal Care

Requests to forgo potentially life-prolonging treatment and to hasten death in terminally ill cancer patients: A prospective study

Jean-Jacques Georges, **Bregje D**, **Gerrit Van der wal**, VU Medical Center, Amsterdam, Netherlands, **OAgnes Van der heide**, **Paul J Van der maas**, Erasmus MC, Rotterdam, Netherlands

Aim: This study investigates the background and evolution of requests to forgo treatment and hasten death in terminally ill cancer patients.

Method: Clinical specialists, general practitioners and nursing home physicians participating in a nationwide study on end-of-life decision-making were asked whether they were treating a terminally ill cancer patient, whose life expectancy was longer than 1 week but no longer than 3 months, and who they would continue to treat until the patient's death. Of the 120 physicians who had a patient who met the inclusion criteria 85 (70,8%) completed a questionnaire each month until the patient's death. The questionnaire provided information on the patient's symptoms, concerns, and requests involving end-of-life decisions.

Results: Most patients suffered from cancer of the gastro-intestinal tract or the respiratory system, 66% died within two months after the initial interview. The prevalence of requests involving end-of-life decisions increased during the last 3 months of a patient's life. The evolution of a request was especially related to an increase in the number of severe symptoms and concerns. Requests to forgo treatment were related to general weakness, while loss of dignity was a major reason for requests to hasten death. Patients who made no requests had fewer symptoms at the moment of inclusion and a significant decrease in concerns before death. Physical suffering alone appeared to lead to less drastic requests than suffering blended by concerns and psychological problems leading to requests for hastened death.

Discussion: The results emphasise the importance of gaining insight in terminally ill cancer patients' suffering to provide them meaningful assistance.

Abstract number: 356
Presentation type: Poster
Session: Terminal Care

Food intake, views on physician-assisted suicide and voluntary cessation of eating and drinking of hospice patients

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Food intake, views on PAS and VCED of hospice patients. We interviewed hospice patients to determine their views on shortening their lives, and to see what needs, as they defined them, hastening death or voluntary cessation of eating and drinking (VCED) would address. Then we prospectively followed groups of hospice patients to see what their energy intake was, and thus to see whether energy intake could be a factor in hastening their death as they wanted. This study reports patients' views about VCED and data on what hospice patients eat. Many of these patients said that suicide is ethically acceptable. While the professional debate centres on whether VCED is an ethical alternative to physician-assisted suicide (PAS), the patient's focus is not on this issue of professional acceptability. They want to know if they stop eating will it hasten their death. They want to die reliably, and they want to know if they don't eat, can they predict a sooner death. Transcribed and qualitatively analysed interviews are used to present the patients viewpoint. An audit of the food consumption of all patients in the hospice was conducted by one of the researchers using visual estimation methods. Data for the analysis of food intake was 315 meal remains for 56 inpatients. Of the 56 inpatients, 27 were male and 29 female. Ninety percent of the patients had a diagnosis of malignancy. Survival was 1–102 days. Overall energy intake was low, and there were 12 patients who had verified zero total intake. Most patients were consuming less than 1/3 of their maintenance energy requirements, the median intake was 1.67 MJ/day. The relationship between energy intake and survival is significant but poorly predictive.

Abstract number: 357
Presentation type: Poster
Session: Terminal Care

Parenteral hydration; Evidence and practice, a hospice perspective

Declan Cawley, **Kathleen Sherry**, **Miriam Taddjali**, Ayrshire hospice, Ayr, Great Britain

Background: The debate around food and fluids involves deep-seated cultural, spiritual and psychological issues for patients and their treating clinicians. In advancing cancer there are potential reversible conditions that can mimic the clinical deteriorating picture of terminal cancer.

Aim: To assess the current practice of parenteral hydration and the views of the clinicians caring for them.

Methods: Case note review of patients administered fluids and a questionnaire distributed to all current clinical staff working in the inpatient unit.

Results: Over a 6-month period 46 patients had 50 episodes of fluid administration with most (87%) having disseminated malignant disease, considerable debility (ECOG 3–4(93%)) and significant proportion (74%) of these patients died. Documented reasons for administration (68%) were opioid toxicity, clinical dehydration and hypercalaemia. Litttle discussion was evident with patients (60%) and in a less proportion of family/carer domain (41%). Only 24% of patients/family reported any improvement in the clinical picture. Returned questionnaires (61%) revealed the majority of staff (95%) felt there was a place for parenteral hydration in the hospice setting, can improve symptoms (100%) 21% of respondents felt it prolonged life, 19% felt that it was "unacceptably intrusive", and was used "too much". Discussions with patient and/or carer only 57% of clinical staff felt adequate discussion had taken place when regarding commencing fluids and 52% of staff felt it was "the same to discontinue fluids as to withhold them". 53% of staff felt that fluids had no place in the "terminal phase" of a patient's cancer journey.

Conclusions: The results highlight a lacking evidence for parenteral hydration use in this setting. A fluid prescription sheet was devised to contain key trigger points. The diversity of opinions highlighted need for clinical vignettes as a means of ongoing education and reflective practice.

Abstract number: 358
Presentation type: Poster
Session: Terminal Care

Dying a good death at a palliative care unit: An anthropological study of cancer patients in Japan

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Aim: Hospices and palliative care units (PCUs) help patients die a 'good death' by encouraging them to live as themselves until their last day. This is a challenging practice which has been rarely observed in the main stream health care system (see Sudnow 1964). The aim of this paper is to examine how the ideal of good death is put into practice in Japan.

Method: Participant observation was conducted at a PCU with 28 beds in Japan for a period of 11 months from 1999 to 2000. A total of 89 patients were observed. Qualitative data was collected by 1) attending the staff meetings, doctors' ward rounds, meetings between a doctor and a patient or a family, and PCU outpatient clinics; and 2) having conversations with each patient, the PCU staff, and patients' families. This data was then analyzed according to standard anthropological methodology.
Findings: Analysis of observational data shows that at the PCU, death is considered good when patients do not experience social death before the physical one, or both kinds of death coincide. A good death is beneficial for the PCU staff as it reduces the level of stress they would otherwise experience. My field observations reveal that many patients fail to die in a good way, because: 1) Good pain relief often makes them think they are getting better, which in turn makes them less able to accept the physical changes and death; 2) It is difficult for them to set realistic goals to 'live' until their death; 3) It is difficult for them to maintain a sense of self or to build a new one due to rapid physical deterioration.
Conclusion: It is difficult for patients to die a good death, and too much emphasis on it causes stress for both patients and staff. It is therefore important to seek 1) how each patient wishes to die and 2) the way to support those who have inevitably died socially before their physical demise.
Sudnow, D. (1967) Passing On: The Social Organization of Dying, Prentice-Hall, N.J.

Abstract number: 359
Presentation type: Poster
Session: Terminal Care

Home Paliative Sedation of Terminal patients

Ora Rosengarten, **Yonat Lamed**, **Ayelet Feigin**, **Jeremy Jacobs**, Clalit Health Services, Jerusalem, Israel, **Timna Zisling**, Klalit Health Services, Jerusalem, Israel

End of life sedation may offer relief of otherwise intractable symptoms. Little has been published about terminal sedation at home, mostly in countries where Hospice services are scarce. The Jerusalem Home Hospitalization (HH) service of the Clalit Health Services offers full medical care to patients in the home setting, some in the terminal stages of their disease. Between 12.2000–12.2004 23 patients were treated with palliative sedation at home: 12 for intractable pain, 3 for delirium, 2 for vomiting, 5 for restlessness and 6 for existential suffering (some for >1 reason). 4 of the pts with existential suffering were able to express it, for 2 decision was taken. The characteristics of pts: 10 males, 13 females. Age-45–82 y. Diagnosis: cancer – 6 breast, 4 pancreas, 2 lung, 2 colon, 7 others, ALS-2. Population sector: Arab-1, orthodox-8, ultra-orthodox-none, non-religious-14. Duration of sedation-several hours to 11 days, median 3 days. The drugs used (in some >1 drug): Morphine-17, doses 1–100 mg/hour, midazolam-10, doses 0.5–5 mg/h, promethazine or haloperidol-4, doses 0.1–5 mg/h, TTS Fentanyl was continued in 3 pts with previous use. Results: excellent relief was achieved in 14 pts, reasonable relief in 4, mild relief in 3. Sedation was stopped in 2 pts because of side effects. Except for 2 pts with whom families were unable to cope, all pts terminated their life at home with intense support of the HH. All families expressed deep satisfaction. The characteristics of patients choosing sedation at home are difficult to point out in this small group, but they tended to be of higher socio-economical status and non-religious. The major predictive factor for pts getting sedation was the attitude of the treating physician, those more experienced with palliative care offering sedation more frequently. Conclusion: For patients and families wishing to stay at home at the end of life, home sedation may offer a much better option than hospitalization.

Second group of Posters

Abstract number: 360
Presentation type: Poster
Session: Assessment

Is Opioid Tolerance Clinically Measurable as a Component of a Cancer Pain Classification System?

Sonya Lowe, **Cheryl Nekolaichuk**, **Robin Fainsinger**, Division of Palliative Care Medicine, Dept Onc, Royal Alexander Hospital, Edmonton, Canada, **Peter Lawlor**, St. James' Hospital and Our Lady's Hospice, Dublin, Ireland

Background: Opioid tolerance is a poorly understood phenomenon which incorporates multiple clinical factors. The opioid escalation index percentage (OEI%), defined by Mercadante, has been used as a surrogate marker. Tolerance was included as a prognostic feature in the original Edmonton Staging System (ESS) for pain classification in advanced cancer patients. Through further refinement, the five features of the revised ESS (rESS) – Pain Mechanism, Incident Pain, Psychological Distress, Addictive Behavior and Cognitive Function – have demonstrated value in predicting pain management complexity. Tolerance was not included in the rESS, due to difficulty defining and applying this concept.
Hypothesis: Advanced cancer patients with younger age, neuropathic pain, incident pain, psychological distress and addictive behavior will have an OEI% >5%.
Methods: A secondary analysis was performed on a multicenter validation study of the rESS, involving 532 advanced cancer patients with a pain syndrome from two different hospice settings, an acute care consultation service and a tertiary palliative care unit. Associations between OEI% and other variables (i.e. age, rESS features) were calculated using Chi Square Goodness of Fit and Fisher's Exact Tests.
Results: Approximately 44% (n = 232) of the patients had an OEI% > 5%. There were no significant associations between OEI% and age, neuropathic pain, incident pain, psychological distress and addictive behavior.
Conclusions: The reductionist approach of dichotomizing the OEI% in data analysis may oversimplify the multifactorial nature of opioid tolerance, as well as the complex heterogeneity of patients' clinical trajectories in a broadly inclusive study sample. Further subgroup analysis of this data, and future studies in more homogeneous study selection samples may help to better elucidate opioid tolerance and a potential role in a cancer pain classification system.

Abstract number: 361
Presentation type: Poster
Session: Assessment

Validation of a Simplified Anorexia Questionnaire

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Purpose: The Functional Assessment of Anorexia and Cachexia Therapy (FAACT), a modification of the Functional Assessment of Cancer Therapy General (FACT-G) has a validated 12-question anorexia subscale (A/CS-12) which provides a reliable measurement of nutritional status. The length of A/CS-12 may be burdensome for physicians and patients. Therefore, a Simplified Question Questionnaire was developed and validated against the A/CS-12.
Methods: A prospective pilot crossover study of 20 cancer patients with or without anorexia was conducted. The Simplified Questionnaire consists of two questions: a numerical rating scale (0–10) and categorical scale for appetite loss (mild, moderate, or severe). Each subject completed both questionnaires upon enrollment and again one week later. To prevent the order of questionnaires from biasing results, we randomly changed the order with each interview session. Questionnaires were completed in person and by phone interview.
Results: The mean age was 61 years (range 40–79); 13 (65%) were female. The most common cancer types were lung, gynecologic, breast, and gastrointestinal. Most patients (75%) had good performance status (ECOG = 1 or 2). Out of the 15 with both-time points questionnaire data; five (33%) had Questionnaire and A/CS-12 changes in the same direction. Based on the 17 with one-time point Questionnaire scores, 46 of 135 pairs

(34%) were ordered the same way by both the double Questionnaire and the A/CS-12.
Conclusion: The Simplified Anorexia Questionnaire correlated poorly with changes in the A/CS-12 in this pilot study. This may improve, as more patients are added. Agreement between the measures was poor. Additional accrual is presently occurring to adequately assess the validity of the Simplified Questionnaire.

Abstract number: 362
Presentation type: Poster
Session: Assessment

Does assessment by symptom clusters improve the efficiency of symptom assessment

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Introduction: Symptoms occur in non-random (clustered) distributions. Assessing sentinel (most prevalent) symptoms in a cluster may shorten the process. We used clusters from a 1000 patient dataset to determine if absence of sentinel symptoms precludes assessing r cluster symptoms.
Method: Agglomerative hierarchical analysis of symptoms identified 8 clusters used to assess an 181 patient dataset. Chi square was done to compare non-sentinel symptoms between those with and without sentinel symptoms.
Results: Age and gender matched between groups. Performance status was better ($p<0.001$), lung cancer less prevalent ($p=0.043$), dry mouth, belching, bloating were more prevalent and pain, constipation, nausea, vomiting less prevalent in the comparison group ($p<0.04$) Fatigue cluster; 130 with and 51 without easy fatigue (sentinel symptom), 69% and 59% had other cluster symptoms, dry mouth ($P=0.22$). Anorexia cluster; 111 with and 70 without anorexia, 63% and 29% had early satiety ($P<0.001$); 44% and 14% had taste change ($P<0.001$); 71% and 31% had weight loss ($P<0.001$). Sleep cluster; 82 with and 99 without sleep problems,39% and 22% had anxiety ($P=0.014$);46% and 26% had depression ($P=0.005$). GI cluster; 24 with, 157 without dizziness, 42% and 8% had dyspepsia ($P<0.001$); 46% and 32% had belching ($P=0.18$); 54% and 27% had bloating ($P=0.008$). Nausea cluster 50 with131 without nausea, 32% and 5% had vomiting ($P<0.001$). Aerodigestive cluster; 78 with103 without dyspnea,58%and26% had cough($P<0.001$); 30% and 22% had hoarseness ($P=0.27$); 19% and 9% had dysphagia($P=0.039$). Cognitive cluster; 55 with, 126 without edema, 22% and 28% had confusion ($P=0.40$). Pain cluster; 122 with, 59 without pain, 48% and 22% had constipation ($P<0.001$).
Discussion: Non-sentinel symptoms were more prevalent with the sentinel symptom than without. Absence of sentinel symptoms did not exclude cluster symptoms.
Conclusion: Cluster assessment with sentinel symptoms is an inadequate means of assessing symptoms.

Abstract number: 363
Presentation type: Poster
Session: Assessment

Cachexia, weakness and depression-definitions from palliative care team members

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The core documentation for palliative care patients is an ongoing quality assurance project. In the evaluation phase 2002 57 palliative care units, 8 inpatient hospices, 4 oncology departments and 2 geriatric departments documented a total of 1566 patients. After the documentation period a telephone interview was conducted with staff in the units to evaluate preferences and dislikes in the documentation system. In the interview staff was asked to give definitions for cachexia, weakness and depression in their own words to provide a background for the evaluation of the symptom checklist of the core documentation. The interviews were transcribed and content analysis was performed. Items included in the definitions of cachexia fell into the categories energy, nutrition or bodyweight. Some items included measures and numbers, whereas others used images as symbols. Items on depression were categorized in loss of drive, negative emotional state (either reactive or non-reactive) and two smaller categories of introversion and somatic symptoms. Somatic symptoms that define depression in non-cancer patients were named only rarely in the definition of depression. Weakness was defined using item categories of power and activity or impairment and loss of function. Cluster differentiation was more difficult for weakness than for the other definitions. Definition of common symptoms such as cachexia, weakness and depression may be based on different concepts, and this may influence documentation behaviour and treatment approaches in different palliative care services.

Abstract number: 364
Presentation type: Poster
Session: Assessment

Care in Palliative Care Unit EPQ-PCU Quality Perception Scale

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Introduction: The aim of the project was to elaborate and validate a measurement tool of the perception of care by the patients hospitalised in Palliative Care Units (PCU). A preliminary study was conducted on the feasibility of a survey form among patients hospitalised in two PCU. Following a bibliographical research on the concept of satisfaction in palliative care and on validated measurement tools, the development of the form consisted in, first, defining the topics to explore, and then, drafting the items. The form consisted in 24 items covering 10 topics. Additional information in order to specify the study sample was also collected.
Method: The feasibility of the tool was tested during a prospective survey among all patients hospitalised in the two PCU, in the form of a guided interview with an external surveyor. The data collection took place between March and April 2005 during five weeks. The analysis laid on quantitative and qualitative data in order to conclude on the feasibility of the collection, the acceptability and the expected modifications on the measurement tool, within the teams as among the patients. On the 33 patients present in the two units, 9 interviews were conducted. The average duration of the interviews was 20 minutes, the surveyor attendance time within the units was estimated at 15 hours. The results showed that this first version of the form included non-relevant items, 5 ones regarding patient's understanding, and 6 regarding statistic validation. Project prospects The project prospects are to carry on this approach initiated by the two hospitals by improving the Care in PCU EPQ-PCU Quality Perception Scale and analyzing its use and results within several PCU. A multicentric study is contemplated.

Abstract number: 365
Presentation type: Poster
Session: Assessment

End-of-Life Issues and Hospice Care in US and in Hungary

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Objective: The goals of palliative and hospice care are similar everywhere: provide holistic care to persons with illness unresponsive to curative treatment. The aim is to maintain quality of life, ensure dignified death and support family members. Studies in North America have investigated perceptions of good end-of-life care. They suggest that

hospice care meets the needs of dying patients. Little is known about whether the Hungarian hospice movement addresses the needs of Hungarians with life limiting illnesses. The objectives of this study are to learn more about the attitudes of Hungarians toward death and end-of-life care comparing these findings to those in North America. The comparative study also seeks to find out how much patients know about hospice care in both countries.
Methods: Self administered survey, developed by the authors, was derived from published literature. It contains 30 items, including forced choice and open ended questions. The survey was administered to consenting adult patients seen in family practice settings in the U.S. and Hungary.
Results: Our study finds that there may be similarities and differences in attitudes in North America and Hungary. For instance, in the U.S., only 8% of people said that their biggest fear would be at the end of life loss of dignity and control compared to 55% of Hungarians. In Hungary much higher number of patients (38%) named pain and suffering as greatest fear than in U.S. (16%). In both countries patients similarly would like to know their prognosis, in the U.S. 97%, in Hungary 93%.
Summary and Conclusion: Hungarians are less likely to speak freely with family about death and dying, but just as likely would like to know their prognosis. Our understanding and development of hospice care must be informed by ongoing culturally specific assessment to provide better care for the terminally ill and their families.

Abstract number: 366
Presentation type: Poster
Session: Assessment

The Pat-C Project. Implementation of Computerised Tools in Health Care Units-The Importance of Key Personnel

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Background: The introduction of computerised tools in health care units is influenced by the user's acceptance of the tools. To focus on how to make this implementation meaningful for the intended users will be important in that connection.
Aim: To identify aspects among the users that are associated with successful implementation.
Methods: Data were obtained from two different studies. Through a systematic literature search categories of importance in an implementation process were identified and described. Eleven studies that met the following inclusion criteria, description of implementation in a hospital ward, containing a systematic approach and evaluation of the implementation, were included. Additionally a qualitative approach with structured interviews was used. Seventeen respondents, including nurses, physicians and physiotherapists in both inpatient and outpatient palliative care settings, participated in a depth interview two years after the implementation process.
Results: A main finding from the review was that one of the most essential factors in an implementation process is to develop an adequate training program if the introduction of computerized tools is to be successful. The program must contain people who are specially trained to assist users when and where they need it, thus we named them "key personnel". This was supported by the interviews. In the interviews the respondents expressed a need for special trained persons with skills and motivation stationed at the unit. "If people are glowing for their projects I think it would be nice if they were present so we can take part in the glowing" was a typical statement.
Conclusion: Both studies pointed to the importance of key personnel for successful implementation. Their role in the clinical setting needs to be identified. The results of these studies have implications for implementation planning in connection to management, organisation and training.

Abstract number: 367
Presentation type: Poster
Session: Assessment

Errors in Symptom Intensity Self-Assessment by Patients receiving Outpatient palliative care

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Background: Patient based symptom scores are the standard method for assessment in Palliative care. There has been limited research on the frequency of errors upon using this approach. The Edmonton Symptom Assessment Scale (ESAS) is a reliable and valid assessment tool routinely used for symptom intensity assessment in our cancer center.
Objective: To determine if patients were scoring the symptoms on the ESAS in the way it was supposed to be scored.
Settings: The study was carried out at the outpatient Palliative care center.
Design and Subjects: Retrospective review of sixty consecutive patient charts was done where the patient had initially scored the ESAS. The physician looked at this scoring on the ESAS and went back to the patient to do the scoring again to see if the patient had scored it in the way it was intended to be scored. The same physician did assessment on all of the patients.
Outcome Measures: Level of agreement (Weighted Kappa) before versus after the physician visit; Screening performance of patient completed ESAS for mild and moderate symptom intensity. Results: Complete agreement ranged from 58% (sleep) to 82% (wellbeing); the weighted Kappa ranged from 0.49 (drowsiness) to 0.78 (wellbeing). There was more agreement for positive symptoms such as dyspnea, nausea, anxiety, and depression and less agreement for negative symptoms such as sleep and appetite. The screening performance of the ESAS showed less sensitivity for nausea, drowsiness if intensity was mild and less sensitivity for pain, nausea, anxiety, and drowsiness if intensity was moderate.
Conclusions: Vigilance needs to be maintained about the ESAS scores done by the patients particularly for symptoms of sleep, appetite, and pain. There is a likelihood of error if doctors or nurses do not routinely check the way patients have completed the assessment form. More research is needed to determine the best way to teach patients how to minimize errors in self-reporting of symptoms.

Abstract number: 368
Presentation type: Poster
Session: Assessment

Evaluation of global tools for the assessment of nausea and vomiting in palliative care

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Background: Nausea and vomiting are common symptoms in palliative care patients. However, there is a lack of consensus regarding specific tools for assessment of nausea and vomiting in this group. These symptoms are often included as part of global quality of life or symptom assessment tools.
Aims of the study: This APM task group aimed to identify which global quality of life or symptom assessment tools would be most effective for clinical monitoring and research of nausea and vomiting in palliative care.
Methods: A literature search identified 30 tools. Global tools that included nausea and or vomiting as part of their symptom assessment were reviewed.
Findings Tools were identified that have been psychometrically tested, were simple to use and could be used for assessment of nausea and vomiting in a palliative care setting. These included the Adapted SDS-2, EORTC QLQ-C30, Macadam and Smith and modified Rotterdam, which all assess nausea and vomiting separately and are based on the patient's perceptions.
Discussion: Global tools may have a role in the assessment of emesis, and related symptoms, in palliative care. Overall the Adapted SDS-2 could help quantify nausea and vomiting in clinical practice but more research into developing a specific nausea and vomiting tool for palliative care patients would be useful.

Abstract number: 369
Presentation type: Poster
Session: Assessment

Living with incurable cancer at the end of life – patient's perceptions on quality of life

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Introduction: Patients with cancer comprise the largest group in Sweden that is currently offered palliative care, and the goal for medical and nursing staff is to provide patients with the best possible quality of life (QoL). In order to achieve this a valid description of the content in QoL at the end of life in the palliative context is needed. The aim of this study was to describe patients' perceptions of QoL in incurable cancer at the end of life. when being cared for in their homes by a palliative homecare team.

Methods: Purposeful sampling was used to get as comprehensive descriptions as possible. Five patients participated in repeated focus groups and content analysis was performed to describe and interpret the concealed message in the texts.

Results: The findings were presented through five themes: ''valuing ordinariness in life'', ''maintaining a positive life'', ''alleviated suffering'', ''significant relations'' and ''managing life when ill''. The themes describe that the patients could participate in daily and social life despite cancer. The relation with family and palliative team deepened during the progress of illness, in such that a resonance developed in communication. Other findings of importance were that patients' memories helped them to maintain a positive life and to alleviate suffering the patients used individual strategies to relive pain by emotional and physical distractions. To manage life as ill meant taking actions with creative thinking in solving problems as a way to cope and achieve QoL.

Conclusion: The present study showed that the patients emphasized what they could perform and enjoy in daily life, not on their shortcomings.

Abstract number: 370
Presentation type: Poster
Session: Assessment

Resilience in palliative care: A paradox?

Christine Rogger, **Francine Warmé**, **Dominique Paillet**, Cesco, Collonge-Bellerive, Switzerland

Introduction: we developed in our geriatric and palliative care unit of 19 beds in the Geneva University Hospital a project about resilience, hope and the paradigm of transformation. This project began in 2001 with a 64 years old woman with an advanced cancer who required some complex technical care, had severe dyspnoea and couldn't communicate. Caregivers discover that she had done a lot of embroideries during her life and could do an exhibition of her work in the care unit. After this experience we decided to better explore hobbies or passion, sometimes hidden, of hospitalised patients to enhance communication between patients, families and caregivers.

Method: retrospective chart review of these last 4 years.

Results: ten patients, aged between 53 and 92 years, profited from this ''resilience, hope and the paradigm of transformation project'' (puzzle, embroidery, Tai-Chi, song, poems, bowling, jewellery, sticking, painting, rose meal). Six families participated also. Results for patients were very positive, because they felt themselves more useful, enthusiast, confident, and recognized, even if it was sometimes very emotional. Experiences were also very positive, even if emotional, for caregivers. They discovered much better patients' history, they considered more the patient as a person, than a ''very sick'' patient and attachment between caregivers, patients and family was often consolidated.

Conclusion: this ''resilience, hope and the paradigm of transformation project'' helped patients to feel more in control of their life and more confident. But it also helped us, caregivers, to better take care of patient, as a ''whole'' person.

Abstract number: 371
Presentation type: Poster
Session: Assessment

Measurement of Breathlessness in Palliative Care: A systematic review

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Background: Breathlessness is a common symptom in advanced stages of various diseases with high impact on patients' quality of life. There is a plethora of assessment tools available to measure breathlessness. This systematic review identified all those measures available via standard search techniques and reviewed their usefulness for patients with advanced disease.

Methods: A systematic literature search was performed in Medline. All studies focusing on the development or evaluation of tools for measuring breathlessness in chronic respiratory disease, cardiac disease, cancer, or MND were identified. Their characteristic with regard to validity, reliability, appropriateness and responsiveness to change were described. The tools were then examined for their usefulness in measuring significant aspects of breathlessness in advanced disease.

Results: Thirty eight tools were initially identified, two were excluded. Twenty-nine were multidimensional, 11 of these were breathlessness-specific and 18 disease-specific. Four were unidimensional measuring the severity of breathlessness and three measured exercise tolerance. The majority of disease-specific scales were validated for COPD, few are applicable in other conditions. No one tool assessed all the dimensions of this complex symptom which affects the psychology and social functioning of the affected individual and their family-most focused on physical activity.

Conclusion: As yet there is no one scale that can accurately reflect the far-reaching effects of breathlessness on the patient with advanced disease and their family. Therefore, at present, we would recommend combining a unidimensional scale (e.g. VAS) with a disease-specific scale (where available) or multidimensional scale in conjunction with other methods (such as qualitative techniques) to gauge psychosocial and carer distress for the assessment of breathlessness in advanced disease.

Abstract number: 372
Presentation type: Poster
Session: Assessment

How do patients perceive and experience systematic symptom assessment in palliative care? A qualitative interview study

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Background: A valid symptom assessment is a prerequisite for good symptom control. The Edmonton Symptom Assessment System (ESAS) is one of the most widely used symptom assessment tools in palliative care. However, little is known about how patients experience and value the systematic use of this tool.

Research aims: The aim of the study was to explore how palliative care patients perceive and experience systematic symptom assessment by use of the ESAS, and their views about how such registration can be used most efficiently.

Materials and Methods: 14 out-patients and 4 in-patients at a palliative care centre and 4 close family members were interviewed by a specially trained lecturer in nursing. The interviews were semi-structured, based on interview guides (one for patients and one for family members), and took place between January 2004 and May 2005. All interviews were tape recorded, transcribed, and analysed.

Results: The patients found the items relevant and easy to understand – The instrument was appreciated as a time-saving and important check-list – The ESAS made the patients feel included and responsible for their own treatment, and they experienced a coherence between their ratings and the care and treatment offered – Uncertainty about correct answers and how to interpret the scale was rather common-Several patients reported being restrictive in their symptom scoring, experiencing a need to save the upper part of the scale for a more advanced state, or comparing themselves with others – The patients had not regarded the ESAS as a communication tool, but instinctively agreed to this when asked – The relatives also perceived the ESAS as a useful tool, but clearly stated that this was the patients' business

Conclusions: The ESAS was evaluated as a useful and efficient tool, making the patients feel secure and well taken care of. However, thorough explanation and repeated information are necessary for optimal use.

Abstract number: 373
Presentation type: Poster
Session: Assessment

Resilience and Palliative Care

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A new concept of resilience (the capacity to be positive and build a new life in the face of great difficulties) is permeating palliative care. An increasing worldwide literature on resilience related to a range of specialties, is a rich source of data in extracting its meaning for end of life care (Oliviere and Monroe, 2006 publication agreed). The aims of the research were to: explore the concept and meaning of resilience in palliative care; to identify key findings in the international research and literature on resilience; to conduct a series of study days on resilience based on a range of topics relevant to palliative care; and to undertake a thematic analysis of the study material generated for the study days. A qualitative study based on a series of nine study days on working with individuals, children, spirituality, rehabilitation, bereavement, families, creativity, teams and organisations. Speakers, who are leaders in the field of palliative care or eminent academics and practitioners from the fields of psychology, psychiatry and sociology also represented the range of professions in palliative care. 36 papers were produced with course handouts and exercises. A thematic analysis was conducted of the material examining the texts, and citations to identify core and secondary themes that relate to resilience. The results of this study throw light on a range of concepts employed in palliative care that promote resilience as well new theoretical constructs. A number of core themes that underpin resilience have emerged and the tools in palliative care that promote coping and achievement. A new framework is identified and is being developed to give a better balance between the assessment of 'risk' and 'resilience' in working with patients, families, carers and teams to improve practice. Methods of intervention that are resilience-promoting are emphasised.

Abstract number: 374
Presentation type: Poster
Session: Assessment

Cognitive assessment of Greek pain patients: Validation of the Pain Catastrophising Scale

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Introduction: Pain catastrophizing is an important cognitive construct, linked with many aspects of the pain experience, including pain intensity, emotional distress, pain-related disability, and pain behavior. The Pain Catastrophizing Scale (PCS), an instrument often used to assess this construct, reflects three aspects of catastrophizing: Rumination (R) 4 items, Magnification (M)-3 items, and Helplessness (H)-6 items. The PCS validity and reliability have been shown for the original and the Dutch versions of the scale.

Aim: To validate the Greek PCS version Methods: Forty-three chronic pain patients (59.3 ± 16.7 yrs, 9 men) attending the Pain Clinic completed the Greek PCS and the catastrophising subscale of the Coping Strategies Questionnaire. Other measures completed were the TSK (Tampa Scale of Kinesiophobia), the HADs and the Short-Form McGill Pain Questionnaire. The development of the Greek PCS followed the standardized official procedure of the cross-cultural instruments validation.

Results: The internal consistency was satisfactory for PCS total (Cronbach's a =0.90) and for its subscales (R: a =0.75, M: a =0.62, H: a =0.87). Convergent validity was demonstrated through the high correlation of PCS with CSQ-catastrophising (r =0.88*). The intercorrelation among subscales was similar to the literature (R –M: r =0.54*, R –H: r =0.66*, M –H: r =0.62*). Divergent validity was shown through the moderate correlation of PCS with SF-MPQ affective score (0.49*), SF-MPQ sensory score (0.47*), kinesiophobia (0.48*), anxiety (0.49*) and depression (0.43*). Exploratory factor analysis (Max Likelihood method) identified 3 distinct factors identical to the original (R, M. H).

Conclusion: The Greek version of the PCS is a valid measure similar to the original. Further aspects of reliability and sensitivity to change of the Greek PCS are necessary to be demonstrated in future studies. *: $p < 0.01$.

Abstract number: 375
Presentation type: Poster
Session: Assessment

Barthel index of daily living accurately predicts survival in a palliative care unit

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The rate of change in physical functioning may be a better tool for estimating survival in terminal cancer patients than performance score. We therefore prospectively analysed terminal cancer patients with ps 0–1 admitted during 18 months for prognosis either by karnofsky scoring by an oncologist or by barthel score as done by an occupational therapist.

Patients and methods: patients admitted from 9/2004 unitil 10/2005 were evaluated. The modified barthel index was determined weekly from admission for the duration of inpatient stay. The score at admission +ps, mean weekly change in score during inpatient stay and survival from date of admission were recorded.

Results: a 10 point drop in barthel score predicted death in the next four weeks in 17 out of 20 pts whereas performance score remained 3 in all of them. in patients where barthel score does not change over time, prognosis was >2 months.

Conclusions: 80% of patients with advanced cancer, admitted for palliative care, die within one month once their activity of daily living (as measured by the modified Barthel score) drops by 10 of more points per week. This outweighs the Karnofsky performance score (as used in clinical practice) by its greater predictive value.

Abstract number: 376
Presentation type: Poster
Session: Assessment

E-MOSAIC: Electronic monitoring of symptoms and syndromes associated with cancer in daily outpatient care for advanced cancer patients

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Objectives: Monitoring of defined symptoms and syndromes has the potential to improve advanced cancer care, but is underused in daily practice. Symptom self-assessment by electronic devices was shown to be feasible, but did not yet include syndrome assessment.

Aim: to improve palliative care of patients with advanced cancer in daily oncology practice through provision of real-time information on patient's symptoms and syndromes.

Methods: A palm-based assessment instrument (E-MOSAIC) was developed in a multicenter and multiprofessional (nurses, MD) approach. It has 3 elements, filled out by the pat (1) and personnel (2, 3). E1: Visual-Analogue Scales of 9 symptoms (Pain, Fatigue, Drowsiness, Nausea, Anxiety, Depression, Dyspnea, Anorexia, overall well-being); up to 3 optional symptoms (from a list of 20); and pat estimated nutritional intake. E2: actual body weight and Karnofsky PS. E3: pre-defined, simplified list for actual medication for pain, [including Morphin Equivalent Daily Dose], fatigue and anorexia/cachexia syndromes. A Longitudinal Monitoring Sheet is printed for the physician. The compliance, time needed, and experiences of patients with the palm were evaluated using a structured questionnaire. A comparison of palm- and paper-based symptoms, and palm test–retest for the symptoms was performed.

Results: 54 patients (median age 64 y [range 30–85], 25 female, 29 male) from 3 institutions completed E-MOSAIC. 4 pat. had optical, and 6 understanding problems, and 1 pat. was too tired, resulting in 3/54 pat. not completing the E-MOSAIC. Median time to complete was 3 minutes. 10 pat. preferred paper, 16 no preference, 28 preferred palm; 50 pat. agreed to continue using palm, 4 refused. Wilcoxon-rank-sum test confirmed no significant differences of palm versus paper, except for nutritional intake, test-retest reliability was high.

Conclusion E-MOSAIC is acceptable for palliative care outpatient setting and a reliable monitoring tool.

Abstract number: 377
Presentation type: Poster
Session: Assessment

Cancer management and cultural beliefs about health and illness: An anthropological study of cancer patients in Japan

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Aim: Disagreement about treatment between patients and medical staff is often observed at palliative care units (PCUs) in Japan. Although patients enter a PCU to receive the most advanced pain relief, they often do not want those recommended by the staff. In this paper I clarify the Japanese concept of tairyoku (body power) and demonstrate how this concept can be used to explain the disagreement between patients and PCU staff regarding treatment.

Method: Participant observation was conducted at a PCU with 28 beds in Japan for a period of 11 months from 1999 to 2000. A total of 89 patients were observed. Qualitative data was collected by 1) attending the staff meetings, doctors' ward rounds, meetings between a doctor and a patient or a family, and PCU outpatient clinics; and 2) having conversations with each patient, the PCU staff, and patients' families. This data was analyzed according to standard anthropological methodology.

Findings: The concept of tairyoku is used as a measurement of the bodily condition. Patients also believe in its curative power on cancer. In order to increase tairyoku level; 1) Patients try to maintain a balance between exercise, nutrition, rest, and a good state of mind; 2) Patients often choose not to take medical treatment which they think will make them less able to eat and move and hence reduce their tairyoku level; 3) When their pain is fully relieved, patients often prefer to stay on at the PCU and increase their tairyoku instead of spending time at home. Many patients try to cure cancer at the PCU but they finally accept their death when they realize that they cannot regain their tairyoku despite their efforts.

Conclusion: The concept of tairyoku is important for patients to manage their illness and to sustain their autonomy. It also plays an important role in helping patients accept death. Although patients' behaviours or narratives concerning tairyoku do not always medically make sense for the PCU staff, they should not be made light of.

Abstract number: 378
Presentation type: Poster
Session: Assessment

A simple standardized method of quality of care assessment and outcome in terminally ill patients: The pcssc scale

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Introduction: In terminally-ill patients quality of care assessments are often difficult to perform. In exhausted patients, tests have to be short and simple. "ASK THEM DIRECTLY" is the most simple method. A short questionnaire has been developed containing four direct questions about the quality of Pain relief, Care, Spiritual care and Social support, modalities which are mentioned in the WHO definition of palliative care, followed by a question concerning possible outcome: Comfort of the patient. Together these questions form the PCSSC scale. The purpose of the study was to assess possible correlations between the PCSS dimensions, Comfort and pain relief measurements.

Material and methods: Terminally-ill patients were questioned by an independent observer. According to our formerly performed study1 an abacus was applied for answering the questions: "What is your grade for the quality of pain relief?,... for the quality of care?,... for the spiritual support? for the help and support received from family, friends and others?... for your well-being, quality of life". The tests were performed two times weekly. The first 4 questions were correlated with the fifth question and the measured routine pain measurements. Test retest reliability was assessed.

Results: In 38 out of 39 conscious patients could respond adequately to the questions. Patient inclusion and analysis of data is ongoing, results regarding reliability and correlation with patient outcome will be presented at the conference.

Conclusion: The PCSSC can be measured without discomfort in terminally ill patients. The PCSSC scale could be a useful tool for optimising patient care, and compare the quality of care between institutes, by involving patient's opinions in decision making. However, 8–10 scores in comfort are not always achievable due to the deleterious patient's condition as a consequence of their disease state.

Reference

1. Journal of Palliative Medicine 2005; 8: 490–491.

Abstract number: 379
Presentation type: Poster
Session: Assessment

The Brief Pain Inventory: Differences in the interference scales in cancer patients and in chronic pain patients

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Background: The Brief Pain Inventory (BPI) measures pain as intensity and as interference with functions. It is disputed how the interference items measure pain interference in patients with functional limitations not caused by pain. We aimed to examine the interference items in two different patient groups. Methods: A total of 176 advanced cancer patients and 32 patients with non-malignant chronic pain completed the BPI. In accordance with the Norwegian BPI validation study the seven interference items were grouped into two subscales (pain interference with physical and psychological functions). Linear regression analyses were performed to test whether the interference scales performed identically in the two groups?.

Results:

Table 1

	Intensity 4 items		Physical 3 items		Psychological 4 items		Intensity-Physical Correlation	Intensity-Psych Correlation
	Mean	SD	Mean	SD	Mean	SD		
Cancer (N =176)	2.5	2.1	3.7	3.2	2.4	2.4	0.74 p <.001	0.71 p <.001
Chronic pain (N =32)	5.5	1.7	4.8	2.8	4.4	2.3	0.33 p =.06	5.2 p <.001

Regression analyses with pain interference on physical or psychological functions as dependent variable showed no effects of age, education or sex. The coefficients for intensity, group Chronic pain (versus group Cancer), and their interaction were 1.8 ($p < 0.001$), 1.5 ($p = 0.26$), and −0.68 ($p = 0.006$), respectively for interference with physical functions, and 0.97 ($p < 0.001$), .27 ($p = 0.80$), and −0.14 ($p = 0.47$), respectively for interference with psychological functions. Pain interference increased more with increasing pain intensity in cancer patients compared with in chronic pain patients. Conclusion: The results may suggest that cancer patients who generally experience pain with progression of disease and concurrent symptoms report interference from disease rather than exclusively interference from pain.

Abstract number: 380
Presentation type: Poster
Session: Assessment

Validity of the Doloplus-2 for observational pain assessment

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Self-report tools for pain may be invalid in cognitively impaired. Doloplus-2 is an observational pain assessment tool developed for pain assessment in cognitively impaired. It was found valid and helpful for assessing pain and regarded easy to administer in a pilot study performed for translation and validation purposes in 2004. However, pain-experts' ratings were used as pain criterion, but neither the inter-rater reliability of the experts' ratings nor the Doloplus-2 was tested. The objective in this study was to further test the criterion validity and the inter-rater reliability of the Doloplus-2.

Methods: Doloplus-2 was administered to 73 cognitively impaired patients by nurses. As a criterion for pain, pain was rated on a numerical rating scale by a pain-expert. Regression analyses were performed to evaluate the criterion validity of the Doloplus-2, expressed by its ability to explain the variation in the expert's ratings. The expert's pain ratings in 15 patients were compared against ratings performed by two geriatricians for tests of inter-rater reliability. Inter-rater reliability of the Doloplus-2 was evaluated on 16 patients using two blinded administrators simultaneously.

Results: The total Doloplus-2 score failed to explain the expert's ratings except from in a subgroup of 16 patients who were administered the Doloplus-2 by a specialized geriatrician nurse (R-square 0.54). Inter-rater agreement was estimated with intra-class coefficients of 0.77 for Doloplus-2 administrators, and 0.74 for the expert ratings.

Discussion: There was poor agreement between the Doloplus-2 and the pain-expert's ratings, but good inter-rater reliability. Possible causes may be low specificity in the Doloplus-2, differences in training/educational background of the Doloplus-2 administrators or limitations of using an expert's ratings as the pain criterion. Present findings contradict previous results and imply further research.

Abstract number: 381
Presentation type: Poster
Session: Assessment

Argentine validation of the palliative outcome scale (POS)

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Background: Validation of tools used to measure patient-reported outcomes should be considered a key task in evaluation and research in palliative care (PC) in order to look for evidence based knowledge in the field. As most of these tools have been developed in English-speaking countries they need to be validated in the target culture and language to be properly applied in another context.

Objective: To validate a Spanish-Argentine version of the POS in patients assisted by PC teams in Argentine.

Methods: Content and consensus validity from interviews with PC experts and patients and face validity through 2 focal groups and 65 in-deep interviews with patients were evaluated. Correlation/agreement between patients and staff (weighted k); internal consistency (Cronbach alfa); responsivenes to change and time to complete the questionnaire were also measured.

Results: Semistructured interviews with 65 patients and 20PC experts showed good content validity (CV) by qualitative means. Quantitative testing of CV (Lynn's method) was high (m 0.86/0.85 for patients/staff). Consensus validity was also reached. Focal groups emergents were intrinsic/personal, extrinsic and particular aspects, all of them covered by the POS. Patients interviews showed the POS was clear, relevant and easy to complete. Patient/staff agreement was acceptable (±1 score agreement >75% in 27/29 ítems); weighted kappa was >0.3 for 4/10,7/10 and 7/9 ítems at 3 consecutive measurements. Internal consistency was good (Cronbach's alpha 0.67/0.70 for patients/staff). Responsiveness to change reached statistical significance in 5 items for patients and 4 for staff;time to completion was less than 12 min. for both.

Conclusions: Psychometric and qualitative properties of the Argentine version of the POS showed to have high validity. These results support the application of the Argentine POS to measure outcomes of PC patients with advanced cancer in this country and possibly in Latin America.

Abstract number: 382
Presentation type: Poster
Session: Assessment

The PAT-C project: International Classification of Functioning, Disability and Health (ICF) – a tool for classifying aspects of functioning of relevance for palliative care?

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Background: Function(ing) is a broad term without a single definition and is used to describe a wide range of activities and health states, such as lung function, physical function (PF) and social function. Thus, the term function(ing) is imprecise and needs to be broken into subdomains. The WHO's International Classification of Functioning Disability and Health (ICF) is a generic framework and offers a unified standard language and framework for the description of health and health related states from the perspective of the body (Body Functions and Structures), the individual and the society (Activities and Participation).

Aim: To discuss how ICF can be used as a framework to classify relevant aspects of functioning for assessment in palliative care. This is exemplified through the PAT-C project.

Methods: The PAT-C PF project aims at developing a palliative care computer-based assessment tool based on self-report, where relevant PF items are extracted from existing questionnaires and tests. An expert group as part of the PAT-C performed evaluation of relevant ICF domains to be included in the PF assessment tool.
Results: The experts found domains of "activity" to be relevant for daily life functioning, and thus of relevance to assess in palliative care patients. "Body structure and function" was also regarded relevant, but requires clinical assessment and is thus not relevant for self rating.
Conclusions: This work exemplifies how ICF can be used as a conceptual framework in palliative care to define various aspects of functioning. Using ICF in this way can improve communication among researchers and clinicians and make assessments more precise.

Abstract number: 383
Presentation type: Poster
Session: Assessment

The PAT-C project: What aspects of physical functioning should be assessed in palliative care patients?

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Background: Physical dysfunction is experienced by all palliative care patients. Several instruments for assessing physical functioning (PF) are available in palliative care. However, there is a lack of consensus on which aspects of PF to include in standardised assessments.
Aims: To identify, extract and classify relevant PF items in PF instruments, in order to develop a computerised palliative care assessment tool (PAT-C, PF-module) for patients' self-report or proxy-rating.
Methods: A systematic PubMed search was conducted, using physical function(ing) and terms related to population and assessment. 250 instruments were found 44 were found relevant and screened for PF items. The International Classification of Functioning Disability and Health (ICF) was chosen as the conceptual framework and was used to classify items. Among the ICF domains, mobility and self-care were selected as basic dimensions for PF assessment in palliative care. Mobility and self-care items were extracted and further classified into subgroups according to ICF.
Results: Commonly used mobility items were related to 1) performance of activities like; getting in/out of bed and chair, stair climbing, lifting and carrying objects 2) performance of movements; moving in bed, bending down, maintaining standing, walking/getting around and 3) sport or leisure activities; running, swimming, biking, general physical activity. Self- care items included washing/bathing, (un)dressing, grooming and using toilet.
Conclusion: Domains of self-care and mobility, excluding strenuous sport activities, were regarded relevant for the assessment of PF in palliative care. Further work includes ranking items from low to high function within each selected domain in order to develop a computer-based intelligent assessment tool of PF.

Abstract number: 384
Presentation type: Poster
Session: Assessment

Comparison of pain quality descriptors in patients with gastrointestinal and urogenital cancer

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Aims: The purpose was to explore differences in the words used to describe pain in patients with gastrointestinal and urogenital cancer.
Methods: A Greek version of the McGill Pain Questionnaire was used in 186 advanced cancer patients. It assessed the intensity and quality of pain of 77 patients with urogenital cancer and of 109 with gastrointestinal.
Results: Significant differences were found between gastrointestinal and urogenital cancer only in Sensory and Miscellaneous categories. Statistically significant differences were revealed between patients <60 and >60 in all classes (Present Rating Index-Sensory, Affective, Evaluative, Miscellaneous. Patients with gastrointestinal cancer reported more intense pain through the Numbers of Words Chosen from sensory and miscellaneous classes than patients with urogenital cancer. Patients with poor performance status selected more frequently the intense pain descriptors than those with good performance status. Multivariate logistic regression analyses showed that patients who selected the word 'flickering' are 2.896 times more likely to have gastrointestinal cancer ($p = 0.065$); those who selected the descriptors 'throbbing' and 'tingling' are significantly more likely to have urogenital cancer ($p = 0.006$ and 0.025 respectively). Patients who chose the word 'beating' to describe their pain are 9.15 times more likely to have poor performance status. Patients who selected 'lancinating' are also 3 times more likely to have poor performance status ($p = 0.017$ and $p = 0.048$ respectively) while those who reported less intense words are more likely to have good performance status. Finally, patients who selected 'pounding' and 'blinding' are more likely to be less than 60 years old ($p = 0.018$ and $p = 0.008$ respectively) while those reported their pain as 'tugging' are 2.5 times more likely to be >60 ($p = 0.041$).
Conclusion: The findings revealed that cancer type, age and performance status might affect the selection of pain descriptors.

Abstract number: 385
Presentation type: Poster
Session: Assessment

End-of-life care in three different types of care settings in the Netherlands

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Comparison of end-of-life-care between different types of care settings may lead to further improvement of this care. We compared characteristics of care and quality of life during the last three days of life between patients dying either in hospital, nursing home or a primary care setting. We looked at the burden of symptoms, medical and nursing interventions, and aspects of communication. We included 239 of 327 patients who died in the southwest of the Netherlands either in one of five hospital departments, one of seven nursing home departments, or one of three primary care settings between November 2003 and February 2005. Eighty-seven patients were excluded because they did not give or were not able to give informed consent. After the patient's death a nurse filled in a questionnaire. One case was missed because we did not receive a questionnaire. In all settings, the symptom burden during the last three days of life was mainly related to fatigue, lack of appetite, shortness of breath and pain. Set up of a syringe driver and antibiotics were significantly more often applied in hospital patients than in primary care patients and nursing home patients. This also holds for measurement of body temperature and blood pressure. In hospital, patients and family were more often informed about the imminence of death of the patient than in primary care or nursing home. The GP and other professional caregivers were significantly less often informed about the imminence of death of hospital patients than of primary care patients and nursing home patients. In hospital non-resuscitation was significantly more often explicitly discussed with patients, family, and caregivers than elsewhere during the last three months of life. In hospital routine medical and nursing interventions are more often continued during the last three days of life of the patient than in primary care or nursing home, but there seems to be more explicit communication about the patient's imminent death.

Abstract number: 386
Presentation type: Poster
Session: Assessment

Symptom profiles and palliative care in advanced pancreatic cancer – a prospective study

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Purpose: Describe the prevalence and severity of disease-related symptoms, QOL and need for palliative care in advanced pancreatic cancer patients.
Methods: A prospective study was performed in 51 patients with advanced pancreatic cancer at Ullevaal Univ. Hospital from May 2003 to June 2005. All patients (22 females/29 males, mean age 62, range 44–80) completed ESAS for symptom registration, the EORTC QLQ-C30 quality of life questionnaire and the pancreas specific QLQ-PAN26 at first contact, and ESAS in the following clinical visits or phone consultations. QoL scores were compared with age and gender adjusted general population (GP) values. Need for palliative interventions were registered.
Results: Forty-six patients (90%) died during follow-up (median survival 99 days, range 8–497). Patients reported significantly impaired QOL on 9 of 14 scales/items ($p < 0.05 < 0.0001$) relative to the GP at inclusion. The most prevalent symptoms on the PAN26 were pancreatic pain, digestive and sexual problems, while fatigue, loss of appetite and low sense of well-being were most pronounced on the ESAS 43 of 51 (84%) initial consultations and 93 of 161 (58%) follow-ups (104 clinical/ 57 phone-calls), resulted in palliative care interventions, most frequently changes in opioid or laxative medication and dietary advice. The ESAS symptom profiles showed increasing intensity of symptoms the last 8 weeks before death, except for pain at rest and appetite.
Conclusion: All instruments revealed problematic areas. ESAS seemed particularly useful during follow-up due to its brevity and symptom relevance, also for phone consultations. Pain was seemingly well-managed, in contrast to the worsening of most other symptoms. Multidisciplinary interventions, based on systematic follow-up of symptom assessment are necessary for adequate palliation in pancreatic cancer. Advanced pancreatic cancer is ideal for palliative care studies due to the homogeneity of the disease trajectory.

Abstract number: 387
Presentation type: Poster
Session: Assessment

Were you tired? Response shifts in palliative treatment of small cell lung cancer

Marjan Westerman, **Anne-mei**, **Gerrit Van der Wal**, EMGO/VU University medical centre, Amsterdam, Netherlands, **Tony Hak**, RSM Erasmus University, Rotterdam, Netherlands, **Harry Groen**, University Hospital, Groningen, Netherlands

Objective: To demonstrate adaptation, so-called response shift (RS), to changing health in small cell lung cancer (SCLC) patients [Schwartz & Sprangers, 1999]. These patients receive only palliative chemotherapy. Information about impact of treatment on QoL is essential, but RS complicates interpretation of outcome data. This paper provides information about RS's in the rating of fatigue (FA) with EORTC-QLQ-C30 question 'were you tired' by which the interpretation of changes in scores can be improved.
Methods: A qualitative exploratory longitudinal multiple case study. SCLC patients were recruited from five outpatients' clinics for lung diseases in the Netherlands. Interviews were conducted at equivalent points in treatment: start and 4 weeks after start chemotherapy; end and 6 weeks after end chemotherapy. EORTC-QLQ-C30 and -LC13 in a think aloud protocol. Audio recording QoL measurement. Results 24 patients were interviewed (12 men, 12 women, age 38–73). Patients experienced the impact of every new cycle of treatment as more severe but scores remained stable because they felt better off than expected and compared to sicker patients and were still able to cope with the treatment. Patients explained spontaneously and variously their rating 'not at all' (e.g. normal) and 'a little' (e.g. my fault). Discrepancies were found: FA reported in the informal interview but not in the QOL measurement.
Conclusion: RS's (reconceptualization and recalibration) explain only partially underreporting of FA. Patients apply a two-track strategy to cope with deteriorating health. They don't deny the seriousness of their situation but at the same time they are tending to present themselves more optimistic and positive in the QoL measurement than in the informal interview. Patients seem to distance themselves from the image of 'the very sick cancer patient' evoked by the questionnaire.

Abstract number: 388
Presentation type: Poster
Session: Assessment

Individual quality of life in advanced cancer patients admitted to a symptom control unit in a university hospital

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Objectives: The aim of this study was to assess changes in advanced cancer patients' individual quality of life (IQoL) and explore correlates of these changes. IQoL is patient-centred, and therefore a suitable outcome variable in palliative care, but seldom researched.
Methods: Advanced cancer patients were included in an 11-bed unit for palliative care and intensive symptom control in an academic hospital. IQoL was measured with the Schedule for the Evaluation of Individual Quality of Life, Direct Weighting Version (SEIQoL-DW). The SEIQoL total score (range = 0–100) is based on the patients' ratings and weighing of five life area's of which the patients think are important for their quality of life. Pain was measured using a numeric rating scale (0–10), and fatigue was measured using a visual analogue scale. Patients were interviewed within two days after admission (T0) and at discharge (at least one week later; T1). Mean interval between interviews was 8.5 days (range = 7–14).
Results: 29 patients were interviewed at T0 (9 men, 20 women, mean age = 60.6), and 16 patients were followed up at T1. Mean SEIQoL scores improved notably from 53.9 to 67.3; mean pain levels dropped from 3.8 to 2.4. The correlation between pain level and IQoL at T0 was −0.49, and −0.73 at T1. The correlation between fatigue and IQoL was −0.63 at T0. Life area's most often nominated were relationships with family members and friends, symptoms and aspects related to maintaining control.
Conclusions: Individual QOL improved, and the improvements appear to be related to the adequacy of symptom management. SEIQoL scores were moderately-strongly correlated with pain and fatigue. The results suggest that in order to achieve optimal IQoL in advanced cancer patients, palliative care should not only focus at symptoms, but also at aspects important to the individual patients. Especially family relationships and aspects of control are important.

Abstract number: 389
Presentation type: Poster
Session: Assessment

Implementation of Edmonton Symptom Assessment System (ESAS) as a routine in daily clinical practice in a cancer hospital

Nina Aass, **Ina Thon Aamodt**, **Sjur B Hanssen**, The Norwegian Radium Hospital, Oslo, Norway

The Norwegian Radium Hospital is a regional cancer hospital serving approximately two million inhabitants in the Southern and Eastern part of Norway. The hospital has about 250 beds. During 2005 ESAS has been introduced in all wards at the hospital. Personnel from the palliative care research unit have been responsible for the introduction which very systematically has included one-two wards with similar groups of patients at a time. Key words in the process have been: Motivation, information, continuous follow-up, evaluation and adjustment. Teaching has been individualised to the needs of different groups of health care personnel. Although all personnel are involved two nurses at each ward have a specific responsibility for the project. All patients irrespective of the treatment intention (curative or palliative) and irrespective of the intention with the hospital stay (diagnostic work-up, treatment, follow-up etc.) are asked to fill in the questionnaire. ESAS is routinely filled in at admittance and then twice weekly, eventually more often if specific problems are identified. Practical work with the scheme is the responsibility of the nurses. The scheme is part of the patients' records and used at the daily rounds. Both physicians and nurses have found the instrument helpful as a quick assessment of common symptoms in daily clinical practice, and ESAS is now part of the routine. Continuous follow-up and teaching of new personnel is important to maintain this practice. Conclusion: ESAS is a useful instrument with regard to a quick assessment of common symptoms in cancer patients treated with palliative as well as curative intention. Dedicated personnel for teaching and continuous follow-up are important for the successful implementation.

Abstract number: 390
Presentation type: Poster
Session: Assessment

Development and validation of a comprehensive screening questionnaire for palliative care needs

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Aim of Project: This project aimed to develop a new holistic, comprehensive screening measure (SPARC), to facilitate the referral of patients with advanced illnesses into specialist palliative care.
Method: A multi-method design to develop a self rated instrument. Study 1: Item generation Study 2: Measure development: Developing items into questions Study 3: Pilot study: Testing the questions and response formats with patients Study 4: Item analysis and reliability testing: Further testing of the questions and further item analysis to edit the measure Study 5: Validity testing: Preliminary assessments of validity.
Results: Studies 1–3: Items were identified via a systematic review of the literature and 34 interviews with professionals and patients in Sheffield, UK. Following consultation with the research team and the project advisory group an initial list of 281 items was reduced to 45 common symptoms and problems, to develop an initial measure with 65 questions. This contains questions about physical symptoms, emotional issues, spiritual issues, social, independence, and practical issues. Studies 4 and 5: The next stage of development is to further reduce the questions on the measure. We are comparing SPARC with two current outcomes that are commonly used in palliative care and assess similar symptoms and problems, namely, the Hospital Anxiety and Depression Scale (HADS) and the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ-C30). Patients are also randomly allocated to complete either the Palliative Outcome Scale (POS) or the Edmonton Symptom Assessment Scale (ESAS).
Conclusions: We have developed a multidimensional screening measure which gives a profile of needs to identify patients who could benefit from additional supportive or palliative care. Data from current studies will be used to further reduce the items. Scoring guidelines are also being developed.

Abstract number: 391
Presentation type: Poster
Session: Assessment

Subjective well-being and quality of life in palliative patients

Norbert Krumm, **Saskia Jünger**, **Lukas Radbruch**, University Hospital Aachen, Aachen, Germany, **Friedemann Nauck**, Malteser Hospital Bonn Hardtberg, Bonn, Germany

In the context of the German Core Documentation 2002 a self report questionnaire assessing pain, symptoms and the subjective well-being (MIDOS) was applied to patients at PCUs. According to our experience the question: "How do you feel today?" is easy to answer for patients and requires only little time. The investigation was based on $n = 745$ MIDOS questionnaires of patients on PCUs at admission. The question on well-being was compared to staff assessment on the restrictions in the Activities of Daily Living (ADL) and a symptom checklist with 8 physical and 4 psychological symptoms, 2 nursing care and 3 social problems collected in the basic documentation component. The well-being diminished significantly ($p < 0.001$) with an increasing number of restrictions in ADLs. For good subjective well-being a mean of 2.18 ($SD = 2.12$) restrictions was reported; for average well-being 3.29 ($SD = 2.38$) restrictions and for bad well-being 4.08 ($SD = 2.64$). Further exploration revealed a significant association of well-being with all ADL-restrictions except finding meaning, keeping occupied, feeling as man/woman. Restrictions for patients with bad/very bad well-being were mostly reported for the ADL-items resting (35.8% of patients), security (38.9%), excretions (44.1%), eating (46.0%), movement (68.8%) and washing (71.9%). Well-being also was associated with all items on the symptom checklist and diminished significantly ($p < 0.001$) with an increasing number of symptoms and problems. For good subjective well-being a mean of 7.01 ($SD = 3.57$) items on the checklist was reported; for average well-being 9.51 ($SD = 3.16$) restrictions and for bad well-being 10.78 ($SD = 2.90$). The results show that a particular question about the well-being can illustrate the whole spectrum of quality of life in palliative patients. It also may serve as an entrance into a process to identify factors leading to an improvement of the patient's individual quality of life. Further studies are on the way.

Abstract number: 392
Presentation type: Poster
Session: Assessment

General Practitioner-Patient Communication in Palliative Care; A Qualitative Study among Patients, GPs and End-of-life care consultants

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Background: General Practitioners (GPs) play a central role in providing Palliative Care (PC) in the Netherlands. Good communication between health care professionals and patients is considered an essential requirement for the delivery of high quality care. Our literature review yielded the following key elements for GP-patient communication in PC: GPs need to be easily accessible; GPs need to be able to listen well; and GPs need to anticipate. These results are mainly based on studies performed outside the Netherlands. This presentation reports on three qualitative studies to investigate the essential factors and pitfalls for GP-patient communication in PC in the Netherlands.
Methods: We interviewed end-of-life care consultants to find out whether they experienced major communication problems in the daily PC provided by GPs. In focus groups GPs discussed their experiences and opinions with regard to GP-patient communication. Patients receiving PC from their GPs were interviewed about their experiences and opinions on how their GPs were communicating with them. The focus groups and patient interviews were audio-taped and the transcribed texts were methodically analysed.
Results: The 22 consultants, the 20 GPs, as well as the 8 patients confirmed the three essential elements that were identified in literature. Furthermore, many more detailed factors (e.g. exploring the patient's wishes and needs; being honest) and pitfalls (e.g. making promises that can not be kept) were mentioned. We have summarized these elements into three categories: Availability, Active listening, and Anticipating (AAA).
Conclusions: These three studies provide more detailed information on the essential factors and pitfalls in GP-patient communication in PC. Based on these results an instrument should be developed in which all essential

factors are summerized. Such an instrument should enable GPs to identify the gaps in their PC communication skills and to formulate personal learning goals.

Abstract number: 393
Presentation type: Poster
Session: Assessment

Palliative care assessment (PACA) tool – an effective clinical outcome measure for a hospital palliative care team?

Stephanie Gomm, **Sarah Wenham**, Hope hospital, Salford, Great Britain

Background: Research on the effectiveness of hospital palliative care teams (HPCT) is limited. The Palliative Care Assessment (PACA) tool is a valid and reliable research outcome measure in cancer patients when assessing symptoms, insight into diagnosis and prognosis, and facilitation of placement.
Aim: To compare the use of PACA in assessing the effectiveness of interventions in routine practice of a HPCT for patients with malignant and non-malignant disease.
Method: PACA scores were recorded prospectively at each visit for in-patients referred to a HPCT over a 4 month period. Data was analysed for first visit, second visit (days 4–7) and last visit for: i) symptom control (0–3) for pain, nausea & vomiting, dyspnoea, anorexia and constipation ii) patient and relative insight into diagnosis and prognosis (1–5) iii) effect on placement facilitation (1–4) Wilcoxon's signed-ranks test compared changes in PACA scores between first and last visits. Mann-Whitney U test compared PACA score differences between patients in cancer and non-cancer groups.
Results: 128/196 patients were eligible.99 (51%) males. Median age 72, range 18–93 years. 158 (81%) cancer patients,38 (19%) with non-malignant disease 31% had one visit, 20% had 2 visits, 49% received 3 or more visits. PACA scores showed statistically significant improvement between first & last visits for: i) symptoms : pain ($p < 0.0001$), nausea & vomiting ($p = 0.0013$) and constipation ($p = 0.0062$) ii) insight : for patients ($p < 0.0001$) and relatives ($p < 0.0001$) iii) placement: for patients ($p < 0.0001$) No significant difference was demonstrated between the cancer and non-cancer group PACA scores for placement, insight and symptoms (pain, anorexia and constipation); border-line significance was demonstrated for nausea & vomiting ($p = 0.0434$).
Conclusions: The use of PACA demonstrates the clinical effectiveness of interventions by a HPCT in everyday practice and is valid for non-malignant and cancer referrals.

Abstract number: 394
Presentation type: Poster
Session: Assessment

Hospitalized patients' experienced suffering – in life with incurable cancer

Susan Rydahl-Hansen, Bispebjerg Hospital, Copenhagen, Denmark

Susan Rydahl-Hansen. RN, PhD, Senior lecturer. PMA, Bispebjerg Hospital. Denmark. The concept "suffering" is central within WHO'S definition of palliative care but few researchers have made empirical studies about the phenomenon.
Primary objective: To describe the characteristics of a group of hospitalized patients' experienced suffering in life with incurable cancer.
Secondary objective: 1: To describe the characteristics of the suffering which appear within the reality that the patients are a part of as hospitalized. 2: To describe the characteristics of the suffering, which the nurses describe in the nursing diagnoses. 3: To illustrate the characteristics of the suffering, which the nurses do not perceive, realize or respond to or attach importance to and describe in the nursing diagnoses. 4: To illustrate which of the contextual features that can be important, when the nurses do not recognize, respond to, or attach importance to in describing the nursing diagnoses.
Results: The phenomenon is by 12 patients described as: "The experience of living on the edge of an increasingly unpredictable existents at the mercy of the body, the consciousness, the illness, the death, the treatment, the professionals, the language, the past, the present and the future, influenced by increasing powerless ness, increasing loneliness and isolation, and the experience of existing in an persistent, and with time, unconquerable struggle to maintain and regain control". It was primarily the nurses who defined the context and thereby also which actions, feelings and experiences that were accepted in palliative nursing. The patients' attempt to describe their suffering typically drowned in the nurses attempt to prioritize, organize, and execute the bodily and symptomatic effort, which influenced, that the potential signs of suffering that the patients expressed, were often decontextualized into a bodily, symptomatic and treatment-oriented understanding of the situation.

Abstract number: 395
Presentation type: Poster
Session: Assessment

The Charon Index; clarification index differentiating between palliative sedation, euthanasia and unspecified hastening death in end of life decisions

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Introduction: Since 2003 palliative sedation (PS) drew attention in the Netherlands. The definition of PS was not clear and the medical safety conditions were lacking. This induced heated discussions as clear cut differences between hastening death and palliative sedation were lacking, undermining the laborious won safeguards in legal euthanasia.
Aim of this study: Development of an instrument for doctors working in daily practice of end of life care to clarify the difference between euthanasia and palliative sedation.
Method: A focused group discussion was organised on specific items with the purpose to clarify the distinction between euthanasia, palliative sedation and the grey area in between. After this first discussion we used qualitative content analysis of the discussion to write a draft on which each member of the team could comment. The following definitions were accepted: (1) Euthanasia; an active medical intervention to intentionally terminate life at the explicit request of the patient (2) Palliative sedation; an active medical intervention to intentionally eliminate the consciousness of a patient in a situation of intolerable suffering without possibilities to relief this suffering by other interventions and (3) the Grey area; lack of clarity in medical aims and intentions at end of life decisions.
Results: A index of 14 groups with 28 items, identifying the differences between (in the Netherlands acceptable) clear cut intervention euthanasia and palliative sedation or an unacceptable potential death hastening intervention not meeting the criteria of one of these Conclusions; An instrument has been developed, helping in the clarification on particular end of life decisions differentiating on euthanasia, palliative sedation and the grey area in between. Further research is needed to validate this instrument on its discriminative power of medical aims and intentions to doctors involved in end of life care.

Abstract number: 396
Presentation type: Poster
Session: Basic and Translational Research

Pilot quality survey concerning the clarification on decision making in the end of life care; A comparison between four different European countries

Jaap Schuurmans, Groesbeek, Netherlands, **Francine Hirszowski**, Hospital Paul Brousse, unite de soins palliatifs, Paris, France, **CS Verhagen**, **KCP Vissers**, University St Radboud, Nijmegen, Netherlands

Introduction: Quality of medical end of life care may improve if doctors involved in Palliative Care make their intentions of decisions more explicit.
Aims: This pilot qualitative survey explores major terms in the actual practice of end of life decisions within different European cultural contexts.
Method: An open questionnaire based on 4 different ethical problems

concerning; Continuing life sustaining treatment, withholding life sustaining treatment, active termination of life at the request of the patient, and active termination of life without the request of the patient, has been sent to native palliative care doctors working in France (F), United Kingdom (UK), Belgium (B) and the Netherlands (N). Two representing consultants in each country were asked to answer the questionnaire.
Results: Differences between the two countries with legislation concerning euthanasia (B&N) versus the two other countries was reported. On the question regarding what is seen practising around the questioned doctor, very striking intercultural differences were mentioned concerning all cases. Question three on the proposed juridical legislation regarding end of life decision making induced a rich comment from F&UK palliative care doctors. These doctors are anticipating on the integration of the legislation concerning euthanasia in the daily practice of palliative care in their country too.
Conclusions: In all countries the actual practice lacks concrete awareness of aims and intentions underlying the chosen decisions and could be described as mainly operating in ‘grey area’. In B&N, a clear different decision was made in the euthanasia request than in F and the UK. In F and the UK, consultants seem to anticipate on legislation. To our opinion doctors in palliative care should take the lead on clarification of medical aims and intentions underlying the ‘end of life decision making process’.

Abstract number: 397
Presentation type: Poster
Session: Basic and Translational Research

Can bone turnover markers be considered predictive of the analgesic response during pamidronate therapy?

Antonia Martinetti, **Carla Ripamonti**, **Rosalba Miceli**, **Ettore Seregni**, **Luigi Mariani**, **F De conno**, **E Bajetta**, **E Bombardieri**, **Tiziana Campa**, Istituto Nazionale dei Tumori, Milano, Italy

Few data are available on bone marker’s predictivity of the symptomatic efficacy of bisphosphonate therapy in patients with painful bone metastases. We evaluated a panel of bone turnover and bone associated markers, in patients with bone metastases, in relation with pamidronate treatment and corresponding analgesic response over seven weeks. Forty-two patients were treated with two cycles of 60 mg i.v. pamidronate weekly, for two weeks running, with a three-week interval in between. We evaluated serum markers of bone formation: C-terminal propeptide of type I procollagen, osteocalcin, and bone specific alkaline phosphatase. As indicator of bone resorption, we evaluated the serum marker C-terminal telopeptide of type I collagen (ICTP); and two urinary markers the deoxypyridinoline cross-links and the cross-linked telopeptides of type I collagen. The levels of the bone associated markers osteoprotegerin, osteopontin and calcium were evaluated. A mixed effects linear modelling approach was adopted, to account for possible correlation among marker levels and time on study or analgesic response We created an indicator variable that classified the patients as “improved/stationary” or “worsened” regarding the analgesic response. Eighteen patients resulted “worsened” and 24 “improved/stationary”. The results of the mixed effects models in terms of p values for testing the association between marker levels and time on study or analgesic response was: 1. the changes of marker levels over time did not significantly differ between the two groups; 2. for ICTP, osteoprotegerin, and osteopontin, the overall test for time was not statistically significant; on the contrary it was for analgesic response. In conclusion biochemical markers of bone turnover, in particular the ICTP and osteoprotegerin offer the possibility to reliably predict and objectively assess the analgesic response to pamidronate treatment.

Abstract number: 398
Presentation type: Poster
Session: Basic and Translational Research

Is methadone an effective treatment for neuropathic pain?

Matthew Makin, Nightingale House Hospice, Wrexham, Great Britain, **Morley Jack**, **Mark Stringer**, Pain Relief Foundation, Liverpool, Great Britain, **John Bridson**, Cardiothoracic Centre, Liverpool, Great Britain

The original guidelines from Liverpool for the analgesic use of methadone had previously recommended that it should not be prescribed in cases of cancer related neuropathic pain. Encouraged by the finding that Methadone had the potential to act as a functional NMDA receptor antagonist, we used it as an alternative strong opioid in cases of cancer related neuropathic pain that had responded poorly to morphine. Drugs that display NMDA receptor antagonist properties have been shown to strongly potentiate the analgesic action of morphine and attenuate the development of tolerance. We reviewed 54 cases of patients who had been successfully converted to methadone and found the majority of cases had a dominant neuropathic pain syndrome. We also undertook a laboratory study, not only to confirm Methadone’s affinity for the non-competitive binding site of the NMDA receptor, but also to identify from a large number of other opioids those that may offer possible utility in the management of neuropathic pain. Finally through a double-blind randomised control trial we examined whether methadone did indeed have an analgesic effect in cases of neuropathic pain. Combined with the data from our previous clinical study we comment on its overall tolerability and potential to act as an effective analgesic in cancer related neuropathic pain. We present the findings of the clinical studies, laboratory studies and comment on the effectiveness and safety of methadone as a treatment for neuropathic pain.

Abstract number: 399
Presentation type: Poster
Session: Basic and Translational Research

One of our own: Common themes and differences occurring when palliative care doctors and nurses treat patients of the same professions

Annmarie Nelson, Marie Curie Cancer Care, Penarth, Great Britain, **Simon Noble**, Cardiff University, Cardiff, Great Britain

Background: We have recently undertaken a pair of linked studies exploring the issues involved in the care of patients with advanced cancer. Interpretative Phenomenological Analysis (IPA) was used to examine: 1: Senior palliative care nurses’ attitudes to patients that are nurses 2: Palliative care consultants’ views on caring for patients that are doctors. The studies attributed the following subordinate themes during analysis of the interview data: Nurse study: Labelling/Attributional bias Communicative and physical avoidance. – Questionable perks. – Observed negative behaviours of junior staff vs. reported positive self-behaviours – Spontaneous reflections of self-experiences. Doctor study-Labelling/Attributional bias – Avoidance of psychosocial issues – Questionable perks – Medicalisation of care – Differing levels of involvement of the multiprofessional team.
Aims: To explore the similarities and differences in attitudes between the two professions.
Methodology: The transcribed interview data from both studies was merged and common themes explored using IPA. The data was then divided into two sub-groups where differences between the two professions were revealed and discussed.
Results: Both groups assigned different patient ‘perks’ to their own profession. There was questionable benefit to these. Communicative avoidance was apparent in both groups. Nurses also physically avoided nurse–patients, when possible. Nurses tended towards self-reflection and personal experience when discussing own practice to a greater extent than doctors.
Conclusions: Patients from nursing and medical backgrounds receive different levels of care from ‘lay’ patients. The common themes occurring are intersected by the professional culture and working practices of each group. The notions of team working and reflective practice can be seen to influence nurse attitudes whereas issues of status and professional autonomy give weight to doctors’ views.

Abstract number: 400
Presentation type: Poster
Session: Basic and Translational Research

Palliative Care comes into the information age: A policy for clinicians and researchers

Michael Thick, **Ken Welsh**, Imperial College, London, Great Britain, **Julia Riley**, **Sophy Gretton**, Royal Marsden, London, Great Britain

Summary Palliative care has been slow to adopt the full range of available research opportunities. Participation in current genomic and proteomic programmes requires a tight integration between clinical and research colleagues, but highlights the requirement to obtain high quality phenotypic data, and maximize the benefits of this from a necessarily small number of patients. We wish to present a data collection, quality control and analysis policy which are sensitive to current requirements for consent and data protection (ISO17799), and which satisfies the needs of a combined clinical and research department in a palliative care setting. Consent We have successfully trialed the use of a consent process which begins when our patients are well, but allows us to use data and samples before and after their death. Data collection and quality control A senior member of staff is nominated as data controller and Caldicott guardian. He/she is responsible for overseeing the quality process, and the allocation of verified data subsets to each researcher. Excel spreadsheets can no longer cope with the volume and complexity of our genetic data. We now propose an Oracle data suite, which can be partitioned into smaller Excel subsets suitable for individual researchers and clinicians. Periodically the data is reviewed by a group of senior clinicians and scientists, and a decision made to reintegrate that subset (including new data and information derived from it) back into the patient electronic record. Analysis We use data mining technologies for quality control, hypothesis generation and then in depth analysis. In brief, the whole dataset is scanned for significant associations. Many are spurious, but many point to erroneous or missing data. The remainder are examined for likely relevance and tested further. The policy of data reintegration allows ALL our findings to be tested against each new project's additional data.

Abstract number: 401
Presentation type: Poster
Session: Basic and Translational Research

Qualitative Research Training Needs in Palliative Medicine: A Survey of Specialist Registrars in the United Kingdom and Ireland

Natasha Michael, Our lady's hospice, Dublin, Ireland, **Sinead Donnelly**, Palliative Medicine Department, Limerick, Ireland

Qualitative research is increasingly established as a valid and accurate form of research enquiry. Well-designed, innovative research allows for the exploration of sensitive and challenging topics. The medical profession though, have made a minimal contribution to this field.
Aim:
To evaluate the views of trainees in palliative medicine on
The relevance and value of qualitative research
Their confidence in understanding qualitative methods and evaluating studies
Their qualitative research experience and training needs
Method:
Postal questionnaires were distributed to Specialist Registrars in Palliative Medicine in the UK and Ireland (203).
Results: There was a 69% response rate. Majority were trainees from England, female and members of the College of Physicians.
Qualitative studies were valued more for its clinical relevance than scientific accuracy. Majority would have rated as average, their knowledge and understanding of qualitative methods and their confidence in evaluating qualitative studies 40% had received formal training in qualitative methods Two thirds had participated in research during training with a minority of studies having a qualitative design. Barriers to participation included lack of knowledge, support and supervision from senior clinicians and constraints of time and clinical commitments 89% felt that there should be further training in qualitative methods through specifically designed short courses.
Conclusion: High quality qualitative research demands collaboration. For physicians to be able to contribute effectively to this field, it is essential that they enhance their knowledge of qualitative methods and its scientific guidelines. Through this we can ensure a valuable multidisciplinary approach to palliative care research.

Abstract number: 402
Presentation type: Poster
Session: Basic and Translational Research

Generational comparison study of conceptions on death. Is death still a taboo?

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Introduction: Social judgment of attitudes towards death in Hungary is in the focus of our research. We wish to study changes of death concepts in more aspects-as lack or modification of traditions, death concept in relation with age-groups, attitudes, judgment of others' and own death. According to our hypothesis there are generational value-judgment differences existing and death is dealt with as a taboo. Families' communication and exemplary skills are deficient. Religion expectedly emerges as a protecting factor.
Method: Our target population is high school students and the age-group of 55–65 years plus a group of professional helpers. The starting point of the research is the evaluation of the questionnaires completed by 523 high school students in Miskolc, in the subject of death and dying. There is a 300 persons questionnaire survey being performed with questionnaires validated and calibrated by us: Lester Attitude Toward Death (LATD) Scale (21 items) and Neimeyer and Moor's Multidimensional Fear of Death Scale (NMMFD) (42 items). This is completed with guided deep-interviews (5–10 persons per group) which are followed by the descriptive and generational comparison analysis of the data gained.
Results: According to the findings of the Miskolc questionnaires so far, there is a significant difference between the sexes in the emotional reactions experienced when encountering a dead body. The NMMFD scale we administered to 100 high school students. During the reliability study we found high Cronbach-alpha values in "fear from the process of death" and "solicitude for important peers" factors. Factor analysis shows a very strong significance in the "fear from the process of death" factor.
Conclusions: Attitudes toward death have an effect on people's mental health so we pay attention to epidemiologic relations giving a fair to the development of aimed prevention and intervention strategies that may contribute to a decrease in adolescents' fear of death.

Abstract number: 403
Presentation type: Poster
Session: Communication

The influence of a cancer disease on communication in families and palliative care crew

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The aim of this research was to establish the connection between the communication of doctors with their patients and their families and the process of cancer disease treatment.
Materials and methods: 50 patients suffering from advanced cancer were treated in the Clinic of Palliative Medicine in Lodz as well as their families completed the questionnaire. The questions included the following: previous place, kind of administered treatment, their knowledge of their state of health and a predicted prognosis.
Results: 44% relatives agreed to inform the patient about the diagnosis

but not about the predicted prognosis, 38% did not agree to inform about the diagnosis or the prognosis, while 18% of the families agreed to inform the patient both about the diagnosis and the prognosis. 96% of the patients who were aware of the diagnosis but not of the predicted prognosis followed the doctors' advice. In the group of the patients whose families did not agree to inform them about the diagnosis or the prognosis-82% followed the doctors' advice. 56% of the patients who were informed both followed the doctors' treatment.

Conclusion: The result of the research was an evident connection between the level of patients' knowledge and relationships with relatives and the crew of palliative care. The research revealed that the patients treated in oncologic clinics were better informed about state of health and showed a connection between a health service institution and the level of patients' knowledge of health state as well as the predicted prognosis.

Abstract number: 404
Presentation type: Poster
Session: Communication

Family interviews in a palliative care unit

Isabelle Beytrison, Plan-les-Ouates, Switzerland

The family talks are a recognized need in the care of patients in a palliative unit. At first, the aim of this research is to identify the quality of the family talks carried out in a palliative care unit over one year, to show what the most important factors of this quality are. In a second time we would like to show the importance the nurses give to the talks in the care of patients at the end of their life.

Method: We analyzed 242 talks carried out over the year 2004, using a grid of evaluation containing 15 criteria. In the second time, we interviewed the 7 nurses of the unit, in order to know their opinion on the quality of the talks.

Results: On a total of 242 analyzed talks, 163 took place between the families, the nurses and/or the doctors in an unplanned manner, and 79 talks were organized in collaboration with the various partners of care. The 7 nurses recognized the importance and the benefits for the patients to carry out organized, quality family talks. All of them required rules in order to lead formal talks and inter-disciplinary communication (nurse/doctor), and all of them determined a technical method (method of family talk).

Conclusion: This study demonstrated that the nurses need training in the domain of family interviews/talks. There is currently an ongoing project of training, on the method of family talks and on the written transmission of information (targeted via the data-processing tool, to have traceability).

Abstract number: 405
Presentation type: Poster
Session: Communication

Palliative care professional's information preferences

Javier Rocafort Gil, Servicio Extremeño de Salud, Mérida, Spain, **Rafael Mota Vargas**, Servicio Extremeño de Salud, Badajoz, Spain, **Raquel Cabo Dominguez**, **Silvia Librada Flores**, Asociación Española Contra el Cáncer, Badajoz, Spain, **Laura Blanco Toro**, Asociación Española Contra el Cáncer, Merida, Spain

Introduction: One of the main principles of the Regional Palliative Care Program, created to secure the terminally ill patient care, is to ensure that the patient is informed about his or her illness, that he or she has the opportunity to talk about it and has a choice of alternatives throughout the entire process.

Objectives: To determine the level of information that professionals would want to receive in case of terminal illness, i.e. to whom would they prefer to communicate the diagnosis and whether or not they would want to know the full truth of the situation.

Materials and Methods: 126 professionals (doctors, nurses and other) were interviewed during a basic PC course. The professionals were asked three questions in order to weigh up their attitude concerning the manner in which they would want to receive the information if they were seriously ill. The responses are analyzed taking into account their occupation. The potential relationship between variables is studied applying Cramer's V as all of them are nominal.

Outcome: The professionals acting as terminally ill patients would want to know all the information about the diagnosis and prognosis of their condition [92.9%]. They would also want their doctor to inform them throughout the entire illness process [80.8%] and they would like to know how often they would have to resolve any pending issues [87.8%]. This last question was the only one in which there were significant differences ($p = 0.02$) in the professionals' answers.

Findings: The vast majority of professionals would like to have adequate information. The results are similar to those issued by Gómez-Sancho showing that 85.77% of respondents would like to be well informed.

Abstract number: 406
Presentation type: Poster
Session: Communication

Family conference: A safe and well-accepted tool for communication in palliative care of advanced cancer patients in a comprehensive cancer center

Sriram Yennurajalingam, **Marlene Lockey**, **Ellen Pace**, **Tao Zhang**, **Eduardo Bruera**, MD Anderson Cancer Center, Houston, U. States

There is limited evidence for appropriate communication between inpatient healthcare teams and families in the planning of end-of-life care in palliative care patients. The purpose of this retrospective study is to describe the family conference (FC) intervention implemented in patients admitted to a palliative care unit during the period of July 2004 to December 2004. 123 patients records admitted in palliative care unit who had family conference documented during period of 6 months were retrospectively reviewed. Median age was 61 (33–86) years. 49.6% patients were female. Median number of days prior to discharge, the FC was conducted was 3 (0–51) days. There were a median of 4 health care providers (2–9) and 4 (0–11) caregivers present in the FC. Both patient and his/her spouse or family members attended in 59.3% FC's. Split conference (with patient and family separated) was reported in none of the FC's. Advanced Directives was discussed in 19.5%. Discharge options in 92.7%. Prognostication in 89.4%. Care in the palliative care unit 37.4%. Symptom distress (delirium, pain) in 93.5%. Treatment plan including pain management, antipsychotic medications discussed in 91.1%. Topics of nutrition in 25.5%. Cancer diagnosis in 95%. Withdrawl of care including chemotherapy, antibiotics, blood products in 20.3%. Conflict of care with health care providers by the patient and caregivers were expressed in 3%. Patient expressed distress in by 17.3% (17/74) and family in 42.9% during the FC. In the patients who had FC, 13% were discharged to home, 58.6% to hospice and 20.3% expired in the hospital.

Conclusion: Family conference is a safe and accepted modality of communication. The discharge options, prognostication, symptom distress, management of symptoms and cancer treatment were the most common topics discussed in most of the FC's. There was no reported split conferences conducted, which could be rectified in future so as to allow family express distress.

Abstract number: 407
Presentation type: Poster
Session: Communication

What do palliative patients know about their diagnosis and prognosis

Walter Rombouts, **Nancy Cannaerts**, **Mieke De Pril**, **Inge Bossuyt**, **Johan Menten**, UZ hospital Leuven, Leuven, Belgium

This study analyses the expressed knowledge of palliative patients about their cancer diagnosis and bad prognosis at the moment they had for the first time contact with the palliative support team (PST) in the hospital. Literature on this subject is scarce. During this prospective and descriptive research design is in 100 consecutive oncological palliative hospitalised patients registered if and how far they were aware of their real diagnosis and prognosis at the start of the palliative support. The reasons for not living in truth about diagnosis and prognosis were assessed. A preliminary analysis (n = 51/100) revealed that 55% of the patients are fully informed, 15.7% know the diagnosis but not the prognosis and finally 19.6% of the patients don't know the diagnosis neither the prognosis. Young patients are in general better informed then the older ones. Oncological units are more familiar with informing patients about their life threatening situation than non-oncological units. Not informing patients about diagnosis and prognosis are mostly linked with patient and family bounded aspects. Physician related aspects are responsible not to communicate the prognosis. These preliminary numbers will be expanded by a multicenter study in different Flemish palliative support teams to enlarge the number above 350 patients. The results will be presented at the EAPC congress in Venice. Being not fully informed has implications. The patient is sometimes deprived from the most optimal palliative care because important decisions are not taken in time. Both the patient and the family can not function as adequate and responsible partners. Knowing the different reasons why patients, families and caregivers do not like to fully inform the patients will help the PST in the future to better support the treating oncological teams in communication about diagnosis and prognosis.

Abstract number: 408
Presentation type: Poster
Session: Education

Evaluation Of An Educational Study Day For Volunteer Staff

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Aim: This evaluation aims to establish the benefit of a full day education session for volunteer staff in an external venue compared to quarterly sessions held within the palliative care unit. Thirty-five volunteer staff attended the education day and 31 evaluations forms were returned. Relevance to Palliative Care. The employment of volunteers is one feature of palliative care services that is common to all care provisions in whatever country they are operating. However volunteers do come from a range of diverse backgrounds with different expectations values and beliefs. All staff are require to have a minimum knowledge base and a universal understanding of the philosophy, works, values and role of the organisation Evaluation Results. The seven educational sessions were evaluated and a further two questions were related to the venue and catering. For ease of completion sessions were scored as: 1- not relevant to their role 2- good 3-very good or 4-Excellent All individual scores for each session were totalled and a mean average score calculated. The lowest average score was 3.45 the highest 4. The majority of volunteers either scored 3- very good or 4-excellent. One exception scoring 2- good. A multitude of positive comments were annotated on the evaluation form.
Conclusion. The volunteer's educational day proved to be a success not only from the positive results on the evaluation forms but also from the change in the volunteer's attitude and application to their work. Overall Impression. Full day educational sessions have proven to be more beneficial for volunteer's staff and paid staff than the quarterly sessions in relations to attendance, efficient use of resources and team building.

Abstract number: 409
Presentation type: Poster
Session: Education

Clinical Experiences in Palliative Care for Nursing Students

Barbara Bailey, San Diego Hospice & Palliative Care, San Diego, U. States

Background: Nurses need to learn basic competencies in palliative care. The ELNEC curriculum was developed to provide didactic content for use in all US schools of nursing. However, clinical experiences have a more profound influence on nursing practice than classroom experiences. They also influence future career choices. Student nurses need to see palliative nursing practice during formal undergraduate training to learn basic nursing competencies in palliative care in order to meet growing need for palliative nursing.
Setting: US city of 2.5 million people in metropolitan area with ten schools of nursing, 3 of which offer 4-year bachelors degrees in nursing. Large program providing palliative care in 3 inpatient units and home care program serving average daily census of 850 patients per day.
Curriculum: Required 8-hour practicum in inpatient hospice unit using ELNEC curriculum.
Evaluation: 223 nursing students from 2 schools completed the 8-hour curriculum in academic year 2004–2005. This represents a 100% increase in students and a 100% increase in total curriculum time from academic year 2000–2001. Qualitative evaluation shows that 24% saw nurses working as part of an Interdisciplinary Team, 20% identified the role of the nurse as unique in this setting, 10% experienced a change in their perceptions of providing palliative and hospice care and 1% mentioned an interest in the field in the future.
Conclusion: Like physician training, practical experiences are effective for nurses to develop palliative care competencies. A study is needed to assess knowledge and behavioral outcomes in response to this educational intervention.

Abstract number: 410
Presentation type: Poster
Session: Education

Undergraduate training in palliative medicine: What effect does a curriculum without compulsory palliative care have on medical students' knowledge, skills and attitudes?

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Introduction: In 2003 palliative medicine was integrated in the curriculum for medical students in Germany, but not mandatory. This study analyses the effect of a curriculum without compulsory course in palliative medicine on students' knowledge, skills and attitudes towards the care of dying patients and decisions at the end of live.
Methods: In a cross sectional, questionnaire based survey at the medical school of Bonn 1st, 3rd and 5th year students had to grade their knowledge and skills (very certain, slightly certain, rather uncertain, very uncertain). Knowledge was tested answering true/false on basic statements. Attitudes towards end of live decisions were queried.
Results: The return of questionnaires was 78%. Significant increase in self estimation of certainty (very/slightly certain) comparing 1st to 5th year students were detected for the items distinction between palliative and curative medicine (1st 2,8%, 3rd 8,7%, 5th 19,8%; $p < 0.001$), symptom control (4,7%, 7,2%, 21%; $p < 0.001$), pain management (6,6%, 8,7%, 23,5%; $p = 0.001$) and communication (21,1%, 36,2%, 34,6%; $p = 0.036$). No significant differences were recorded for the items accompaniment of dying patients, breaking bad news and integration of spiritual aspects. The low overall certainty is reflected knowledge issues. For instance, only 37,3% of 5th year students answered a question on a maximum dose of morphine correctly. There is a non-significant trend for increased refusal of legalizing active euthanasia (36,7%, 53,6%, 51,3%; n.s.).
Discussion: A medical curriculum without compulsory course indeed increases certainty in some of the core competencies in palliative care, but the overall certainty and knowledge at the end of the training remains low. The WHO claim that palliative care has to be "compulsory in courses leading to a basic professional qualification" has still to be fulfilled in Germany. This study can serve as a baseline to evaluate the effect of mandatory courses in palliative care.

Abstract number: 411
Presentation type: Poster
Session: Education

Exploring the role of community palliative care nurse specialists as educators

Jacqueliine Husband, Marie Curie Cancer Care, Edinburgh, Great Britain

Aim: To explore the role of community palliative care clinical nurse specialists (CNS) as educators.
Background: Existing literature determined an uncoordinated evolvement of the CNS role in the UK, resulting in a broad job remit, with clinical, managerial, research and educational elements. Within specialist palliative care delivering education is integral to the role of CNSs, however many received no formal training in this area. There appeared no mandatory qualification or training programme to support CNSs, with a lack of evidence as to the role the community palliative care CNS had in providing formal education.
Method: A qualitative research approach, hermeneutic phenomenology, was adopted for this study, using a semi-structured interview approach, with a convenience sample of 8 community palliative care CNSs. Formal ethical approval was obtained. The criteria of credibility and validity were applied to ensure the trustworthiness of the data. Colazzi's framework for analysis provided a structured and transparent approach, with a summary of the findings verified by the participants, enhancing the credibility of the data.
Results: Analysis presented 3 main themes; conflict of expectations, credibility as a teacher and making the education role work.
Conclusions: This study highlighted a team approach to addressing the conflict of expectations between the role specifications and practice reality. A national review of the educational and clinical experience pre-requisites, and organisational expectations, is necessary. If the community palliative care CNS is to maintain a presence in formal education, they require the knowledge and skills to deliver it effectively. Research and preparation time must be acknowledged, with the clinical workload decreased. Informal education delivery could be considered inequitable and uncoordinated and further research is required to establish the demand and evaluate the results of this form of education.

Abstract number: 412
Presentation type: Poster
Session: Education

Survey of palliative care concepts among medical interns in India

Parag Bharadwaj, Cedars Sinai Medical Center, Beverly, Hills, U. States, **Ms Vidyasagar**, **Anjali Kakria**, Kasturba Medical College, Manipal, India, **Tanvir Alam**, Private Practice, Bangalore, India

Aim: To assess the level of awareness in palliative care amongst interns of Kasturba Medical College, Manipal, India.
Materials and methods: 44 interns were taken into the study. The interns were assembled in a lecture hall and a survey containing a set of questions in Yes/No format (as given below) was distributed to them. They were given 15 minutes to fill up the survey after which it was collected back and the responses were analyzed. (Y/N/%) 1. Are you familiar with the concept of palliative care (36/8/82) 2. Have you witnessed the care of a dying patient (16/28/36) 3. Are you familiar with the different types of pain (30/14/68) 4. Do you feel adequately trained in managing different types of pa in (2/42/4.5) 5. Are you familiar with any of the pain assessment tools /scales (8/36/18) 6. Are you familiar with the physical signs of the dying process (24/18/55) 7. Do you feel adequately trained to manage symptoms of the dying patient(4/40/9) 8. Are you comfortable talking about death to a terminally ill patient(6/38/14) 9. Have you witnessed your teacher discuss the terminal nature of the patient's disease (20/ 24/45) 10. Do you feel adequately trained in delivering bad news (terminal diagnosis) to the patient (2/42/4.5)
Results: Although Interns have an extra year of clinical experience, they did not perform substantially better than the students in a similar survey. This reinforces our thought that the knowledge base amongst students is probably theoretical and with time needs to be reinforced with a stronger clinical component. The results make a strong case for introducing palliative care during internship. We plan to follow this study with a more objective one.

Abstract number: 413
Presentation type: Poster
Session: Education

Survey of palliative care concepts among medical students in India

Parag Bharadwaj, Cedars Sinai Medial Medical Center, Beverly Hills, U. States, **Ms Vidyasaga**, **Anjali Anjali kakria**, Kasturba Medical College, Manipal, India, **Tanvir Alam**, Private Practice, Bangalore, India

Aim: To assess the level of awareness in palliative care concepts amongst final year students of Kasturba Medical College, Manipal, India.
Materials and methods: 111 final year students were taken into the study. The students were assembled in a lecture hall and a survey containing a set of questions in Yes/No format (as given below) was distributed to them. They were given 15 minutes to fill up the survey after which it was collected back and the responses were analyzed (Y/N/%) 1. Are you familiar with the concept of palliative care (96/15/86) 2. Have you witnessed the care of a dying patient (22/89/20) 3. Are you familiar with the different types of pain (94/17/85) 4. Do you feel adequately trained in managing different types of pain (14/ 97/13) 5. Are you familiar with any of the pain assessment tools /scales (10/ 101/10) 6. Are you familiar with the physical signs of the dying process (42/69/38) 7. Do you feel adequately trained to manage symptoms of the dying patient (11/100/10) 8. Are you comfortable talking about death to a terminally ill patient (32/79/29) 9. Have you witnessed your teacher discuss the terminal nature of the patient's disease (32/79/29) 10. Do you feel adequately trained in delivering bad news (terminal diagnosis) to the patient (16/ 95/15).
Results: The theoretical knowledge of the concepts seemed to be better than the level of confidence in practical aspects. The results make a strong case for introducing palliative care in the undergraduate curriculum. We would like to conduct a more objective study in the near future.

Abstract number: 414
Presentation type: Poster
Session: Education

Implementation of a Pediatric Palliative Care Training Program

Rose Virani, **Betty Ferrell**, **Marcia Grant**, City of Hope National Medical Center, Duarte, US, **Pam Malloy**, **Anne Rhome**, American Association of Colleges of Nursing, Washington DC, US

Research Aims: In 2002, the Institute of Medicine released a report titled "When Children Die: Improving Palliative and End of Life Care for Children and their Families". In response to this report, the End of Life Nursing Education Consortium (ELNEC) developed and implemented a national educational curriculum for nurses in pediatric palliative care.
Methodology: The curriculum focuses on 10 end of life content areas. Participants attended an intensive 3 day Train-the-Trainers program and completed goals for implementing the curriculum in their own settings.
Results: The first national training program was hosted in 2003 and 3 national courses have included 296 nurse educators representing 45 states. Participants rated their current effectiveness in pediatric palliative care at 5.2 on a scale 0 = not effective to 10 = very effective. Participants also identified key barriers in teaching pediatric palliative care to staff including fears associated with dying, cultural beliefs, lack of educational resources, lack of staff time and difficulties in determining prognosis of children. Follow-up goal evaluation occurs at 6 and 12 months. At 12, months participants have reported ?100% increase in educational efforts and significant change in effectiveness of their teaching and overall curriculum. Overall effectiveness of the ELNEC curriculum was rated at 9.06 on a scale of 0 = not helpful to 10 = very helpful.
Conclusion: Improved pediatric palliative care can enhance the quality of life of children and their families as they face serious childhood illness and death. Nurses are key to insuring improved quality care for this population.

Abstract number: 415
Presentation type: Poster
Session: Education

A simulated challenge: Management of end of life care for medical undergraduates

Stephanie Gomm, **Catherine Byrne**, **Philip Lomax**, Hope hospital, Salford, Great Britain, **Chris Harrison**, University of Manchester, Salford, Great Britain

Background: Concern has been expressed that medical students have little exposure to palliative care education in the UK. Recent literature review identified communication skills are one key aspect that undergraduates should be learning when studying palliative care. Adult learning theory suggests that communication skills are acquired more effectively when linked to clinical problem-solving. Post-graduate doctors should be able to manage symptoms and communicate sensitively for care of the dying.
Aim: To evaluate a pilot medical undergraduate teaching course in Northwest England in order to improve management of end of life care.
Method: A cohort of final year medical students assessed by questionnaire half-day teaching sessions involving a clinical scenario (patient with metastatic prostate cancer). Each student undertakes a role- play with a simulated relative as the scenario evolves from admission to death (4 days), incorporating symptom control, communication about dying and bereavement.
Results: 80/96 (83%) completed questionnaires. Median age 23, range 22–30 yrs; 28 males and 52 females 35% from ethnic minority groups 29% and 23% strongly agreed; 65% & 73% agreed respectively that the aims and objectives were clear and fulfilled 98% strongly agreed that the teaching sessions would help in preparation for their roles as junior doctors. There was clear endorsement of the subject material in the course and the majority did not find it too challenging 98% were satisfied with the feedback and realistic portrayal by the simulated relative. Overall feedback indicated lack of knowledge of palliative care and care of dying.
Conclusions: Students valued the course as worthwhile and was not too challenging. Most students confirmed little exposure to knowledge of the dying process and principles of palliative care.
Outcome: The course has been adopted for all final year medical undergraduates.

Abstract number: 416
Presentation type: Poster
Session: Education

An evaluation of role-play in which is introduced to medical students in tutorial education system on palliative care

Toshihiko Nakatani, **Yoji Saito**, **Misuzu Nitta**, **Ruiko Hatto**, Shimane University Hospital, Izumo, Japan

Introduction: It is so important that medical students are educated by a good curriculum in a university. As a method of this subject, we should establish an education curriculum of tutorial system in the main instead of lecture for medical students in our university. Tutorial system is supposed to be excellent than a lecture in enhancing the motivation which students study voluntarily. A role-play has a possibility that students are able to think about another personal position on them own in medical situation. This view is highly required in particular when they face patients on palliative care in the future. We took a role-play for education on palliative care and evaluate the effects to medical education in tutorial system.
Methods: We took a role-play in tutorial system for undergraduate students of fifth year, who were majoring in medicine. The numbers of students were 93 and they were divided into 12 groups. The main theme of role-play was decided in about "a pain in person who is concerned in palliative care" by a lecturer. Every group was able to determine a theme freely along the main theme. The duration of a role-play that was played by a group was about 10 minute. All students played role-plays and appreciated them each other. We investigated into all questionnaires, which were written by each student after performances and appreciations of role-plays.
Results: The percentage of students who had good impressions on this role-play in tutorial system was 89%. The numbers of students who thought about another situation of physicians, patients and families were 62, 52, 27, respectively. There were 21 students who had special interest in palliative care after this role-play.
Implications: It is supposed that a role-play in tutorial system is useful for education on palliative care to medical students enhancing the motivation of own thinking.

Abstract number: 417
Presentation type: Poster
Session: Ethics

Growth of Hospice and Palliative Care in a Latin Country-Ethic disclosures and guidelines

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Hospice and PC in Brazil, officially started 14 years ago, with official engagement of S. Paulo State Government, interested in care for terminally ill cancer patients (pts), making priority in developing Hospice Care in our Health System. Objective and documented official measures for support programs was taken since that, with supervision of the pioneers of the movement, promoting changes in our health care system since that time, with many institutions working in this job.
This study is aimed to document past and current official PC initiatives, in Brazil, his growth, with data based upon official public governmental documents, reporting the impact after 14 years in Care for terminally ill cancer pts, analyzing kind of drug access and availability, including to poor people, laws changes, ethics and legal barriers and actual resources for these pts, contributing to diagnosis real and actual situation for future studies.
Published and public official government initiatives since that time, drug availability, number of services was detected in 14 years, according a review of world hospice and PC documents published, public federal bioethics documents, new federal and regional laws and projects. Logistic, legal and cultural barriers are discussed and analyzed.
Classic problems of PC like opioid availability, drug regulation, wrong concepts about the idea, ethics and legal barriers for his development, was detected.
Growth of interest in Hospice and PC was detected and because listed difficulties, official or private initiatives, disappeared since that time.
As conclusion, isolated palliative services have more difficult to be settled in this country than hospital based services, due economics, cultural, ethical and legal barriers. Authors suggest legal measures officially in course, and more governmental support, must be effective to PC future in this Latin country. For now, Palliative and effective disease treatment based in minimal, or no side effects, must be in course together to minimize legal problems.

Abstract number: 418
Presentation type: Poster
Session: Ethics

Muslim End of Life Ethics in Antwerp, Belgium. S. Van den Branden & B. Broeckaert, Interdisciplinary Centre for Religious Studies

Stef Van Den Branden, **Bert Broeckaert**, Catholic University Leuven, Leuven, Belgium

Background: Given the fact that European societies have changed dramatically over the last few decades they have to a large extent become multicultural and multireligious, palliative care in Europe can no longer take a Christian or secular ethical framework for granted. In palliative care ethics, however, the voices of religious minorities receive only marginal attention.
Research aims: Our large-scale research project (2002–2006) aimed at exploring the way elderly (60+) male Moroccan Muslims living in Antwerp

(Belgium) deal with ethical questions at the end of life. This paper specifically discusses the opinions of our respondents regarding the use of pain medication and euthanasia.
Methodology: Exploratory qualitative study using in-depth interview techniques (19 respondents, 2 in-depth interviews per person, Grounded Theory Approach).
Results: According to our interviewees Allah is the sole curer and sole decision maker in matters of life and death. For our interviewees the life-shortening effect that is often (but indeed nearly always mistakenly) attributed to the use of powerful analgesics is not a big ethical issue, for it is ultimately Allah and Allah alone who determines whether the patient's life will be shortened or not. In any case the use of pain medication, that can help the patient to remain focused on his religion and his trust in Allah, is permitted. Euthanasia, on the other hand, is described as strictly forbidden (haram). Here man takes up a role that is not his at all, thus manifestly and shamelessly denying his dependence on Allah and his willingness to submit to the divine will. Complementary interviews with Moroccan religious leaders and Moroccan general practitioners in Antwerp yielded very similar results. Patience and faith are seen as key virtues, also and even particularly at the end of life.

Abstract number: 419
Presentation type: Poster
Session: Ethics

Medical decisions for incompetent patients: How does the doctor respond to family wishes?

Monica Escher, **Thomas Perneger**, **Claudia Heidegger**, **Jean-Claude Chevrolet**, Geneva University Hospitals, Geneva, Switzerland

Introduction: Patient autonomy must be respected in critical situations like end-of-life decisions or treatment decisions. When the patient is incompetent, the family is often considered a natural surrogate. Under stressful circumstances however the relatives may not be specific and unwittingly convey their own preferences. We showed that a patient is two to three times more likely to be admitted to intensive care when the family wish for it. Other factors can influence medical decisions among which the doctor's personal characteristics.
Aim: To determine if doctor-related determinants are associated with his willingness to comply with family wishes.
Methods: In a national survey intensive care doctors were presented with a case scenario of an incompetent patient with hemolytic uremic syndrome and had to decide on his admission. Half of them received a version where the family requested intensive care and half a version where they did not want it.
Results: Of 402 questionnaires 285 (71%) were returned. The final analysis included 232 questionnaires (57.7%). Most ICU doctors were men (83%) and were involved in admission decision (85%). The most common specialties were intensive care (57%) and/or anaesthesiology (60%). Doctors' characteristics associated with a decision to admit the patient at the family's request were older age (OR 4.9, $p = 0.002$), more time devoted to clinical work (OR 5.1, $p = 0.036$), and working in a non academic setting (OR 4.9, $p = 0.012$).
Conclusion: Not only family wishes and doctors' personal characteristics but also the interplay between both factors influence treatment decisions for an incompetent patient. This finding raises ethical issues about the respect of patient autonomy and the fair allocation of ressources.

Abstract number: 420
Presentation type: Poster
Session: Ethics

Will the development and the implementation of an e-learning program about "Ethical aspects at the end of life" ameliorate the care and the interprofessional approach of the palliative patient?

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Introduction: The law on euthanasia in Belgium regulates only a small fraction of the medical decisions around the end of life; nevertheless the implementation has been considered as a chance allowing to reflect upon the whole problem of the end of life and to create guidelines and an education program.
Aim: To evaluate the impact of the use of a interactive computer-driven teaching program about the ethics at the end of life.
Methodology: Such a program, uniting the possibilities of an interactive computer-driven education and of teaching small groups out of the work-floor, has been developed. Besides the formal content, the program offers also different in-depth explanations, guidelines and links for self-study.
Results: After a pilot phase, the program is implemented on the different wards. It is offered to each of the caregivers in two sessions: the first session is an individual one, in the second the interactive dialogue with the computer ends in a group discussion, leaded by members of the palliative support team, indeed accompanying the whole process of implementation of this end-of-life education program. Compiling inter-professional groups out of the different nursing wards will promote the communication between the different professions. A brochure is offered as a hand-out. Content and process of this computer-driven end-of-life education program are evaluated; a questionnaire has been developed allowing to assess knowledge, skills and attitudes as well as the facilitation of communication. Results will be shown during the presentation.
Conclusion: The first evaluations are proving the course is of a high level and very attractive. The question still remains whether such a huge project results really in a better quality of care of the palliative and terminal patient.

Abstract number: 421
Presentation type: Poster
Session: Ethics

Towards an integrated conceptualization in end-of-life care

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Scientific literature concerning end-of-life care shows a broad diversity towards theoretical and practical concepts. We were interested in this diversity which spans over more than two decades. But we wanted to go one step further. The goal is an integrated approach of the conceptual basis in end-of-life care. A crucial condition for this approach is an open-minded view towards several ethical principles. We searched scientific databases for multiple concepts in end-of-life care. Most recent articles (from 2000 on) were screened for conceptual elaborations and were put in spread sheets to compare their semantic meanings. This literature research was necessary in attributing towards an integrated conceptual frame for end-of-life decision making. Next, a panel of experts from relevant organizations and academic centres were consulted in constructing such a conceptual frame. A new classification had to be made, usable and practical for every participant working in an end-of-life care environment. Definitions of end-of-life concepts, like 'palliative care', 'sedation', 'euthanasia' and 'physician assisted suicide', 'therapeutic obstinacy' and 'natural death' show indeed considerable diversity. Important is that we took all these concepts and put them in an integrated scheme, a model for further discussion. Palliative care, natural death, active life-ending acts and avoidance of therapeutic obstinacy are not opposed to each other but are part of the integrated trajectory of the patient. Therefore, conceptual clarity is the first step to take. An integrated conceptual basis in end-of-life care is in the benefit of multiple groups. If professionals and patients can rely on the same conceptual basis, this will ameliorate the communication between them. Such an integrated terminology could lead to a well-defined instrument to work with.

Abstract number: 422
Presentation type: Poster
Session: Ethics

LEIFartsen (Life End Information Forum-physicians)*: Improvement of expertise on end-of-life care among physicians

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In Belgium, the law on euthanasia has been implemented since september 2002. In Februari 2003, in Flanders (the Flemish speaking part of Belgium; 60% of the Belgian population) a platform was founded of approximately 200 physicians with a special training in end-of-life care (with special attention to palliative care) and ethical decision making (including euthanasia, palliative sedation and withdrawal/withholding of futile treatment). The participating physicians are called ‘LEIFartsen’ (Life End Information Forum) and include both GP’s and specialists working in hospitals. The training is interdisciplinary and is very similar to the formation of SCEN artsen (which is the Dutch equivalent in The Netherlands). According to the conclusion of the first report of the Federal Committee on Euthanasia, the LEIFartsen-platform may be the reason of the much higher willingness for registrating euthanasia-cases by the Flemish physicians (more than 80%) in contrast (less than 20%) with their Walloon colleagues (working in Wallonia: French speaking part of Belgium and containing 40% of the Belgians).
Preliminary results on both training and activities of the LEIFartsen are reported.
*granted by the federal Belgian government and Recht op Waardig Sterven

Abstract number: 423
Presentation type: Poster
Session: Ethics

Attitudes of terminally ill patients towards participation in research

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Introduction: Much of what is known about recruitment difficulties in palliative care studies relates to views of healthcare professionals. Such ‘gatekeepers’ may seek to protect patients from potential harms but their concerns may not accord with patients’ own views. Patient perspective was thus explored in a study of people receiving palliation.
Methods: Hospice inpatients with stage 3 or 4 cancer completed a semi-structured questionnaire. In analysis a set of 5 items was aggregated to derive a scale measuring willingness to research participation. Associations between willingness score and clinical variables, previous experience/understanding of research, and other attitudinal variables (e.g. perceived importance of research) were assessed via univariate analyses. Respondents also identified from an a priori set of factors those which would likely influence participation.
Results: 47 patients completed questionnaires (mean age 68.9 years), 14 reporting previous research participation. ‘Willingness to participate’ score showed good reliability (Cronbach’s alpha = 0.93). Scores ranged from 5 to 25 (higher scores indicating greater willingness), were negatively skewed (median 22, IQR20–24) and showed positive inclination for research. Scores were not associated with age, gender or education. Among factors assumed likely to deter participation, being time-consuming and lack of personal benefit was a disincentive for only 12% and 15% of patients respectively.
Conclusions: In this pilot study a measure of patient willingness has been developed and shows a strong interest in active participation in clinical research amongst a traditionally vulnerable group. Some concerns about research participation (time expenditure, lack of personal benefit) are not necessarily shared by patients. Whilst ethical consideration of harms is required to protect vulnerable groups, medical paternalism may damage patient autonomy and inhibit advances in care for such patients.

Abstract number: 424
Presentation type: Poster
Session: Ethics

How general practitioners determine whether the requirements for prudent practice are met in case of a request for euthanasia or physician-assisted suicide

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Object: In the Netherlands, euthanasia and physician-assisted suicide (EAS) is only permitted when the following requirements for prudent practice, among others, are met: the patient’s request is voluntary and well-considered; the patient’s suffering is unbearable and hopeless; there are no realistic alternatives for treatment. This study aims to obtain information about how general practitioners (GPs) determine whether or not these requirements are met.
Method: All GPs in 18 of the 23 Dutch GP districts received a written questionnaire in which they were asked to describe the most recent request for EAS they received, if any. The response rate was 60% (n = 3614). Of the respondents 1681 could describe a most recent request for EAS.
Results: To determine whether there are no other reasonable alternatives for treatment, most GPs used their own experience (66%) and consulted a colleague or relied on his judgement (54%). To determine in what extent the patient’s suffering is unbearable most GPs had conversations with the patient (95%) and patient’s relatives (71%), observed the patient (68%) or relied on the patient’s opinion (52%). The extent of hopelessly suffering was mainly determined by the lack of alternatives for treatment (81%), but also conversations with the patient (75%) were important. Almost half of the GPs consulted a colleague or relied on his judgement (48%). To determine whether the request is well-considered, GPs had conversations with the patient (99%) and with patient’s relatives (67%). In general GPs used more than one source to determine whether the requirements are met. If GPs decided to grant a request they used more sources.
Conclusions: GPs use different ways to determine if requirements for due care are met. They also use more than one source of information, especially if they decided to grant a request. A reason for this could be that GPs, because of the large implications, want to be extra sure of their decision when granting a request for EAS.

Abstract number: 425
Presentation type: Poster
Session: Ethics

The scrabble and feel it words in palliative care objective

Caroline Matis, Cervens, France, **Isabelle Beytrison**, **Marie Preumont**, **Mireille Balahoczky**, Hug-Cesco, Geneve, Switzerland

Objective: The situations at the end of the lifetime do not support the improvisation and imply that the doctors and looking after them are well prepared. Ethical questions emerge and all caregivers after must think of it if they want to act with professionalism at the proper time. The language being polysemous it is important to give a common direction to the words. The goal of this presentation is to report the case of the team of a palliative unit care concerning the decision taken in team by communicating in a more precise way, more anticipated with patient and family.
Method: On the basis of a research task, the method was of: to communicate by giving a direction to the words (weekly meeting), to use a tool to plan the care by evaluating the symptoms, to adopt a common attitude to decide and choose a policy (creation and use of the Intermediate Card of Decision ICD).
Results: On seven situations worked in three months according to the method of the ICD, the consensus were reached for each one of it. The principal advantage concern a better knowledge of the patient and his situation, of a clarification of the problems, a listening and a division in the team, a catch of retreat and a direction common to the team.

Discussion: Each decision retained by respecting quality of life of the patient and his entourage was transmitted to the doctors, in a climate of comprehension and the continuity of the decision-making in team.
Conclusion: Althrough we could not always meet us for lack of time or priority of the moment, the exploitation of this tool shows the possibility of visualizing in the same way the problems. The confrontation of results of the various meetings reveals a concensus of team based on the direction of the words.

Abstract number: 426
Presentation type: Poster
Session: Ethics

Are Euthanasia (EU) and Palliative Care (PC) reconciliable: A Belgian experience

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Background: Belgium 2002. Law on EU approved by Belgian Federal Parlement.
Aim: How a Palliative Care Unit (PCU) Team was able through multidisciplinary discussion based on a special frame, to improve his approach to meet EU demands. Before 2002 the team used to manage such a request by classical approach, at least once being at the death end, possibility left just to refuse. After 2002 this approach was juged as not longer acceptable neither for the demanding patient nor for the PCU Team. During last years, PCU Team learned to try several instruments to approach patients and family in hopeless state, to propose alternative solutions with respect of medical ethic and psychosocial position of diying.
Conclusion: EU is definitively not an alternative treatment in palliative care. But in some instances the patient has to be answered even in case of rude requirements. Such a response seems to be possible by team work and polidisciplinary approach of the patient.

Abstract number: 427
Presentation type: Poster
Session: Ethics

Breaking Bad News to Cancer Patients: Transitioning from Taboo to Truth-Telling in Russia

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Telling the truth is one of the bioethical questions in oncology and palliative care. It is one of the most difficult questions especially in the community where telling the truth has been forbidden for many years. Nowadays the attitudes towards this problem are being changed. Aims The purpose of this study is to examine the attitude of doctors to telling the truth to cancer patients. Method 200 doctors (113 oncologists and 87 GPs) participated in an interview to express their opinion on the main principles of breaking bad news to cancer patients. We examined doctors' points of view on whether it is necessary to tell the truth to cancer patients or not, how much we must tell and when, what are the basic conditions, and principles of breaking bad news. Results The majority of the doctors consider that it is necessary to tell the truth to cancer patients (91%). It has been suggested that ineffective or insensitive news disclosure can have a long term adverse impact on the patients, and it can cause difficulties in doctor-patient communication (83%). More than a half have noted that it is important for doctors to develop the skills of breaking bad news effectively. The respondents think that they must do it with care and intelligence in different periods of illness, though oncologists consider, that a doctor must inform a patient about his or her diagnosis at the first appointment.
Conclusions: The research has shown that the necessity of telling the truth to cancer patients is obvious. But doctors, both oncologists and general practitioners, must be well prepared in developing the skill to break bad news. Good practice guidelines have been introduced into education practice in the State medical Academy for breaking bad news and are followed in clinical practice today.

Abstract number: 428
Presentation type: Poster
Session: Ethics

Cardiopulmonary resucitation (CPR) in palliative care (PC). Frequency or recommendation and deliberation with the patient and family

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Context: PC programs operate differently in different areas of the world, due to culture, beliefs, and health care systems. In Argentina there is a false belief among health professionals and general population that CPR must be offered and done to every patient who suffers a cardiopulmonary arrest. For most patients in Palliative Care Units (PCU) CPR is not recommended, as it can expose them to futile, painful and invasive experiences.
Objective: Describe the frequency of: CPR recommendations in patients admitted to a PCU – Deliberation about this procedure with patients, families or both Methods: Retrospective analysis of data recollection from 58 patients' medical charts at different moments of their hospitalization in the PCU, from January to December 2004.
Results: CPR recommendation was analyzed in 98% of the hospital admissions. The recommendation of CPR was very infrequent: 17% on admission and 12% at the end of hospitalization. CPR was never carried out. In 73% of the hospitalizations the decision to not begin CPR was deliberated with the family, but this was only done with 2 patients.
Discussion: Our results show that the practice of DNR in Argentina is applied differently from other countries (USA, Canada, UK). Family participation in care and decision making process reflects the more active role of families as a unit of care in Argentina (Latin America) It is important to clarify the medical indications, ethical principles and legal aspects related to CPR in Palliative Care in Argentina; and whether it is mandatory or not to discuss these issues with patients and families. Do Not Resuscitate orders policies should be developed in our country. Coinciding education on end of life care should be a global part of initiating such a policy.

Abstract number: 429
Presentation type: Poster
Session: Ethics

Alternative methods of treatment of neoplasmatic disease in palliative patients

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Introduction: The main goal of the study was to find out what is the usage of alternative medicines in palliative patients. Alternative or parallel methods have always existed in treatment of patients suffering from neoplasms and especially in palliative patients. Treatments of not proved effectiveness this is the most common name in medical vocabulary used to describe alternative methods. It is still not clear what kind of benefits if any, administration of alternative medicines brings. But the volume of drug market seems to be growing quickly. Alternative medicines include large amounts of various vitamins, minerals or silicon preparations. There is a common opinion that alternative methods of treatment are not beneficial to health and, what is more, they may be harmful to patients.
Material and method: In the first part there is a short review of popular alternative methods, the second is a discussion on the results of the questionnaire. In the questionnaire study 100 patients were asked to give answers to certain questions. One of them concerned alternative treatment methods used by patients. At that time the patients were in the palliative care unit.

Results: The results were as follows: 75% admitted that they take alternative medicines, 8% refused to give answer and 17% claimed not to use any. The most common and the best known medicines are: shark's cartilage (used often when radiotherapy and chemotherapy is taken), equally popular is a set of south american herbs (Vilca Cora) and silicon compounds (Novit). In most cases, patients take other medicines on their own, without doctor's permission.

Conclusions: Most patients take such medicines. In most cases the doctor is not aware of the fact that alternative medicines are used by patients. It is a serious problem but right now it seems to be underestimated.

Abstract number: 430
Presentation type: Poster
Session: Ethics

Terminal sedation: Justification on base of the double effect is problematic

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Object: Terminal sedation is defined as the induction of a pharmacological induced coma in immanently dying patients suffering from refractory symptoms. Terminal sedation is often justified by the rule of double effect. This rule includes that a negative side effect can be justified, under specific restrictions, in order to achieve a positive targeted effect. Specific restrictions are: (1) the act is not immoral in itself, (2) the act is undertaken with the intention of achieving the good effect, without intending the bad effect, even though the latter might be foreseen, (3) the act does not bring about the good effect by means of the bad effect and (4) the act is undertaken for a grave and proportional reason. Our object is to investigate if this rule is appropriate to justify terminal sedation.

Method: Relieve of suffering is defined as the main effect of terminal sedation. The reduction of consciousness and life shortening effects are defined as bad side effects. The justification of sedation is succesful if the rule can be applied properly.

Results: First, the reduction of consciousness. This is a means to obtain the relief of suffering (against restriction 3). Furthermore, the effect of reducing consciousness is often intended for terminal sedation (against restriction 2). Second, life shortening effects. Life shortening effects for terminal sedation are seen as a bad side effect that needs to be justified morally. Contrary, since euthanasia is accepted by Dutch legislation, life shortening is under certain conditions acknowledged as an accepted outcome of medical treatment. This contradiction makes it difficult to apply the rule of double effect.

Conclusions: The rule of double effect is difficult to apply for terminal sedation, because 'reducing consciousness' and 'life shortening effects' as side effects are difficult to distinguish from the main effect of relieving suffering, at least for the Dutch situation.

Abstract number: 431
Presentation type: Poster
Session: Ethics

The role of advance directives in decision making and improving end-of-life care

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Objective: To investigate the attitude of primary care patients toward living will document.

Design: Cross-sectional descriptive study.

Setting: Urban primary care clinic. Patients 150 primary care patients, selected by a consecutive sampling. Criteria for exclusion: <18 years old, first visit, major physical o psychological disease at the time of visit.

Main measurements: Patients received written information on the living will document along with the anonymous self-administered questionnaire with closed questions.

Results: The response rate was 52%. Mean age was 51.7 (SD 17.2). Fifty-eight per cent were women. Most of the respondents had a positive attitude toward living will document (98%). Forty-one per cent of the respondents affirmed they would use the living will document in the future, while 55% would consider it, and 4% would not use it. Sixty-one per cent would deal with the living will document only with their loved ones, 13% solely with their physician, and 26% would do so with both. Forty-nine per cent of the respondents believed that their loved ones would ensure that their wishes would be respected in case they became mentally incapacitated later in life, and 34% confided exclusively in the living will document. Twenty-two per cent had already talked clearly with someone about end-of-live care, and 38% had talked in general terms. Forty per cent said they had not talked about it. Only 3% felt uncomfortable with the inquiry. No significant differences were found in relation to age, gender, or previous health status in any of the variables.

Conclusions: Patients believe that the living will document is useful and show no inconvenience in speaking to their doctor about end-of-life issues. In addition, and preferably, they wish to include their loved ones in this dialogue: the living will document is not sufficient.

Abstract number: 432
Presentation type: Poster
Session: Ethics

Ethical issues in information processes significant to patients' daily life: An exploration of video-taped consultations in palliative gastroenterological cancer care

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There are tensions in the way palliative care is conceptualized, e.g. between "specialist" and "generalist" palliative care, and between caregiving ideals and limits imposed by the realities of caregiving. These tensions may be communicated implicitly or explicitly in the provision of information to patients. How this is done may raise ethical concerns. In a pilot study, we examined information processes in conversations between patients and physicians in clinical consultations for gastroenterological cancer care. How can the voice of the patient manifest itself within the frame of the medical agenda of the consultation? A limited sample of 6 consultations with 6 gastroenterological cancer patients in need of palliative care (and in 4 cases, significant others) was chosen in order to permit a deep case-oriented analysis of extensive qualitative data according to the principles of socio-cultural approaches to conversational analysis. The body of data was provided by transcriptions of video-taped consultations and follow up interviews. A content analysis was followed by focused analysis of selected sequences pertaining to turning points between the 'voice of medicine' and the 'voice of lifeworld'. The tentative result reveals that conversations are directed by an agenda, which means that allowing the everyday perspective of the patient to bear on the medical perspective is problematic. Consequently, there is conflict in the data regarding the perspectives of the conversation subjects. In conclusion, we found it feasible to realize data collection and to conduct the conversational analysis of the videotaped transcriptions. The tentative result of the conversations is of significance not only for conducting consultations, but also for all members of palliative teams providing information to patients.

Abstract number: 433
Presentation type: Poster
Session: Ethics

Use of antibiotics in palliative care

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The research working group of the german association of palliative care examines the use of antibiotics in palliative medicine. The second subproject of the study investigates attitudes of the carers towards the use of antibiotics with palliative patients. Participants were palliative and oncological units and hospices in Germany. A questionnaire based on the results of a focus group and expert interviews was applied. The main indications for the use of antibiotics were urinary infection, pneumonia and (malodour from) infected wounds. The physician himself and the team were specified as relevant decision makers for application of antibiotics. In contrast, the decision about withholding antibiotics is rendered predominantly by the team, the relatives and the patient himself. About 83% of the participants discuss the use of antibiotics with the patients before prescription; about 10% say they explicitly do not do this. Inefficiency and deterioration of general condition were main reasons for withdrawal. However, half of the participants indicated that antibiotics frequently were continued until death. About 80% of the participants reported that sometimes antibiotics were withheld although they were indicated. Main reasons for withholding in these patients were short life expectancy, low performance status or patient's preferences. Similarly 47% reported that antibiotics were used although withholding was indicated. Reasons were the patient's or the relative's explicit wishes, severe symptoms and residual uncertainty of the physician. As antibiotics are an increasing cost factor in palliative care, these results should be considered very carefully. Furthermore, they indicate the necessity of developing guidelines. This will be implemented in subsequent steps of the project.

Abstract number: 434
Presentation type: Poster
Session: Ethics

Telling the truth? Who wants and who needs it? Preliminary results

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There is no such an investigation made yet in Bulgaria about monitoring the preferences of the Bulgarians according: 1) Telling the truth about health condition and life expectancy to the patients with life threatening diseases and 2) The place where to perform the terminal care of these patients. 3) Patients' attitude towards religion and specific spiritual aspects of palliative care in Bulgaria because of the Bulgarian orthodox tradition In order to understand these preferences in the Interregional Cancer Hospital' Vratsa were interviewed 250 persons-patients with different types of cancer and their relatives. The interview had two main sections asking one and the same questions but from different point of view. The obtained results are very interesting. For example the great number of the answers of the question 'If your relative suffers from cancer does he/she have to know the truth about his/her health condition'? are NO. But while answering the question 'If you suffer from cancer do you have to know the truth'? the answers are predominantly YES. Almost the same differences can be seen in the answers of the other questions as for the preferences where to be the patients' last days; who is to tell the patient the truth; should the relatives be informed etc. Having in mind the interesting results obtained till now and the desire to get more reliable results the authors are going to continue the investigation and to have all necessary data till the end of March 2006.

Abstract number: 435
Presentation type: Poster
Session: Ethics

The transition from curative to palliative treatment in intensive care units: A multiprofessional survey

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Background: The transition from curative to palliative therapy is particularly difficult in the setting of intensive care. There is insufficient data about the practice of end-of-life decision making in German intensive care units and the problems encountered by the staff.
Aim: The aim of the study was to investigate the perspectives of nurses and physicians on limiting life-sustaining treatment in intensive care units.
Methods: We conducted an anonymous, self-administered questionnaire survey among the 268 nurses and 95 physicians on all 10 adult intensive care units of a university hospital in Germany.
Results: The response rate was 56% for nurses and 51% for physicians. The median self-reported confrontation with limiting life-sustaining treatment was once a week for physicians and three times per month for nurses. According to the respondents, the limitation most often concerned cardiopulmonary resuscitation, dialysis or antibiotics, least artificial nutrition or hydration. Yet, 48% of nurses and 35% of physicians did not feel confident about the decision-making process. 58% and 63%, respectively, rated their professional training for this task as poor. Basic legal knowledge was scant in both professions. The most commonly reported difficulties in end-of-life decision making were legal uncertainty, ethical scruples and communication problems. Nurses were less satisfied than physicians with the communication process (25% vs. 69%, $p<0.001$) and the ensuing decisions (42% vs 83%, $p<0.001$). While attending physicians perceived the decision-making to be a collaborative team process, residents and nurses regarded it more as a unilateral act by the attending physician ($p=0.001$). As physicians reported documentation in systems largely inaccessible for nurses, 37% of nurses were unaware of any documentation.
Conclusions: Limiting life-sustaining treatment is common in German intensive care. Legal education of staff, communication and documentation needs improvement.

Abstract number: 436
Presentation type: Poster
Session: Ethics

Anxiolytics and palliative sedation in a tertiary palliative care unit in Germany

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Palliative sedation has been reported in 19% of the patients in a recent publication from Germany. However, this percentage seems high if palliative sedation is considered only as the last resort if all other efforts for symptom relief are inadequate. In the Department of Palliative Medicine a retrospective chart survey was performed to identify the use of benzodiazepines for symptom relief and palliative sedation. Patients assessed intensity of pain, six other symptoms and well-being on a categorical scale. From September 2003 to Dezember 2004 161 patients had been treated in the unit. Benzodiazepines were given to 112 patients (28 patients more than 1 benzodiazepine). Lorazepam (100 patients, median daily dosage 1 mg, range 0.1–72 mg) was used most frequently. Oxazepam (25 patients, median 10 mg, range 0.5–10 mg) was used mostly as continuation of previous sleeping medication. Midazolam (10 patients, median 48 mg, range 1–144 mg), diazepam (4 patients, median 15 mg, range 1–15 mg), zopiclon (5 patients, median 7.5 mg, range 1–15 mg) and clonazepam (2 patients, median 3.84 mg) were used less frequently. Patients treated with lorazepam assessed significant higher intensity scores for sedation and anxiety, but lower scores for dyspnea and well-being. Differences for pain, nausea, constipation and weakness were not significant. Continuous application of midazolam with a syringe driver was used in 5 patients (3% of all patients) because of intractable symptoms or existential distress. In one patient with pharyngeal cancer sedation was initiated to prevent a locked-in syndrome, as speech was impossible because of the tumor growth, the eyes were swollen shut by severe lymphedema of the head which also prevented the use of hearing aids. In this retrospective survey a high percentage of patients was treated with benzodiazepins, but palliative sedation was required only in very few selected cases.

Abstract number: 437
Presentation type: Poster
Session: Ethics

"Relieving burden and receiving attention." Older Persons' Views on Living and Dying with Dignity in Nursing Homes

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Background and Aims: Enhancing "Dying with dignity" is one of the goals of the hospice movement. However, exactly how "dying with dignity" is defined and who is to define it is not questioned, although this seems most important in order to use dignity as concept to improve end-of-life care. Nursing homes are gaining importance as places of dying in western modern societies and it seems important to improve end of life care in these institutions. To do so, the view of those who are most concerned is most essential. The aim of the study was to find out the meanings of dignity for elderly nursing home residents and their views of death and dying to understand better how end-of-life-care in nursing homes that draws upon dignity has to be fashioned.

Methods: Qualitative Research based on the Grounded Theory Approach. The study involved 25 elderly people in German Nursing Homes. Criteria for Theoretical Sampling included characteristics of the organisations as much as of the residents. The data collecting process run from November 2001 to February 2003. Data Analysis followed several coding procedures (Grounded Theory) and was supported by Atlas/ti programme.

Results: A concept of dignity from the perspective of nursing home residents was designed. Relational dignity is in its core, accordingly "dignifying social encounters" are a prerequisite for dignity. Several strategies of the interviewed elderly to appertain dignity through relieving burden are worked out. In this context having no family, being in need of care, especially having dementia, seems to threaten dignity most. Attitudes towards dying and death with dignity are strongly linked to this interface. Dying with dignity then often means "dying at the right time".

Conclusions: Enhancing dignity as a key concept in palliative care for the elderly means to focus on dignifying social relations and daily encounters, paying attention wherefore older people are recognized.

Abstract number: 438
Presentation type: Poster
Session: Ethics

The meaning of dignity in palliative care settings

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The word dignity is frequently used in palliative care without definition. The aim of the study was to gain an understanding of the meanings of the term dignity when used in palliative care settings by paid staff and volunteers. Ethical approval was gained for the study. All paid staff and volunteers (n = 196) were asked to complete a short anonymous questionnaire outlining their definition of the word dignity.

Miles and Huberman's framework for qualitative data analysis was used to analyse the data. This involved data reduction using coding and theming; data display showing the main themes and finally conclusion drawing. The response rate was 45% (n = 88).

The results showed that although the word dignity had many different meanings to our respondents, the key themes that emerged were 'respectful relationships' and the maintenance of personal control. These were expressed in terms of a range of attitudes, actions and reactions.

In conclusion, we recommend that the word dignity should be used to mean respect within relationships and the promotion of personal control.

Abstract number: 439
Presentation type: Poster
Session: Ethics

Big decisions or multiple steps: Decision-making about chemotherapy in advanced cancer

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Aim: Patients with advanced cancer often request and receive chemotherapy for a long period. At the end of patients' life some physicians have difficulties prescribing chemotherapy because it is unlikely to prolong life or to alleviate symptoms. From palliative care perspective the continued use of chemotherapy might be hard to understand. In a longitudinal study about how patients and physicians make decisions about treatment options, we want to learn more about the reasons why the use of palliative chemotherapy is continued.

Methods: 13 patients with advanced pancreatic or colorectal cancer who were making decisions about chemotherapy were studied by observing and performing semi-structured in-depth interviews with both patients (if possible three interviews with intervals of 2–3 months) and attending physicians from an outpatient oncology department of an academic hospital in the Netherlands.

Results: We found that in the frequent outpatient consultations many small decisions were made, like to wait and see, to try out and evaluate chemotherapy, decisions about reducing the dose, and about postponing cures for a holiday or having a 'breathing space'. This temporary ending of chemotherapy quite often turned into forgoing chemotherapy. Decisions to postpone or stop the chemotherapy for a while seemed to vary in patients from different oncologists. Small decisions occurred especially in advanced colorectal cancer, which has a relatively long disease course, compared to advanced pancreatic cancer.

Conclusion: The decision whether or not to continue palliative chemotherapy is often conceptualized as a big decision with a dilemmatic character, namely a one moment decision in which fixed options need to be weighed personally. This concept does not fit to the process-like reality of advanced cancer care that appeared to consist of multiple small decisions.

Abstract number: 440
Presentation type: Poster
Session: Non Cancer

Quality of life of patients with end-stage COPD and lung cancer compared

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Objective: To compare quality of life of very severe chronic obstructive pulmonary disease (COPD) patients and advanced non-small cell lung cancer (NSCLC) patients.

Background: COPD leads to a progressive loss of lung function. Little is known about the needs and preferences of patients with very severe COPD (GOLD stage IV). We explore the quality of life of these patients and put results into perspective by comparing them with quality of life scores of patients with advanced NSCLC.

Methods: We are conducting a prospective study of 80 GOLD stage IV COPD and 16 NSCLC patients stage 1Mb or IV. The recruitment of lung cancer patients is still continuing. For both groups, only patients aged = 60 years are included. Patients fill in a self-administered quality of life questionnaire every three months, containing SF-36, GARS, Karnofsky and HADS. Follow up ends when four questionnaires are completed or when the patient drops out. Analyses are based on non-parametric testing (Mann-Whitney U Test).

Preliminary results: Preliminary results are given for the baseline questionnaire only. COPD patients had significantly lower scores in physical functioning (median 10, sd 19) compared to NSCLC patients (median 50, sd 28). In general health perceptions, COPD patients had lower scores than NSCLC patients, but these were not statistically significant (median 20, sd 18 and 30, sd 22 resp). COPD patients also had significantly worse ADL scores (median 34, sd 8) than NSCLC patients (median 25, sd 8). In addition, the self-reported Karnofsky scores were significantly worse for COPD patients (median 60, sd 14) than for NSCLC patients (median 80, sd 13).

There were no differences in anxiety and depression scores between the patient groups.
Conclusion: Very severe COPD patients experience more problems in activities of daily living and a lower perception of general health than advanced NSCLC patients. The next step in our research is to examine possible explanations for these differences.

Abstract number: 441
Presentation type: Poster
Session: Non Cancer

Foregrounding the need for paediatric palliative care in non-cancer patients

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This paper will situate the need for paediatric palliative care in non-cancer patients. It is based on data from a national needs analysis of paediatric palliative care in Ireland. The study aim was to identify the number of children in Ireland with palliative care needs. Sources of data, quantitative and qualitative, were official mortality statistics for certain categories (International Classification of Disease) under 18 years and responses from a large-scale study (over 550 responses) of medical, nursing and other professional service providers as well as families with children who were dying or who had died. Service providers were drawn from the statutory/voluntary sectors, both hospital and community based, including paediatricians, general practitioners, clinical nurse managers/specialists, palliative care staff and social workers. Quantitative data from questionnaires were organised by the focus of the research question, qualitative data were analysed for emergent and recurrent themes. The numbers of children with palliative care needs was found to be significantly higher than previous estimates, with a significant number dying within the first week of life. Considerable variation was found in the range and level of service on offer for different diagnostic categories of children with similar palliative care needs. Location of death was also varied, most children with cancer dying at home whereas others were much more likely to die in hospital. Specifically the provision of services for children with high levels of dependency and a long or uncertain illness-death trajectory were insufficient e.g. children with severe neurological disability and children with cystic fibrosis. Future developments in the area of paediatric palliative care should be shaped by the key principles of inclusiveness, comprehensiveness, partnership and flexibility.

Abstract number: 442
Presentation type: Poster
Session: Non Cancer

Palliative care and advanced heart failure: Preliminary epidemiological data

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Background: Heart failure (HF) is one of the most frequent causes con death and morbidity. Among patients affected by HF, it's possible to identify a subgroup of patients with advanced and therapy refractory symptoms without any chance of treatment of the underlying heart disease. As terminal ill neoplastic patients do, HF patients experience very important symptoms and have a very poor prognosis.
Aim of the study: to determine the number and the characteristics of patients with advanced or refractory HF admitted in our hospital, to identify in-hospital prognosis and to follow patient's course into the hospital.
Materials and methods: we enrolled patients admitted for HF at the emergency department of San Giovanni Battista Hospital (Turin, Italy) and presenting with these criteria: known cardiomyopathy; at least one admission for worsening HF in the previous 6 months; NYHA class III or IV despite of optimal therapy; at least 3 symptoms or signs suggestive for decompensated HF; one or more of the sequent: sodium <130 mEq/l; blood creatinine >1.4 mg/dl; GOT >45 U/l; GPT >40 U/l; total bilirubine >1 mg/dl and direct bilirubine >0.2 mg/dl. Results: in 6 months, we enrolled 74 patients (14.5% of all 508 admitted for HF). 63.5% were males. Mean age was 72.7 years; mean length of in-hospital stay was 20.7 days. Patients were admitted in 28.3% of cases in cardiology or cardiosurgery, 64% in internal medicine, 5% in the emergency department. In-hospital mortality accounted for 16% of patients.
Conclusions: selected patients represent an important subgroup of all patients affected by HF. Most of these patients are old, with high mortality rate and very poor quality of life, so they share important features with patients affected by terminal neoplastic diseases. In this population palliative care might be used to control symptoms and ameliorate quality of life. Anyway, palliative care model should be modified and adapted to the unique features of advanced HF patients.

Abstract number: 443
Presentation type: Poster
Session: Non Cancer

Establishing hospice based services for non-cancer patients in the United Kingdom

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A growing body of literature indicates high levels of unmet health and social needs among non-cancer patients towards the end of life. Much less has been published about the successful provision of palliative care services for these patients. As part of an on-going formative evaluation of innovative hospice services for non-cancer patients, funded by Help the Hospices, we interviewed key personnel involved in establishing these services, about the main facilitators and inhibitors in the process of setting up and delivery of the projects.
Methods: Key informants were interviewed using a semi-structured interview schedule about their experiences of establishing and providing services for non-cancer patients. Interviews were tape-recorded, transcribed verbatim and analysed using a framework approach.
Findings: Preliminary findings indicate that a strongly committed individual, support from management, a flexible approach and adequate initial funding are all essential to introducing new services. Key inhibitors include concerns about a decreasing level of provision for cancer patients already in contact with services, the impact of working with non-cancer patients on hospice staff who may feel they are working without their area of expertise, and issues about securing future funding for the service. Patients were on the whole reported by staff as being satisfied with the services provided. Caring for non-cancer patients raised many issues, including the acceptability and desirability of services to patients, symptom control and rehabilitation concerns, and issues relating to resuscitation and other invasive end of life interventions.
Conclusions: The evaluation indicates that the provision of palliative care for non-cancer patients within services predominantly serving cancer patients raises issues of training and resources, arising from the differing needs of the new patient group.

Abstract number: 444
Presentation type: Poster
Session: Non Cancer

Depression and Anxiety in End Stage Renal Disease: A Prospective Analysis

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Background: Palliative care has been traditionally linked to cancer but increasingly has a role for patients dying from non-cancer conditions including End Stage Renal Disease (ESRD). There have been dramatic changes over the last decade in the demography and management of patients with ESRD. Depression is the most common psychiatric complication in patients with ESRD, with sub clinical depression likely in about 25% of patients and major depression in 5–22%. The reported incidence maybe over-estimated because symptoms of uraemic origin are similar to that of depression.

Aim: To determine the prevalence of depression and anxiety in a cohort of patients undergoing haemodialysis in a large regional centre.

Methods: We prospectively ascertained the point prevalence of depression within this group. Using a validated screening tool, Hospital Anxiety & Depression Scale (HADS), initial point prevalence was calculated.

Results: 124 patients were recruited. Initial point prevalence reveals 25.8% of haemodialysis patients had a diagnosis of moderate to severe depression (HADS D >11, HADS A+D >20). A high level of anxiety was also identified with 24.2% having moderate or severe anxiety (HADS A > =11). 12% of patients had a mixed disorder (HADS D and HADS A > =11).

Conclusions: Preliminary findings suggest a high prevalence of depression and anxiety within this group. As is the case in traditional palliative care patients, our results suggest that depression is a key symptom in renal failure that requires to be addressed.

Work in progress: A pharmacological based algorithm has been implemented and patients identified with depression will be treated and followed up. Patients with anxiety will receive counselling. We plan to repeat point prevalence in 3 months (January 2006) and assess whether actively diagnosing and treating depression in this renal failure population is worthwhile.

Abstract number: 445
Presentation type: Poster
Session: Non Cancer

Communication skills training needs assessment of cardiologists in the Merseyside and Cheshire cardiac network

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Introduction: Effective communication between health professionals and patients is essential for the delivery of high quality care (Doh Cancer review 1999). The current NICE guidelines (2003) state that good communication skills are essential for best management. It is therefore important that clinicians have received communication skills training and are confident in how to use this training for the benefit of their patients.

Methods: In this study we conducted a health needs assessment of communication skills amongst cardiologists in the Merseyside and Cheshire Network. Communication skills were evaluated by a self-report postal questionnaire distributed to consultants, specialist registrars (SpRs) and staff grades (Fallowfield et al. 2001). Communication skills were assessed by a series of confidence ratings and thematic short answer questions, specifically charting competencies in teaching of communication skills, their own communication skills, and previous training received.

Findings: The findings suggest that most cardiologists have had some training (68.75%). However, specific courses were not identified by the majority of respondents in this category. Respondents frequently made reference to informal on the job training rather than attendance at particular communication skills courses (56.25%). Difficulties interacting with emotionally withdrawn patients and discussing body image and sex were identified by low mean scores.

Conclusion: From this study it is evident that most cardiologists have had some communication skills training although not in the form of formal courses. The results indicate that those doctors who have had training are more confident in communication skills and are possibly more adept at self-evaluation of communication skills. These findings compliment previous research findings that communication skills can be taught and that overall confidence levels increase after training.

Abstract number: 446
Presentation type: Poster
Session: Non Cancer

Dying from stroke in an acute care setting

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Introduction: The needs of patients dying from stroke have received little attention. The aim of this retrospective study is to identify symptoms and review caring strategies of such patients.

Method: Patients dying from stroke in our tertiary hospital and followed by our palliative care consultant team from June 2000 to June 2005 were selected. Data on demographic parameters, symptoms and various treatments were collected.

Results: 43 patients were identified. Median age was 85 years (range 68–96); median duration of hospitalization was 12 days (4–115). At admission, 28 patients (65%) had communication difficulties due to aphasia and 13 (30%) were comatose. The major symptoms identified during hospitalization were pain in 32 (74%), dyspnea and/or bronchic secretions in 32 (74%), dry mouth or thirst in 26 (60%), constipation in 17 (40%), agitation in 14 (33%), anxiety and/or low mood in 13 (30%). A nasogastric tube feeding was present initially in 19 patients (44%) and the day before death in 8 (19%). At this time, pain was treated by a non-opioid antalgia in 7 patients (16%) and by opioids in 30 (70%); daily median dose (oral morphine equivalent) was 36 mg (12–240). Respiratory symptoms treatments were anticholinergics in 23 (53%), opioids in 17 (40%) and others in 17 (28%). Parenteral hydration was present in 34 (79%), with a median volume of 500 ml/day (250–1000). The last 48 hours, 23 patients (53%) were free of symptoms and comfortable, 4 (9%) had transitory episodes of agitation and 6 (14%) presented with tachypnea and excessive bronchic secretions due to cardiac failure or pulmonary infection; 11 other patients (26%) had death rattle but suffering was not assessable due to deep coma.

Conclusion: Patients dying from stroke present with numerous symptoms, mainly pain and dyspnea, which can be underestimated due to communication difficulties or conscience level alteration. Further research is needed to explore the needs of these patients in more details.

Abstract number: 447
Presentation type: Poster
Session: Non Cancer

Living with and dying from advanced heart failure: The impact of models of care on patients', carers' and professionals' experience

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Aims: To explore the needs of patients with advanced heart failure, and of their informal carers, from diagnosis to death and bereavement, and assess the extent to which services meet these needs-explore the perspectives of key hospital and community staff-formulate needs-led models of care appropriate for national use.

Method: 30 Patients with end stage heart failure were recruited into the study for a six month period. Interviews were carried out up to three times over this period with the patient, their carer and key health professional. Bereavement interviews were also conducted. Purposive sampling was used to ensure a range of social backgrounds across different models of care.

Analysis: Interviews were transcribed then analysed using an inductive and deductive approach combined, allowing for the development of themes and exploration of emerging issues. Case study analysis facilitated detailed checking of themes against the data. Analysis was ongoing throughout the fieldwork allowing for discussion and review with the multi-disciplinary steering committee.

Results: A range of models of care exist in the area of heart failure. This study found that the model of care impacted on practices of diagnosis disclosure and discussion of prognosis. It was also found that when different models of care simultaneously exist, this can impact on care through facilitating better care or can lead to a breakdown in care. The results will consider the common factors involved in maximising the benefit to patients' and carers'. The impact on the integration of models of care with specialist palliative care services will be discussed.

Conclusions: Models of care rarely operated in isolation, and the relationship between models, particularly between specialist heart failure and palliative care services can impact upon the end of life experience. The implications for addressing palliative care needs for heart failure patients will be presented.

Abstract number: 448
Presentation type: Poster
Session: Non Cancer

An assessment of the palliative care needs of patients with idiopathic Parkinsons disease

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Aims: International and national directives have proposed palliative care involvement for patients with Parkinsons Disease (PD), however, no assessment of palliative care needs has been undertaken in this patient group. The aim of this study was to assess these needs.

Methodology: A cross sectional survey was undertaken. 161 patients were identified from the local PD service and 123 completed face to face interviews with an experienced palliative care physician. Questionnaires were completed on pain both qualitatively and quantitatively [Palliative care Assessment tool (PACA)]; symptoms (PACA); and depression [Edinburgh Postnatal Depression Scale (EPDS)].

Method of analysis: The results were analysed on SPSS-11 and were largely of non normal distribution. As such they were analysed using non parametric methods (eg Mann Whitney Test and Kruskal-Wallis Test). Results were considered significant if $p < 0.05$.

Results: N = 123 patients (52% female). Mean age 74.3 years (range 51–89). Mean Hoehn and Yahr stage was 2.7 (range = 1–5). Pain: 85% had pain. In 50% it had a moderate or dominating affect on their day. 285 pains overall (mean = 2.3). Neither the number nor severity of the pain increased with disease stage. Symptoms: 1575 symptoms were identified (mean = 12.8, range = 0–27). Palliative care type symptoms were common: anxiety 61.8%, dry mouth 53.7%, SOB 35.8%, constipation 23.6%, anorexia 13%, nausea 9.8%, and vomiting 4.1%. Symptom number and severity increased with disease stage. Depression: Using screening and diagnostic cut off scores the frequency of depression was 34.1% and 9.8% respectively. There was no linear association with disease stage and depression rather there were peaks at stage I and stage III/IV disease.

Conclusions: Overall palliative care type symptoms are common at all stages of PD. These findings have been used in the development of models of palliative care in PD and to inform the NICE guidelines for PD in UK.

Abstract number: 449
Presentation type: Poster
Session: Non Cancer

Aging and nonmalignant chronic pain relief in rehabilitation institute (IDR)

Monica Maria Agostoni, **Alessandra Cantatore**, **Cristina Zocchi**, **Geremia Giordano**, **Roberto Caprioli**, Istituto Palazzolo Fondazione don Gnocchi, Milano, Italy

Overview: Pain, both chronic and acute, is prevalent and undertreated. One of the primary reason for undertreatment is the complexity of pain assessment and monitoring: pain is a subjective experience with no objective measures. As the population ages, the number of people who will need treatment for pain is expected to rise. In addiction to disability, untreated pain causes significant suffering: poorly controlled pain may lead to anxiety, fear, anger, depression. The goals of pharmacological therapies in older adult include relief of pain and enhancement of quality of life.

Methodology: We considered 28 patients (92.9% female and 7.1% male), mean age 79?6.8, staying in hospital in september 2005 in IDR, incoming ed outcoming VAS scale and Barthel Index, pain assessment, pharmacological (PT) and/or physical (NPT) therapy, depression. Statistic analysis was done by t-Student test.

Results: 32.1% patients were affected by neuropathic pain, 50% by degenerative joint diseases pain and 17.9% by orthopaedic pain: 42.9% of all the examined had depressed mood. All of them have had pharmacological therapy, 92.9% had also physical therapy (KT, heat, cold, TENS). About PT, according stepladder approach: 21.4% were treated with only 1 agent, 42.9% with two agents and 37.7% with 3 or more agents. 39.3% patients received also an antidepressant, 10.7% gabapentin, 10.7% NSAIDs, 75% opioids for step 2 therapies (tramadol, codeine), 10.7% opioids for step 3 (fentanyl, morphine). Incoming VAS showed a mean score 7 ± 1 DS; outcoming 3.25 ± 1.07 DS: analysis t-Student showed no significance. Incoming Barthel Index showed a 75 ± 19.45 DS score, outcoming 83.4 ± 17.9: t-Student analysis showed a statistically significant $p < 0.05$.

Conclusions: Treated pain increases individuals ability to carry out daily activities (Barthel Index). Non significant VAS score between income and outcome could be related to the short number of the selected patients and the high range of depressed mood.

Abstract number: 450
Presentation type: Poster
Session: Non Cancer

Survey of palliative care services for non-cancer patients in Ireland in 2004

Norma O'leary, **Eoin Tiernan**, St. Vincent's University Hospital, Dublin, Ireland

Introduction: Less than 10% of all patients accessing palliative care services in Ireland in 1993 had a non-cancer diagnosis. The national policy document published in 2001, urged us to consider the needs of non-cancer patients. We wished to determine whether, a decade on, palliative care services have improved for non-cancer patients.

Aims/objectives: To determine the level of specialist palliative care service provision for non-cancer patients in 2004. To explore key service providers views on perceived barriers to the extension of palliative care services to non-cancer patients.

Methods: A questionnaire was drawn up to collect data on the level of palliative care for non-cancer patients. 13 statements representing potential barriers to the extension of palliative care services to non-cancer patients were included for the respondent to grade.

Questionnaires were sent to medical or nurse managers of all the specialist palliative care services in the Republic of Ireland.

Results: 65 questionnaires were returned, representing 100% of all specialist palliative care services.

80% of services provided equal access and level of care for cancer and non-cancer patients. Over 40 different non-cancer diagnoses were taken on. The 3 most commonly referred non-cancer diagnoses were Motor Neurone Disease, Congestive Cardiac Failure and Cerebrovascular Accidents.

12% of services considered each non-cancer referral on a case by case basis.

7% of services limited non-cancer access to MND and Aids patients.

One service cared exclusively for cancer patients.

Abstract number: 451
Presentation type: Poster
Session: Non Cancer

The challenge of identifying heart failure patients who may have palliative care needs

Norma O'leary, **Eoin Tiernan**, **Christina O'loughlin**, **Ken Macdonald**, St. Vincent's University Hospital, Dublin, Ireland

Introduction: Patients with heart failure have unmet palliative care needs. Uncertainty exists as to what criteria should be used for referral of heart failure patients to palliative care services. Referral based on prognosis has

traditionally been used for cancer patients. However, heart failure has a more unpredictable disease trajectory.
Aims/objectives: We wished to determine whether prognosis could be a useful referral criterion for heart failure patients to palliative care services.
Methodology: Demographic data, severity of disease, service utilization, and quality of life data was collected prospectively on patients attending a specialist heart failure unit. The data was analysed retrospectively following the death of the patients to determine whether there was a correlation with proximity to death.
Results: 88 patients were included in the study; 57% male. Mean age at entry: 74 years. New York Heart Association Classification: Class 1:3%, 2:60%, 3:32%, 4:5%. Ischaemic heart disease was the commonest cause of heart failure (55%). Median length of survival following entry onto the programme was 20 months. There was poor correlation between time before death and: Age (Pearson correlation value: -0.197, $p = 0.065$) Ejection fraction ($r = -0.010$, $p = 0.932$) Number of visits to heart failure clinic ($r = 0.169$, $p = 0.116$) Number of admissions to hospital ($r = 0.127$, $p = 0.237$) Average quality of life scores (Minnesota Living with Heart Failure Questionnaire) ($r = 0.139$, $p = 0.352$).
Conclusion: Severity of disease, service utilization and quality of life scores correlated poorly with time before death in this study. However, the study sample was small. Prognosis is not a useful referral criterion for heart failure patients to palliative care services. We need to consider criteria other than prognosis in identifying heart failure patients who should be referred to palliative care services.

Abstract number: 452
Presentation type: Poster
Session: Non Cancer

Are there differences between those patients severely affected by multiple sclerosis included in and excluded from a randomised controlled trial of a new palliative care service?

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Aim: to determine the characteristics of patients referred to a new palliative care service for people severely affected by multiple sclerosis (PwMS) in southeast London.
Methods: We designed a randomised controlled trial comparing a fast track (immediate access to palliative care service) and standard care (access to specialist palliative care after 3 months) for PwMS. Patients were excluded from the trial if: (1) they were recruited before the full service (with all staff) and trial commenced, and (2) they were considered as having urgent needs or refused participation. The service recorded baseline data on all patients referred, including demographic, clinical, and palliative assessments using standardised records and instruments. Ethics permission was granted to analyse anonymous clinical data.
Results: 69 PwMS were referred to the service during the trial, 52 were included, 17 excluded-5 for clinical urgency, 5 refused, 4 were unable to consent, 1 protocol violation, 1 lived outside the study area. In addition, 18 patients were seen before the trial and full service commenced. All groups of patients had similar age (mean 53–54 years), gender, and time of diagnosis. Those excluded from the study were slightly more likely to have relapsing remitting MS, rather than primary or secondary progressive (chi-squared 9.4, $p < 0.05$). There was no difference in most stated reasons for referral, including symptom control, psychological needs, nutrition and hydration, but those seen urgently were more likely to have needs in terms of advance directives (chi-squared 5.9, $p < 0.05$); there was also a non significant trend to more need for end of life decision making.
Conclusion: Patient's referred to a palliative care service appear to have a broad range of symptom, psychological and end of life care planning needs. Those patients seen urgently and not included in the trial appeared to have greater needs for advanced care planning.

Abstract number: 453
Presentation type: Poster
Session: Palliative Care in Elderly

Dying experiences among racially diverse hospitalized older adult patients

Karen Bullock, University of Connecticut/SSW, West Hartford, US, **Karen Blank**, Braceland Center for Mental Health & Aging, Hartford, US

Background: Although many older adults wish to forgo cardiopulmonary resuscitation, mechanical ventilation and other active intervention at end of life, some may desire continuation of medical treatment despite low chances of improved quality of life. While little is known about how race influences the dying experience in U.S. hospitals.
Objective: This pilot study collected data to determine and compare end-of-life care experiences, the treatments received, and the end-of-life care outcomes between older Black and White patients who die in a U.S. hospital.
Methodology: Participants: 111 cases were examined for individuals age 65+. There were 54 Black patients and 57 White patients included in the study.
Measures: Medical records of decedents were examined for measures of illness burden and severity, the treatments received (e.g., cardiopulmonary resuscitation, mechanical ventilation and other active intervention at end of life), documentation of advance directives, "do not resuscitate" orders, evidence of discussion of or referral to palliative care, measures of symptomatology and its management during dying. Outcome variables for the study included the use of palliative care and the timing of DNR orders. Predictor variables included age, gender, race, insurance status, illness burden and severity.
Results: Unadjusted bivariate results found Black patients were less likely to use palliative care than White patients (odds ratio $= 0.60$; $P < 0.001$) and that without a DNR (odds ratio $= 0.24$; $P < .001$) and without a cancer diagnosis (odds ratio $= 0.30$; $P < 0.001$) were less likely to use to use palliative care. The negative relationship between Black patients and use of palliative care was unaffected when controlled for gender, marital status and education. Logistic models revealed that presence of a DNR diminshed the negative relationship between Black patients and palliative care use.

Abstract number: 454
Presentation type: Poster
Session: Palliative Care in Elderly

The complexity of palliative care for people with dementia: A need for 'supportive care for care givers'

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Background: Today the model of palliative care has also found application in Dutch nursing home care for people with dementia in terms of so-called 'experience oriented care'. Core elements are: 1) to view people with dementia as active agents, who are trying to make sense of their world and 2) to support them in adjusting to the consequences of the disease and in maintaining a sense of self. Providing this type of care however is often experienced as burdensome by nurses/nurse assistants who have a high level of contact with dementia patients.
Research aim: to explore the emotional and moral problems encountered by nurses/nurse assistants in establishing an experience-oriented approach to care-giving in dementia.
Method: ethnographical field research in two nursing homes carried out by two researchers. Field notes and additional open interviews (audio-taped and transcribed verbatim) were analyzed using a Grounded Theory approach.
Results: we identified three specific themes or problem areas: 1) the dilemma's of truthtelling and truthfulness, e.g. resulting from the concealment of diagnostic information, 2) the ambivalences concerning reciprocation, exemplified in various efforts to maintain a meaningful care relationship, and 3) the paradoxical normality of dementia, resulting from being submerged all day in the world of dementia. These problems exemplify the progressive loss of a common shared world of meaning that typifies palliative (nursing home) care for people with dementia and differentiates it from palliative care in general.
Conclusion: in order to enable them to cope with the complexity of care giving in dementia, we recommend that nurses/nurse assistants must be able

to rely on 'care for caregivers'. This type of care-that to date is practically non-existent in this realm of palliative care-should not only focus on promoting competence and communicative skills, but also on providing emotional and moral support to those in the front line of care.

Abstract number: 455
Presentation type: Poster
Session: Palliative Care in Elderly

Polypharmacy worsens as death approaches

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Objective: Given the relationship between increasing numbers of medications and adverse interactions, this study longitudinally quantifies the use of medications in a palliative care patient population from referral through to death. This prospective cohort study explores the relative contribution to polypharmacy of symptom-specific medications (SSM) and long-term medications for co-morbid medical conditions (MCMC).
Methods: Prospective medication, demographic and performance status data were collected on the first 260 patients who enrolled and subsequently died in a larger RCT exploring models of palliative service provision in Adelaide, Australia. Medication usage was collected at least monthly from referral until death (mean 124 days, median 93, SD 103, range 11–752). Subgroup analyses of age, performance status and the baseline use of medications for co-morbid conditions was performed.
Results: At baseline the mean total number of drugs taken was 4.9 (range 0–16, SD 2.83), SSM 2.3 (range 0–7, SD 1.54) and MCMC 2.6 (range 0–13, SD 2.40). From referral to the last data point before death (mean 20 days, med 15, SD 23.8), the total number of medications increased, due to SSM prescribing (2.54 more medications, CI 2.20–2.28; $p < 0.001$); there was a decrease in MCMC (1.05 decrease, CI 0.82–1.28; $p < 0.001$). Patients with better performance trend towards using more SSM. The greater number of medications taken by older patients reflected prescribing of MCMC. Shorter duration of survival was seen in patients with lower performance and those taking larger numbers of MCMC.
Discussion: Findings of this study show that more medications are taken over time in patients with life-limiting illness. Although MCMC are reduced, more work is needed to assist practitioners in the appropriate reduction of these medications. Further work is needed on the burden of both the exaggerated physiological and adverse effects of polypharmacy from MCMC at the end of life.

Abstract number: 456
Presentation type: Poster
Session: Palliative Care in Elderly

Recognising the importance of 'lifeworld' and 'system' when developing quality end of life care in care homes: An action research study

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Care homes are now the place where over a quarter of older people die. Most research in this area has been descriptive reporting low morale, recruitment and retention issues and a lack of palliative care knowledge. In this 3-year study an action research methodology was adopted in order to develop staffs' knowledge and care for older people dying at the end of life. Two independent nursing homes volunteered to take part. An exploratory period using focus groups, interviews, participant observation, and documentary analysis confirmed specific context and clinical issues around end of life care and highlighted that dying was peripheral to the nursing home culture where the emphasis was on rehabilitation. Two initiatives inductively derived from discussion with staff as a result of the exploratory period enabled a greater openness towards death and dying. The first initiative was the development of 'collaborative learning groups' (CLGs) following the death of a resident; the second was the adaptation and introduction of an integrated care pathway (ICP) for the last days of life for use prior to the death of a resident providing a system around which quality end-of-life care was advocated. The conclusions drawn from this research are highlighted in a framework in which the two inductively derived actions are combined to pose a model for practice development that acknowledges both the lifeworld of staff in end of life care and the nursing home system. Habermas's Theory of Communicative Action-a substantive theory of 'system' and 'lifeworld'-is drawn upon. By implementing the ICP as an integral part of a system for end of life care within the rehabilitative culture of nursing homes, alongside facilitating learning through a CLG after a resident dies, such a framework encourages development of staff's knowledge of end-of-life care. It also supports the 'lifeworld' of staff caring for dying residents in a climate of increasing number of deaths in nursing homes.

Abstract number: 457
Presentation type: Poster
Session: Palliative Care in Elderly

Development of a peer education programme for advance end-of-life care planning: An action research project with older adults

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Objective: To develop and evaluate the acceptability and feasibility of a peer education programme for enabling older people to obtain information about treatment and care options at the end of life.
Design: Action research framework in four stages: 1. reviewing materials for end of life care education; 2. development of an education booklet; 3. development and delivery of a peer education training programme; 4. piloting of the education booklet in peer led discussions.
Setting: Community based project, Sheffield. Participants: 8 community advisors recruited from voluntary groups and 30 members of the general public. 5 community advisors trained as peer educators. Interventions: 1) An education booklet about end of life care, developed in collaboration with community advisors, was piloted in small group discussions with members of the general public. Peer educators helped to facilitate the small group discussions, supported by the members of the academic team. 2) Volunteer peer educators received a 3 day training course to prepare them for their role.
Outcome measures: feasibility of delivery and acceptability of the booklet and peer education discussions; peer educators' views about their training course; community advisors' views about participation in action research.
Results: Peer education discussions and the related booklet were evaluated as a useful and acceptable means of providing information about a sensitive issue. Peer educators felt that the training course successfully prepared them for their role. Community advisors felt they were treated as equal members of the research team.
Conclusions: Use of an action research approach enabled the development of a feasible peer education programme about options in end of life care. Older adults found this to be an acceptable way of participating in education about end of life care. This project has served as a useful pilot that could be extended to other areas.

Abstract number: 458
Presentation type: Poster
Session: Palliative Care in Elderly

Views on dignity of twelve elderly nursing home residents

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Introduction: The discussion of palliative care and a dignified death has almost exclusively been applied to people dying of cancer. As people in the Western world are getting older and are living with various chronic illnesses affecting their everyday lives, it is relevant to broaden the definition of palliative care to include other groups of people at the end of life.
Aim: The aim was to explore the views on dignity of elderly nursing home residents.
Method: The data collection was carried out between 2002–2003. A purposeful homogenous sample as described by (Patton 1990) was carried out and twelve elderly nursing home residents participated in the study. The interviews were conducted over time, altogether 39 interviews were carried out and the analysis followed the qualitative hermeneutic process as described by Ödman (1979, 1992).
Results: Elderly people, living in nursing homes often suffers from severe bodily losses affecting their handling of basic needs. They were well aware of their dependency and were able to explicitly define their need of a more specialised care. Neither nursing home followed an explicit caring philosophy such as, for example the grounds on which palliative care is based. The elderly people's views on dignity and experience of themselves and the life in the nursing home were often related to how they experienced their body and how the body was treated and cared for by significant others. The attitudes from others could both encourage or hinder the sense of dignity and a dignified end of life.
Conclusion: Our study was limited to the experience of elderly people living in nursing homes. Nevertheless, the findings from the interviews over time provided in-depth illustrations of elderly people's everyday life, nearing death in nursing homes. It is important to address the need of tailored palliative care in different health-care settings in order to offer and provide dignified care at the end of life for all those who need it.

Abstract number: 459
Presentation type: Poster
Session: Palliative Care in Elderly

Veteran deaths – commonalities and differences

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This study arose from a clinical question where palliative care staff had observed differences in the needs of a dying veteran, compared to a non-veteran. While there is a perceived lack of veteran specific palliative care in the literature, studies suggest that veterans have specific needs in relation to end of life care. Supported by the Australian Department of Veteran Affairs, this 2 year study aimed to understand and improve the palliative care needs of veterans as they face the end of life.
The objectives were to investigate: where and how veterans die and what is distinctive; whether the needs of dying veterans are being met; and to make policy recommendations in relation to the needs of veterans. The study used a literature review, a retrospective review of records of deceased veterans and focus group sessions with carers/ spouses and palliative care staff. The literature revealed that in the US, there are a number of veterans 'end of life' care programs. Palliative care is provided through a Veteran's Nationwide Palliative Care Network. Some palliative care education for doctors is carried out in some Veteran hospitals and literature is available regarding aspects of care. In contrast, Australian references are rather limited.
The study population were veterans resident of an area of Melbourne, who died during 2003. Of the 240 Veterans, 180 records are available through the local acute hospital. The medical conditions most frequently documented were: Cancers-lung, bowel & skin, COPD, emphysema, asthma, anxiety, aggression and dementia.
The focus groups are almost completed and will provide information about the experiences of care of veterans, from the professional and non-professional caring perspectives. Information gained from both the audit and the focus groups, will form the basis for developing policy recommendations to the Department of Veteran Affairs. This paper reports of the results of the study as well as these recommendations.

Abstract number: 460
Presentation type: Poster
Session: Palliative Care in Elderly

The relationship between specialist palliative day care and patients' ability to cope over an eight week period

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Aims: To identify if attendance at specialist palliative day care (SPDC) changes coping strategies employed by people facing terminal illness, and whether patients with particular coping styles benefit more than others from SPDC attendance.
Method: A prospective, exploratory pilot study using repeated measures statistical analyses. The Palliative Care Outcome Scale (POS) and the COPE were administered at baseline, and again at one and two month follow-up to a cohort of new SPDC attendees.
Sample: Twenty one patients were recruited from a local day hospice (10 male, 11 female, mean age 75.7 years, range 65–91 years). Currently, three participants have completed the study, eight have completed baseline and first follow-up measures, four are at baseline measures stage, six have withdrawn from the study.
Results: A full range of coping strategies were represented, but 'acceptance' was the most common. The coping strategies did not statistically significantly alter during the study, but there was a trend in mean levels of engagement style strengthening from baseline to first follow-up. No significant relationships were found between a participant's coping style and patient perceived benefits of SPDC attendance. However, 93% of participants reported that SPDC attendance helped them cope with their illness.
Conclusions: This study indicates that SPDC attendance may strengthen adaptive coping styles. SPDC attendance is perceived to be beneficial by patients regardless of coping style employed. This was a small pilot study with the usual problems of patient recruitment and retention. Also, it was uncontrolled for both comparator group and extraneous variables. However it is an interesting start. Further research is required to confirm these findings, and determine the mechanisms that make attendance beneficial.

Abstract number: 461
Presentation type: Poster
Session: Palliative Care in Elderly

Observation and report of palliative care needs by nursing assistants

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The Palliative Care Training program is a six-hour course using a case study method and a 5-POINT Guide to communications that teach staff how to look for physical (pain and other symptoms), psycho-social and spiritual needs of patients. The training was validated in training of 154 direct care staff in 11 New York City nursing homes. Post-test training evaluation showed 87 percent of nursing assistant trainees had positive improvement in understanding and application of observation and reporting skills. This change exceeded chance by over a thousand to one ($p = <0.000$). Data analysis showed that personal traits of trainees did not influence response to the training and the training was equally effective with trainees of different ethnic backgrounds, language, level of education and experience. Data was collected from 148

Palliative Care Indicator reports completed on a monthly basis for 109 residents, of whom 72 percent had a diagnosis of dementia and 61 percent required total care. Pain was the single most frequent indicator reported, 30 percent. The 22 symptom categories were 56 percent of reports. The 7 psychosocial indicators were 24 percent, including sadness and depression, 14 percent. There were four reports of spiritual needs. The majority of reports indicated multiple symptoms or needs, which often were reported over several days. Many of these indicator reports were followed immediately by one or more interventions by clinical staff and documented in case records with a note of a nursing assistant's report. Clinical responses were pain medications, 22 percent, medications or treatment of symptoms, 56 percent, and medications, treatments or case note responses for psychosocial symptoms, 20 percent. Several nursing assistants reported indicators of approaching death for residents who died unexpectedly.

Abstract number: 462
Presentation type: Poster
Session: Palliative Care in Elderly

A study to explore the characteristics, quality of life and concerns of informal carers of older people with heart failure

Sarah Barnes, **Merryn Gott**, **Sheila Payne**, **Chris Parker**, University of Sheffield, Sheffield, Great Britain, **David Seamark**, University of Exeter, Sheffield, Great Britain

Aims: To explore the characteristics, quality of life and concerns of informal carers of older people with HF.

Method: 213 informal carers of people >60 with HF participating in a longitudinal study were recruited from GP practices in 4 diverse areas of the UK. The carers are completing carer strain, quality of life and service satisfaction questionnaires every 3 months for 2 years. This paper presents baseline data and findings from 17 interviews, where both patients and carers were present, and 9 focus groups with health care professionals.

Analysis: Between methods triangulation was used to add breadth and depth to the data. Questionnaire data were entered onto SPSS and analysed using bivariate and multivariate statistics. Qualitative data were analysed thematically with the aid of NUDIST.

Results: 76% of carers were female, 70% were >60 and 73% were the spouse of the participant. 25% of carers <60 showed strain (compared to 10% of those aged 60–70 and 5% of those aged >70). 21% of those caring for someone with NYHA III or IV showed strain compared to 6% of those caring for someone with NYHA I or II. The following factors were identified as predictive of lower quality of life as measured by the SF36 physical functioning and mental health scales; being the spouse, experiencing 2+

co-morbidities and showing symptoms of depression. Qualitative data identified carers' concerns as; responsibility of handling medication, loss of social life and frustration. Patients' concerns related to the change of roles, dependence on the carer and the carers' co-morbidities. Health professionals identified carers' concerns as symptom control and helplessness.

Conclusion: Informal care is crucial in palliative care and little is known about the characteristics, quality of life and concerns of the informal carers of people with HF. These findings highlight the need to recognise that carers are mainly older women, often experiencing multiple co-morbidities themselves.

Abstract number: 463
Presentation type: Poster
Session: Palliative Care in Elderly

Delivering palliative care to people with dementia

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Aim of the study: The aim of this study was to explore the end-of life care needs of people with dementia from palliative care and geriatric care perspectives and to identify the challenges for the provision of palliative care in this area. Sample Frame Purposive sampling of professionals and relatives of deceased dementia patients was used to include people who had experience of caring for and coping with issues regarding dementia and end-of-life care.

Methodology: A qualitative study that used in-depth interviews.

Methods of analysis: Content analysis of interview transcripts was carried out.

Results: Key challenges for the provision of palliative care for people with dementia include the lengthy last phase of the illness; cognitive difficulties affect autonomy and decision-making; a greater reliance on family members or professional carers to assess distress and pain. A hospice is unsuitable for people with early or middle stage dementia when the problems of agitation, restlessness and wandering may be more pronounced; these aspects cause difficulty for staff and other patients. Palliative care demands considerable resources in terms of numbers of appropriately trained staff. In dementia care there are currently insufficient resources to provide trained staff in end-of-life care and to meet the educational and training needs of existing staff. A need for training in end-of-life care issues, such as pain and symptom management, ethical-decision making and family support was identified by dementia care staff.

Conclusion: Both domains, palliative care and dementia care, have expertise, experience and professional knowledge that are of mutual benefit. Developing partnerships between dementia and palliative care could overcome current resource difficulties and provide palliative care for people with dementia.

Abstract number: 464
Presentation type: Poster
Session: Palliative Care in Elderly

Sustained release (SR) hydromorphone in the treatment of elderly patients: Excellent efficacy and tolerability

Uwe Junker, **Hanna Ludwig**, Sana Klinikum Remscheid, Remscheid, Germany

Aim: To evaluate efficacy and tolerability of SR hydromorphone in palliative care of tumour patients with a focus on the elderly.

Methods: Multicentre observational study with 1,419 tumour patients with severe pain. Analysis of the subgroups "younger patients" (<60 years, n = 374, mean age 50.9 ± 7.3 years, 49.5% female) and "elderly patients" (= 60 years, n = 1,045, mean age 71.7 ± 7.7 years, 47.3% female).

Results: The (co)-analgesic pre-treatment of the groups was comparable. The dose of hydromorphone increased during the treatment phase of about 3 weeks from a mean of 14.9 ± 12,5 to 23.4 ± 19.6 mg (younger patients) and from 13.3 ± 10.6 to 19.8 ± 19.4 mg (elderly patients). The decrease of pain intensity, measured by VAS (0 = no pain; 10 = strongest conceivable pain), was similar in both groups (from 7.0 ± 1.5 to 2.5 ± 1.9 in the younger and from 7.0 ± 1.5 to 2.4 ± 1.6 in the elderly patients). The frequency of the opioid typical symptoms tiredness and constipation before onset of hydromorphone treatment tended to be higher in the elderly (60.6% vs. 56.4% tiredness, 34.9% vs. 28.6% constipation). Under hydromorphone treatment the rate of patients suffering from these symptoms was lower, without differences between the age groups (tiredness 4.8% in the younger, 6.0% in the elderly patients, constipation 5.3% vs. 5.9%, respectively). Compared with the total group, tumour patients showed a tendency to a higher incidence of the opioid-typical symptoms tiredness and constipation prior to hydromorphone therapy and comparable low incidence in the treatment phase.

Conclusion: SR hydromorphone reduces pain effectively in younger and elderly patients. Opioid-typical side effects are reduced significantly in both age groups with a tendency to better vigilance and lower constipation in the elderly compared to intial values. This demonstrates the good tolerability of hydromorphone in elderly patients.

Abstract number: 465
Presentation type: Poster
Session: Palliative Care in Elderly

Clarification of problems in palliative care consultation

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Background: In a national programme Palliative Care Consultation (PCC) teams were trained to provide comprehensive palliative care advice. A task of the PCC team consultant was to further clarify the problems posed in the request for consultation before giving advice. It is known that the number of problems identified by PCC teams (additional problems) after clarification was two times higher than the initially posed problems.

Aim: To identify the additional problems derived from clarification in palliative care consultation and to study factors influencing identification of additional problems.

Methods: Data were derived from the standard registration forms of the teams covering a two year period. Descriptive data on domain specific ratios of additional problems versus total number of problems are presented. Multilevel logistic regression analysis on problem level is carried out with additional problem (yes/no) as dependent variable and the potential influential factors characteristics as independent variables: domain of palliative care, discipline professional providing consultation, profession requesting care provider, type of consultation and patient characteristics.

Results: The total number of problems was 13.855. The percentages of additional problems were 53% in the physical domain, 70% in the psychosocial domain and 52% in the organisation of care domain. Logistic regression analysis revealed that additional problems were more likely to be identified in the domain of spiritual and psycho-social problems, in bedside consultation, when the requesting care provider was a clinical physician and when the patient was accommodated in hospice or hospital.

Conclusion: Additional problems were more frequently identified in a hospital setting. Adequate consultation depends on sharing information between the professionals requesting and providing advice. Clarification of requests is an important tool in palliative care consultation.

Abstract number: 466
Presentation type: Poster
Session: Policy

Support and advice given in palliative care consultation

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Aims: In this national multicentre study, we concentrated on the support and advice given by Palliative Care Consultation (PCC) team members to the requesting care providers, a topic yet unexplored. Study aims: 1) determine extent and nature of support and advice given in PCC, 2) determine factors influencing differences herein.

Methods: Support and advice were recorded on a specially-developed standard registration form. From it, we used the following: 1): support and advice classified according to four domains (pharmacological, information, practical support, advice to refer to other professional care providers). 2): consultation characteristics: problem domain, type of consultation, profession requesting care provider, professional(s) which gave support or advice.

Analysis: Frequencies and proportions to study extent and nature of support and advice given. Logistic regression analysis to determine factors related to support or advice.

Main results: More than half of all support and advice was pharmacological, information giving was the second most frequent action. Over 10% of all actions concerned practical support. For most elements of the consultation characteristics significant relationships with support and advice in all four domains were found. Pharmacological advice was more common when it concerned telephone consultations, GPs as requesting care provider, advice given by clinical or nursing home physician and problems in the physical/pharmacological domain. On the other hand advice to refer was more common concerning psychosocial and organizational problems coming from other requesting professional care providers than GPs and adviced by GPs, nurses or multidisciplinary team.

Conclusions: This study shows that support and advice given by PCC teams is influenced by several elements of consultation characteristics. In order to go along with future developments and to arrange an optimal composition of PCC teams this information is relevant.

Abstract number: 467
Presentation type: Poster
Session: Policy

Barriers to Palliative Care (PC) research

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Objectives: Research in PC is difficult due to general features of PC (multidimensional, multiprofessional) and particular national characteristics.

Aims: 1) to explore barriers to PC research (B-PC-R) from PC professionals involved at various stages of research, 2) to develop a quantitative assessment instrument B-PC-R, and 3) to quantify B-PC-R in various regions.

Methods: Aim 1: 28 interviews (open, in depth format) with 52 PC professionals were ad verbatim transcribed and analysed applying deductive and inductive methods, supported by MaxQDA software for coding. Aim 2: A pilot questionnaire B-PC-R is presently produced and a blinded, multiprofessional led dissemination strategy prepared. Aim 3: All researcher identified by the Swiss PC Research Initiative will be invited.

Results: Aim 1: 5 main categories of B-PC-R are defined: 1) ethical, 2) financial & time resources, 3) methodological, 4) planning and conducting a study, 5) politics. The 31 subcategories include: 1. Perceived burden; No benefit; Scruples of pat. Dependence; Disturbing clinical care; Institutional care approach; Vulnerability of PC-Pat. 2 Insufficiency of dedicated time; Conflict clinical work/research; Insufficient financing. 3. Pat. Accrual; Demanding inclusion criteria; High attrition rate; Shortness of hospital stay and pat's life; Polymorbidity/complexity; Getting informed consent; Missing data; Cultural/ethnical difficulties (incl. language); Gatekeeping; Data protection; Ethical committee; Randomisation; Insufficient standardized tools; Pat' access to research places; Insufficient infrastructure support and academic collaboration. 4. Insufficient staff; No study experience, insufficient training; Multidisciplinarity. 5 Low status of PC-Research; Inconsistent definitions for PC. Aim 2 and 3: it is expected that the B-PC-R will be disseminated in february 2006 providing results to be presented on site.

Conclusions: B-PC-R are characterised, quantitative results will be presented.

Abstract number: 468
Presentation type: Poster
Session: Policy

Complementary therapies in cancer: Patients' views on their purposes and value pre and post receipt of therapy

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Background: Although complementary therapies (CTs) are commonly used by cancer patients, there are few data regarding their views on the purposes & value of CTs, nor on whether receipt of CTs modifies these views.

Aim: To compare cancer patients' views on the purposes & value of CTs before & after receipt of therapy.

Methods: Pre & post therapy surveys of consecutive patient samples from three cancer-focused CT services in North West England.

Results: 107 patients completed pre & post therapy questionnaires (mean age 54yr SD 11.3; 88 females??)

Table 1

Main findings (N =107)	Pre therapy N (%)	Post therapy N (%)	% change
Role of CTs			
Integral to treatment	10 (9.3)	18 (16.8)	+7.5 p =0.001
Something extra	73 (68.2)	81 (75.7)	+7.5 p =0.001
Substitute for usual treatment	1 (0.9)	3 (2.8)	+1.9 p =0.87
Unsure	12 (11.2)	4 (3.7)	−7.5 p =0.01
Other	6 (5.6)	1 (0.9)	−4.7 p =0.81
Attitudes to CTs			
Committed	71 (66.4)	84 (78.5)	+12.1 p =0.001
Accepting	70 (65.4)	75 (70.1)	+4.7 p <0.001
Curious	80 (74.8)	53 (49.5)	−25.3 p =0.009
Positive	84 (78.5)	83 (77.6)	−0.9 p <0.001
Main pre-therapy expectations and post-therapy experiences of CT			
Improve(d) general well-being	97 (90.7)	90 (84.1)	−6.6 p =0.19
Improve(d) emotional well-being	93 (86.9)	85 (79.4)	−7.5 p =0.06
Pleasant experience	89 (83.2)	100 (93.5)	+10.3 p =0.01
Help(ed) me cope	90 (84.1)	78 (72.9)	−11.2 p =0.03

Pre therapy 57 (53.3%) believed CTs would improve symptoms; 42 (39.3%) they would reduce side effects and 63 (58.9%) they were an opportunity to talk. Post-therapy values were respectively 39 (36.4%; % change −16.9); 27 (25.2%; −14.1) and 68 (63.6%; +4.7)

Conclusions: Patients typically had positive views of CTs pre-therapy & more so post-CT. There was more expectation of psychosocial benefit than symptom relief; this was more marked post-CT. Arguments could be developed for increasing CT provision based on patients' positive views & perceived psychosocial benefit. However more evidence of efficacy is needed if CT use is to become widespread using public funding.

Abstract number: 469
Presentation type: Poster
Session: Policy

Effects of contemplative end-of-life care training on spirituality of health care professionals

Anne Bruce, University of Victoria, Victoria, Canada

Introduciton/Objective of the study: Little is known about the spiritual well being of health professionals working with dying patients and their families. The aim of this study was to evaluate the effects of an innovative 22-week spiritual care course on health professionals working in end-of-life care.

Methods: A mixed method design with pre-test/post-test questionnaires and qualitative focus group interviews were conducted. Outcome effects were measured using Spiritual Well-being (FACIT-Sp): Self-Transcendence Scale (STS), Functional Assessment of Chronic Illness Therapy; and Idler the Index of Religiosity (IIR). Three focus groups were conducted using semi-structured open-ended questions linked to course objectives.

Summary of results: Preliminary themes identified using thematic analysis of qualitative data include: confidence in being authentically present, enhanced communication skills, personal healing, and deeper understanding of spiritual dimensions of dying. Preliminary analyses of quantitative data suggest significant increases in feeling peaceful, being able to turn inward for comfort and overall increases in attitudinal scores.

Conclusion: Preliminary findings from this study suggest that contemplative approaches to end-of-life care presented through this innovative format have significant benefits for health professionals. Educational approaches used in contemplative end-of-life can enhance personal and professional understanding of spirituality and foster spiritual well-being.

Contribution to current palliative care practices: The study contributes to our understanding of contemplative practices in addressing spiritual dimensions of dying and in preparing health professionals working in the challenging domain of palliative or end-life-care care. TOPIC THAT BEST DESCRIBES THE ABSTRACT Caring for the Caregiver: Integrating Spirituality.

Method of presentation: Research Findings – oral presentation prefered.

Abstract number: 470
Presentation type: Poster
Session: Policy

The use of medications beyond their licence in palliative care

Asha Hameed, **Helen Emms**, **Catherine Lewis-Jones**, St Johns Hospice, Wirral, Great Britain

Introduction: In the United Kingdom, all medications need product licences corresponding to specific indications. Symptom control in palliative care requires using drugs in situations for which they don't have a product licence, given at doses higher or lower than that specified or via a route of administration which does not comply with the specifications of the licence.

Aims of this study: 1. To assess patients understanding of "The Use of Medicines Beyond Licence: Information for Patients'' leaflet produced by The Pain Society/Association for Palliative Medicine. 2. To understand the importance to patients of being told their use of a medication is beyond its licence. Method A six item structured questionnaire attached to a copy of the leaflet was distributed to hospice day care patients and out patients over a four week period.

Results: 20 patients participated. 17/20 (85%) felt they completely understood the point the leaflet was trying to make. 6/20 (30%) said the information in the leaflet gave them some cause for concern. 75% (15/20) felt it was very important that a doctor or pharmacist informed them their medication was prescribed beyond its licence. 25% (5/20) had been made aware of this fact. 11/20 (55%) believed it was the responsibility of the initial prescriber to inform them. After reading the leaflet and completing the survey, 10% (2/20) patients wished to further discuss their medication with the available doctor or pharmacist.

Conclusion: Professional membership organisations recommend obtaining informed consent before initiating such prescriptions to prevent confusion, anxiety or poor compliance when patients receive medication with information leaflets not reflecting their understanding of why they have been given that drug. No participant in this study felt no information should be provided if they were prescribed such drugs yet 75% (15/20) patients were unaware of their own medication being in this category.

Abstract number: 471
Presentation type: Poster
Session: Policy

Problems of comparative research in the state-of-art of palliative care in the EU

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Introduction: In 2004, a study on the state-of-art of palliative care (PC) in 11 European countries was conducted in order to explore which developments and achievements are recommendable for further governmental commitment in the development of PC in Germany.
Methods: Review of literature and policy documents, development of a questionnaire send to national experts including a glossary of the terms used, interviews with national experts about open questions and to gain deeper insight in national concepts of PC, and another review of literature published during the course of the study.
Results: Even though it could be shown that PC is developing dynamically, the task proved to be difficult, for many countries do not have national databases on the development of PC. Furthermore, publications rarely comprise current data. In Germany, i.e. there is a distinction between hospice services and palliative medicine services which makes comparative analyses difficult. Substantial problems arise because of unclear nomenclature. What is a hospice service, as referred to in the literature? It may be a voluntary bereavement service, a palliative care unit, an inpatient or outpatient hospice, an educational programme, or other. Moreover, the same service may be subsumed under different types of services of a certain country in the literature. Also, there is no pan-European definition of a palliative care patient and data on expenditures on palliative care research are hardly available at all.
Conclusion: It is highly recommendable to agree on an international glossary of definitions and an international database of PC services in order to enhance comparative studies and research. Listings of services according to an agreed sample of definitions, however, will not necessarily simplify assessments of the development of PC, unless there are agreed quality standards-national and/or international – that are required and to be fulfilled by the different types of services.

Abstract number: 472
Presentation type: Poster
Session: Policy

Advanced Directives – The German Debate

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An advanced directive (AD) is an instrument to direct one's own medical treatment in the event of incapacitating illnesses or injuries and to ensure that others are aware of these decisions. It is widely seen as the ultimate means to safeguard patient autonomy. Nevertheless, there has been an ongoing controversial debate in Germany about AD, including the involvement of working groups on the highest political level, i.e. appointed by the German Ministry of Justice, or the Study Commission of Ethics and Law in Modern Medicine of the German Bundestag, the German National Ethics Council and the Ethics Commission of the Land of Rhineland Palladium. The work was targeted at questions concerning the binding character and crucial aspects of the wording of AD and the probable necessity of legal adjustments. The outcomes of the work of these bodies show major differences with regard to aspects that must be seen as of far-reaching ethical implications. Should AD be applicable in cases where patients have not yet reached the process of dying? Should they be of binding nature, if non-treatment is requested regardless of the severity and course of a patient's illness? Must they be put in writing, centrally registered, signed on a regular basis or only once? Does an AD that is applicable to the situation in question absolve the obligation to explore the current will of a patient? In which way should the declared, probable or natural will of a patient be considered? However many legal, ethical, formal and other problems are being discussed, the current debate lacks the backup of sufficient research in how citizens, and particularly palliative care patients who have been dealing with existential matters for some time want their AD to be dealt with. Would they prefer a "dialogical model", are they afraid of being tied down to anticipated judgements about future situations, do they fear to be restricted on receiving treatments that they expressively asked for?

Abstract number: 473
Presentation type: Poster
Session: Policy

Palliative care research in Scotland – A scoping exercise

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Background: Despite the rapid growth in the number and range of palliative care services and in the management and care of dying patients, the evidence base for palliative care in Scotland is unclear.
Objective: To conduct a time limited, scoping exercise, to discover the current evidence base in palliative care research in Scotland and develop a research directory of planned, and in progress research. Research Questions 1. What is the current evidence base for palliative care research in Scotland? 2. What key themes, if any, can be identified? 3. What are the gaps in the evidence base? 4. What recommendations can be made for future research?
Methods: Database searches of EMBASE, Medline, CINAHL, psycINFO, Web of Science and AMED were searched from 1990–2005 using a detailed search strategy. Hand searches of key palliative care and research journals were included. Unpublished research was identified using Google scholar and contacting key stakeholders. All retrieved articles were graded using a validated tool. Planned, and in progress research was identified from detailed questionnaires sent to individuals who responded to an initial contact form. This will form the basis of a research directory, which will be available online and widely distributed.
Results: The database search identified 34 articles that met the inclusion criteria. 11 themes were identified, with the most popular being: models of palliative care provision. The most common methods used were qualitative or survey design with only one RCT identified. Only 15 studies involved patients.
Conclusions The review identifies a lack of research in palliative care within Scotland, there is, therefore, an urgent need to increase the evidence base and infrastructure in relation to palliative care research and particularly RCT's in Scotland. We therefore recommend more RCT's and more patient focused research. The paper will outline ways in which we intend to this.

Abstract number: 474
Presentation type: Poster
Session: Policy

A baseline study on the provision of hospice/specialist palliative care services in Ireland

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Background: Since 1994, palliative care (PC) in Ireland has had increasing presence in health policy, culminating in a national blueprint for service development, by the Department of Health and Children (2001). Now in 2005 a review of actual progress, factual data on regional variation & a new impetus for policy development is required.
Research aims: To present a national overview of service provision in hospice/PC on a consistent regional basis; to identify deficits and gaps in terms of government policy; to project future service needs and resource requirements.
Sample: All specialist PC inpatient units, day care services, home care services, bereavement services in Ireland and all regional health authorities.
Method: Two templates were designed to collect standard data on i) demographics and services activity (units, beds, homecare visits etc) and ii)

actual and recommended staffing levels (including associated costs). These templates provided a data collection framework which was applied to existing regional needs assessments in PC, (conducted between 2002–2004) and to frame a telephone questionnaire to PC service providers and health authority personnel. Complete regional data were returned to respondents for validation. A steering committee guided the study.
Analysis: Composite data were compiled in table format for each level of service activity and staffing in regional health authorities (n = 10). These were compared to the recommendations of the 2001 policy document to arrive at quantifiable deficits in service provision.
Results: The study confirmed an incremental growth in demand for PC. There are wide regional variations in provision of hospice and PC in all settings, e.g. 9 of 35 acute hospitals have a full PC team, 3 regions have no inpatient facility. A national staff deficit of 704 was identified and per-capita cost deficits derived for regions.
Conclusions: The baseline provides a reference point for PC development and progress monitoring.

Abstract number: 475
Presentation type: Poster
Session: Policy

Resuscitation and the use of automated defibrillators within the hospice environment – A study of staff Members Views

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Applying resuscitation guidelines within a hospice focuses many of the medical, legal and ethical issues involved. Patients interact with hospices at different stages of their disease, from diagnosis, during treatment and the terminal phase. Policy on resuscitation should consider and respond to these changing needs. Evidence shows that outcomes in basic life support are improved by the use of automated defibrillators. Their wide availability within the community sets a standard of basic life support higher than what is currently available in many hospices. This and the less intrusive nature of such machines, merits further consideration. If resuscitation is to be offered to patients in a hospice then it should be optimal. The presence of such equipment within a Hospice would require careful thought, pre-meditated use and sensitivity. Involving staff and their views on such equipment would help transition a hospice from current basic life support facilities to include the presence and use of a defibrillator. This study evaluates views of hospice staff on the resuscitation of different patient populations. The views of clinical and non-clinical staff were obtained via questionnaire on making available resuscitation to staff, visitors, day hospice patients, respite patients, in-patients and those patients with non-malignant conditions. Views on the use of automated defibrillators in these patient groups were ascertained. This study found the majority of staff did not consider resuscitation too disruptive to the hospice atmosphere. This included defibrillation. There was high acceptance of making resuscitation available to staff, visitors and those patients perceived to be at earlier stages of their disease. There was greater variance in opinion for those perceived to be in later stages of their condition. However the majority would be lead by the patient's own choice. These results help direct further debate and policy development on this topic.

Abstract number: 476
Presentation type: Poster
Session: Policy

Mediation in palliative care the coming together of Law and Health for the benefit of the patient

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The activity of the mobile palliative care unit has brought to light the existence of numerous conflicts surrounding the approaching death of patients;these conflicts are largely due to lack of information and an understanding ear. During this end of life period when the roles are often modified, the patient becomes an object, the family are often forgotten and the health workers are paternalistic, kind or far removed from this fading life. As a mobile team we are often witness to these conflicts and suffering and we are often called on to help when there is a breakdown in communication between patients, family and health workers. It is as if they all need someone who can be identified as neutral: the Mediator. In France, mediation was developed principally in the legal field which is where we looked for skills to help us in our daily practice with patients at the end of their lives, their families and health workers. We can therefore define Mediation as "a process of creation, repairing social ties, and resolving conflicts, in which an impartial and independent third-party tries to help restore or improve relations or resolve a conflict by organising exchanges between the people and institutions" Pr Michelle GUILLAUME HOFNUNG, professor of Law. This research work between Law and Health began 3 years ago. It is part of a process of using mediation tools in the field of the accompanying of people at the end of their lives. The challenge is to think together on ways to set up mediation in the health system. At present very few experiments have been set up and we believe that it is necessary to establish mediating structures guaranteeing civil and human rights within the health system until the end of life. Mediation must appear as a new tool for continual improvement in establishments, recreating ties, making sure hospitalised patients are not excluded from society, proposing structures with an understanding ear. The present and future challenge is to maintain a city hospital in the city.

Abstract number: 477
Presentation type: Poster
Session: Policy

Evaluation of a specialist palliative care counselling service using CORE-OM

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Aim: To evaluate the delivery and outcomes of a counselling service in a UK specialist palliative care hospice The UK's NICE Guidance for Supportive and Palliative Care (2004) highlights the need to provide patients and families with systematic psychological assessment and intervention. Yet, there is limited evidence available to support counselling's effectiveness within palliative care. The CORE System (Clinical Outcomes for Routine Evaluation) has been designed to help evaluate key aspects of service delivery and client (patient/carer) outcomes from counseling services within the UK.
Methods: The CORE Outcome Measure (CORE-OM) (Evans et al, 2002) pre and post therapy questionnaires were completed by the client and therapist. CORE-OM assesses global level of distress, subjective well-being, commonly experienced problems or symptoms, and life/social functioning. CORE-PC software analyses clinical thresholds before and after therapy to determine clinical change.
Results: 101 (69%) clients completed pre and post therapy questionnaires (mean age 49, male:female 8:2, ethnicity 96% white British). Mean waiting time (referral to initial assessment) was 10 days (2 to 19). Mean No. of counselling sessions received 7 (2 to 15) 37% clients were on medication, of which 79% were prescribed anti-depressants. The five most common presenting concerns were anxiety/stress (91%), bereavement (72%), inter-personal problems (61%), depression (51%) and self esteem (18%). Pre therapy, 91 clients (66%) were scored above clinical cut-off. After counselling, 66 clients (65%) were calculated to be clinically and/or reliably improved.
Conclusions: Following counseling the majority of clients demonstrably improved, though slightly less than in primary care benchmarks(78%), due to the higher number of clients below clinical cut-off accepted for therapy. Data on accessibility and equity of access and acceptance into therapy will inform the development of future counseling services

Abstract number: 478
Presentation type: Poster
Session: Policy

Spiritual beliefs among nurses and social works

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The aims of this quantitative research are to survey the spiritual beliefs of health care professionals who care for the dying and to compare spiritual beliefs among nurses and social workers, in three different settings: acute care, community based agencies and hospices. The research population was divided into three groups according to their level of exposure to dying patients. This was decided based on two indicators: the percentage of dying patients who are being cared for by the participant (high exposure equal 50% or more; medium exposure equal 10%–49%; low exposure 9% or lower), and the participant's work place (community, hospital or hospice setting). 373 health care professionals participated in the study. 191 (51%) were nurses and 182 (49%) social workers. Most worked in health care community settings (66%), 25% in hospitals, and 9% in hospice settings. One-way univariate ANOVA was used to examine the differences in spirituality between the two disciplines. A 2×3 MANOVA (Profession × Exposure) was used to determine the differences in spirituality according to the levels of exposure to dying patients. In addition, 2×3 MANOVA (Profession × Work Place) was used to determine the differences based on the different work places. The results indicate: 1. No differences between nurses and social workers in their levels of spiritual belief. 2. Nurses and social workers who rarely treated a dying patient hold a more spiritual view ($M = 54.66$, $SD = 18.46$) in comparison to health care providers whose main occupation involved caring for terminal ill patients ($M = 47.80$, $SD = 18.10$). 3. Likewise, the lowest level of spirituality was found among hospice health care professionals. These thought-provoking results will be discussed in light of Existential philosophy (Heideger, 1958) and the characteristics of Israeli society: lack of clear separation between State and Religion; and the massive wave of terrorists' attacks at the time this research was conducted.

Abstract number: 479
Presentation type: Poster
Session: Policy

Physical and psychological condition of health care workers dealing with the seriously ill

Katalin Hegedus, **Zsuzsanna Szántó**, **Mária Kopp**, Semmelweis University, Budapest, Hungary, **Ágnes Riskó**, National Institute of Oncology, Budapest, Hungary

Introduction: Health care professionals undertaking treatment/nursing of the seriously ill are frequently overburdened emotionally, intellectually and physically. This condition can have several, sometimes irreversible, negative consequences: accumulation of unprocessed stress, severe physical and psychological symptoms of mental burn-out, and resultant difficulties in private life. In our survey we aimed to gain a realistic image of the physical and psychological condition and quality of life of professionals working in Hungarian clinical care in order to provide rapid help.
Methods: The basis of the survey was a version of the Hungarostudy 2002 questionnaire, modified for health care professionals. In our sample there are 200 health care professionals (physicians and nurses) dealing with seriously ill and dying patients and control groups of non health care professionals, and health care professionals, chosen from the Hungarostudy survey. In all three groups the proportion of gender, age and education is the same. The results were analysed by the SPSS 10.0 statistical program. The relationship analysis was completed by ANOVA test.
Results: The analysis of the answers of those attending in our questionnaire survey – compared to those working in other health care fields and to the control group of non health care workers-indicates that the ratio of exhaustion and stress-dependent physical and psychological symptoms are prominently, in many cases significantly, higher among health care workers dealing with the seriously ill; addiction is more frequent and social network is less favourable. These data are even worse for nurses than for doctors and other graduates.
Conclusion: we need to improve graduate and post-graduate education concerning the special needs for health care workers treating the seriously ill, and to provide work-based on-going support and attention to health care worker's own mental and physical health.

Abstract number: 480
Presentation type: Poster
Session: Policy

Access to medication in the community by patients and carers in a palliative setting a Systems analysis

Michael Lucey, St. James Hospital, Dublin, Ireland, **Regina Mcquillan**, **Kevin Connaire**, **Martina Corrigan**, **Jacinta Flynn**, St. francis Hospice, Raheny, Dublin, Ireland

Abstract Title: Access to medication in the community by patients and carers in a palliative setting. A Systems analysis. Introduction: Palliative care patients at home need to be able to access specialist palliative care medications with ease and within an acceptable time frame to alleviate their symptoms.
Aim: The aim of this study is to elicit the causes of failure of the system of provision of specialist medications for the patient in the homecare setting.
Methods: Questionnaires were sent to all patients taken on by the St. Francis Hospice home care team over a three-month period asking about any delays in getting medication, in addition to all the registered Pharmacists, and all General Practitioners in North County Dublin.
Results: 171 Pharmacists replied to the questionnaire. q 49.1% Medications not in stock q 49% Medications not on the GMS. q 31.5% Incorrectly written prescriptions q 33% Supplier difficulties. 268 General Practitioners responded to the questionnaire. q 30.6% Need to clarify advice from home care team. q 18.9% Patient or carer unable to attend clinic to collect prescription. q 23.4% No one available to collect and deliver prescription to the pharmacy for dispensing of medication. 22 patients responded to the questionnaire, q 54% Reported no delay. q 40% No advise received to change medications. There were 12 reported drug delays from the home care team. q 50% Pharmacy Stocking Defisiencies. q 2 due to no family/carer available to courier prescription q 2 due to GP prescribing failures.
Conclusions: The most frequent cause for delay in obtaining drugs promptly was that pharmacies did not stock the drugs. Other issues included drugs not being on the GMS, and no one available to collect the prescription or medication. We intend to develop this project further to improve patient access to drugs.

Abstract number: 481
Presentation type: Poster
Session: Policy

Where and how do our patients die?

Jauma Pou Rosa Maria, **Gonzalez Marcos Maria**, **Garcia Hernando Maria**, **Payola Turro Nuria**, Isntitut Catala de la Salut, Banyoles, Spain

Objectives: To know how they die, where and how our patients are attended to these patients died due to disease.
Design: Observational-based study. Location Primary care Censed population in the region of Pla de l'Estany(Catalonia, Spain), from June the 1st to June the 31st 2005.
Methode: Telephone calls to families of the deceased patients, data obtained from the register office, and the undertaker's register. Accidental deaths such as traffic, work or fortuitous accidents are excluded. This study analyses the sexual distribution patterns, causes of death, location, home care, and the family satisfaction, of time to include them in Homecare and Palliative Care programs.

Results: 245 cases included in the study. The average age is 78,2 (15 minimum and 96 maximum) 53,4% are women. Seasonal variability is detected having winter months the highest mortality rate (34%). Fatality occurs in a 26% at home, a 40% at the reference hospital, and an 18% in the geriatric residence, and 11% at the local clinic center and a 5% in other centers. The main primary causes of death: Senility and dementia (26%), Neoplasia (21%), Cardiovascular disease (21%) and Cerebral vascular (8%). More than half of the families of the deceased patients state that the patient did not suffer of uncontrolled pain and they prefer to feel the support of the medical team, whether they have died in hospital or at home.

Conclusions: It would be necessary to inform population and even sanitary professionals of the importance to decide the setting to die and think about home as the most appropriate place, providing that the disease of the patient allows it and the sanitary team is prepared to give a good response. Primary care teams supported by the Palliative Care units should be the responsible to provide care and help to patients and their families on their last days and transfer a positive feeling to terminal patients if they wish to die at home.

Abstract number: 482
Presentation type: Poster
Session: Policy

Taxonomy of palliative and supportive care

Richard Stevens, **Sam Ahmedzai**, University of Sheffield, Sheffield, Great Britain, **Denise Brady**, St. Christopher's Hospice, London, Great Britain, **Melanie Hodson**, Help the Hospices, London, Great Britain

A comprehensive unifying classification scheme for palliative and supportive care literature is needed if the development of the evidence base is to be properly supported in the 21st Century. Practitioners and researchers need access to the best available current knowledge to support health care-related decisions. But there is currently no universally-accepted overall system of classification with which to map and evaluate the field's global knowledge base. In its absence, hospice libraries and other information services in the field have been forced to develop their own ways of organising collections piecemeal. In the new media era, a more systematic approach is needed. Collaborative building of online resources such as the UK's National Library for Health and other repositories of knowledge provide an opportunity for strategic development of a common classification scheme. We present this taxonomy of palliative and supportive care to: (i) stimulate discussion and criticism, and (ii) bring together interested researchers to develop a consensus. Increasingly, the research literature is accessed online, in a non-sequential way which is qualitatively different to how traditional printed sources are usually accessed – so the taxonomy must be sustainable in both new and old media. The field is inherently multidisciplinary and potentially relevant contributions to knowledge can be found in a diversity of areas-so the taxonomy must be flexible in scope for this diversity to be captured. Currently, the literature in some parts of the field is underdeveloped – so the taxonomy must help illuminate sparse areas of the knowledge base to help encourage new research in those topics. The wealth of possible 'answers' now available to palliative and supportive care professionals presents the well-known problems of 'information overload' which can hold back scientific advancement and improvements in services-the taxonomy can help us distinguish 'good' evidence from 'bad'.

Abstract number: 483
Presentation type: Poster
Session: Policy

Barriers for palliative care research among various professions, institution types and countries

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Objective: Certain peculiarities of PC may hamper research such as ethical issues, multi-professionality, the holistic approach, involvement of relatives, or specific methodological problems. Based on the hypothesis that knowledge of barriers to PC research might catalyse tailored research support, we aim to categorize barriers and to explore its variability among different settings by a systematic literature review.

Methods: To retrieve papers, the databases CINAHL (multidisciplinary), PUBMED, and Cochrane were systematically searched by 3 search strings (PC, research, barriers), hand search, snowballing and personal delivery provided additional papers. To categorize barriers, in an inductive, continuous comparison approach the content of papers was analysed (Mayring 2000), barriers characterized, coded (MaxQDA) and compared with those retrieved from interviews.

Results: 72 papers (53 reviews, 7 surveys, 12 other;) were retrieved (11 oncology, 4 mixed, 57 undefined) and 5 main categories with 31 subcategories defined. Barrier main category - Profession1 (MD/nurse/o/nd) - Type of institution2 (M/N/P/o/nd) - Study population3 (No/U/Ao/nd) - Country4 (U/US/C/o/nd) Ethical considerations - 15/7/4/15 - 22/8/6/0/4 - 29/4/5/2 - 13/15/6/4/2 Financial & time expenses - 17/7/5/17 – 23/8/7/2/5 - 32/4/7/2 - 16/15/6/6/2 Study design & methodology - 19/12/12/22 - 27/11/13/7/6 - 48/5/9/3 - 20/22/9/11/2 Human resources - 10/2/6/7 - 12/3/5/2 - 20/0/5/0 - 8/8/2/5/2 Politics - 7/2/2/5 - 6/2/3/2/2 - 15/0/0/0 - 1/6/2/4/2 o: other, nd: not definable 1: MD (23), nurse (12) 2: M: medical (31), N: nurse (12), P: philosophical, psychological, social (14) 3: No: no subjects used (52), U: univ. (6), A: ambulatory (11) 4: U: UK (22), US: USA (26), C: Canada (9).

Discussion: No obvious differences of main barrier categories between professions, institutions and countries were found. Analysis of subcategories might reveal detailed information suitable for tailored support strategies.

Abstract number: 484
Presentation type: Poster
Session: Policy

The social impact of caring for the terminally-ill: Directions for support, research and policy

Samar Aoun, **Linda Kristjanson**, Edith Cowan University, Bunbury, Australia, **David Currow**, Flinders university, Adelaide, Australia, **Peter Hudson**, University of Melbourne, Melbourne, Australia

Palliative Care Australia launched a National Inquiry into the Social Impact of Caring for Terminally Ill People, to plan strategies to enhance support for informal caregivers for the terminally ill. Following a comprehensive national and international literature review, public submissions were invited from individuals, families and organisations. This paper presents evidence from the public submissions indicating that the role of supporting a dying relative has adversely affected the wellbeing of many family carers: physical, mental, emotional, financial and economic aspects of life of caregivers. Furthermore caregivers reported unmet needs for information and communication, service provision and support from health and community services. The paper discusses three sets of challenges that help explain why needs of caregivers providing support to individuals receiving palliative care remain largely unmet: (i) barriers to seeking help including communication process barriers, health system barriers and family-related challenges, (ii) a dearth of research-based interventions focused on reducing the negative aspects of caring and (iii) a number of impediments to effective policy and service development for family carers. Findings from this project have informed a strategic national agenda aimed at enhancing the wellbeing of family caregivers. Evidence collected by the National Inquiry reinforced the importance of policy responses and resource allocations that are focused on helping caregivers perform a vital and important role into the future, particularly as caregivers are increasingly replacing skilled health workers in the delivery of unfamiliar complex care for the terminally ill.

Abstract number: 485
Presentation type: Poster
Session: Policy

Evaluation functional Links between general practioners &Palliative Care Team – Strategies to ensure Effective Multi Disciplinary Team Work

Virginia Morris, North Coast Area Health Service, Tweed Heads, Australia

Background: The pivotal role of the General Practitioner in the care of a Palliative Care patient is well recognised equally is the importance of a Team approach to ensure optimal Care for the patient, family and significant others.
Purpose: The initial study aimed to audit patterns of referral from GPs to P/C Team before and susequent to the undertaking of an educationn package purchased from a University for the GPs. The purpose being to demonstrate that the intervention and the increased awareness of GPs with regard the principles of Palliative Medicine and their mandatory participation in Multidisciplinary Case Reviews with the Team would significantly increase the referral rate to the Service in view of the functions and advantages of the 'shared Care' model.
Method: The activity required a retrospective audit as the pre-test measure followed by a post test susequent to the intervention. The utilisation of the pre test audit to identify non-rererring practices and to ascertain the barriers. It was necessary to use the records of the local funeral directores to identify individuals who died of cancer and the GP who signed the death certificate-this information was cross checked with the Palliative Care Register of patients referred to the Team. This analysis was repeated after the interventions. The research design was a combination of quasi experimental and ex post factor study.
Results: Results indicated that 40% of cancer patients had not been referred to the Team there was little change in the second analysis.
Conclusion: As a result of this study concerted efforts have been made to increase the awareness of theservice to the GPs and to the Community. Additionallyt there has been increased focus on the functions and effectiveness of the Multi disciplinary Team in the delivery of Cancer and Palliative care as will be demstrated in this presentation.

Abstract number: 486
Presentation type: Poster
Session: Policy

Development of local networks palliative care from the perspective of the GP

Wim JJ Jansen, **Roberto SGM Perez**, **Wouter WA Zuurmond**, VU university medical center, Amsterdam, Netherlands

Introduction: The Dutch government policy on palliative care is to develop local networks. At this moment The Netherlands are covered by 72 of networks palliative care. The development of these networks from the perspective of the GP's is the subject of this study.
Methods: Three local networks are selected based on their stage of development. To all GP's in those networks an identical questionnaire was send in Spring 2003 (T = 1) and Spring 2005 (T = 2). The questionnaire consists of 48 questions related to five main goals of networks.
Palliative care: information, shared vision, objectives, transfer of knowledge and structure. Statistical analysis of the data was performed in SPSS in three ways: (1 differences in calculated sumscores between the networks on T = 1 and on T = 2; (2) differences in calculated sumscores per item per network between T = 1 and T = 2 and (3) differences in sumscores per network between T = 1 and T = 2.
Results: The total response rate to both questionnaires was 32% (N = 323). (1) On T = 1 only 'transfer of knowledge' in network 1was significant different from the other two regions. On T = 2 only 'shared vision' in network 1 was significant different from the other two networks (Kruskal Wallis). (2) Results of the comparison of data from T = 1 and T = 2 per network per item shows 2 (network 2/3) to 4 (network 1) items with a significant better result at T = 2. (3) Analysis of differences in sumscores between the three networks shows no significant differences, except the dimension 'objectives' between network 1 and network 3. (Mann-Whitney).
Conclusion: Within the period of two years in any of the three networks one or more items have a significant higher score on T = 2. Network 1 has made the biggest progression: four out of five items shows significant higher scores.

Abstract number: 487
Presentation type: Poster
Session: Policy

Care at home in the last three months of life for people in the South of England following a stroke: Views of bereaved relatives

Amanda Young, **Julia Addington-Hall**, **Angie Rogers**, Univerity of Southampton, Southampton, Great Britain, **Tariq Saleem**, Kings College London, London, Great Britain

There is increased recognition of the relevance of palliative care to people who die from circulatory and neurological conditions. Cerebrovascular disease (stroke) remains the third leading cause of death but very little is known about dying following stroke.
Aims: To investigate the quality and adequacy of care received at home in the last three months of life by people who died from stroke, and by their families, from the perspective of bereaved relatives.
Methods: A Stroke specific version of the VOICES questionnaire for bereaved relatives was developed and piloted. Informants were asked about the use of, satisfaction with services and quality of care in the last 3 months of life. The Office of National Statistics drew a random sample of 495 people who had registered a stroke death in Southern England, sent them a questionnaire and a reminder 3 to 9 months after the death. Data from questionnaires were analysed using SPSS.
Results: 183 questionnaires were returned, a 37% response rate. 61% of deceased were women and 64% were aged over 80 or over. 53% of informants were the deceased's adult child. 554% had spent time at home in their last three months, 42% had lived alone. Most help was provided by family and friends: household tasks 78% family versus health and social services 28%, personal care 54% (45%), night time help 43% (13%), medication 52% (21%). 50% of families helped for more than 20 hours a week; 32% of respondents reported that someone in the family had had to give up work or make major changes in their life to care for the deceased. 27% felt they did not get the help they needed from the health services and 37% from social services.
Conclusion: Family and friends play a key role in supporting stroke patients living at home towards the end of life. Some receive inadequate support from health and social services. Further research is needed to investigate whether and in what ways palliative care might support these patients and their families.

Abstract number: 488
Presentation type: Poster
Session: Policy

Understanding palliative care: An ethnographic study of three Australian palliative care services

Judi Greaves, Royal Prince Alfred Hospital, Camperdown, Australia

Background: Although palliative care commenced in Australia in the early 1980s, there is still lack of understanding about what palliative care is and the depth and scope of this specialty area. Understanding palliative care and the ability to differentiate this from other end of life care is important if people are to make informed decisions about supporting, accessing, and using services appropriate to their needs.
Aim: To enhance understanding of palliative care.
Methods: An interpretive ethnographic study from a symbolic interactionist perspective was undertaken in three palliative care services, one in each of the major Australian cities of Sydney, Melbourne, and Perth. Data collection was by means of participant observation, formal and informal interviews, and examination of supplementary data sources.

Results: Common findings revealed an underlying mission to "make the best of things," which included creating appropriate physical environments with limited resources; care recipients were a similar cohort of middle-aged cancer patients; and staff expressed discomfort in caring for non-conforming (eg. non-cancer) patients. Diversity in the practice settings was highlighted by the use of technology and staff attitudes towards its use, and the status of social activities for patients and their families.
Conclusions: Discussions and decisions about usage, allocation of resources, and service development must take into consideration the various interpretations of palliative care services that exist. There is also need for sound evidence-based studies to examine the impact of different aspects of palliative care service delivery, and the populations best served by them. In this oral presentation, an overview of some key dimensions will be discussed to illustrate in particular the diversity of practice found in these palliative care settings. (This study was undertaken as a PhD thesis, awarded September 2005.)

Abstract number: 489
Presentation type: Poster
Session: Symptoms

Phase I/II trial for implementing a clinical practice guideline for the management of nausea in patients with advanced cancer

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Background: Nausea and vomiting are common experiences of patients with advanced cancer, independent of exposure to chemotherapy. The current approach to nausea assessment and treatment developed within palliative care is based on the neuropharmacologic understanding of the emetic pathway as determined for chemotherapy induced emesis, even if this may not always be directly applicable to nausea in advanced cancer. Clinical practice guidelines (CPG) can be effective in improving health outcomes including symptom control, and tools can help operationalise CPG to improve implementation.
Aim: To develop and implement a CPG and tool for the assessment and treatment of nausea in advanced cancer.
Methods: Open trial in hospital based junior medical officers (JMOs) in oncology wards in two Australian hospitals, with reduction at one week in daily patient self reports of nausea intensity, using a 0–10 numerical rating scale, as the main outcome measure. Pre and post prevalence of nausea and antiemetic prescribing patterns were secondary outcomes.
Results: Symptom audits indicated that nausea was uncommon. During the main period of implementation 31 patients (9% of all admissions) were identified by the JMOs to be eligible for the guideline. Of these, the assessment tool was used in only 15 (48%) and the treatment protocol adhered to in nine (60%), being objectively documented as effective in six of them (67%). Prevalence of nausea reported by patients was lower after implementation than prior (23% versus 39%), suggesting that implementation of the guideline by use of the tool was effective in reducing the prevalence of nausea.
Conclusions: The tool may be a useful guide for anti-emetic therapy in advanced cancer. There are a number of barriers to implementation that need to be overcome for it to fulfil its potential. In this paper, we will present an overview of the study including the tool, results of symptom audits, use of the tool, and barriers to its implementation.

Abstract number: 490
Presentation type: Poster
Session: Symptoms

Tips on eating for patients with advanced cancer: Findings from and exploratory study

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Background: Internationally there is interest in supporting self-management, as a way of helping people to live with illness. One way of supporting self-management is to offer information that can widen choices available to patients (Lorig, 2003). Yet little research based evidence is available to underpin information made available to people with advanced cancer who are experiencing eating difficulties.
Method: The primary research was an in-depth multi-method exploration of weight loss and eating difficulties in people with advanced cancer. The patient participants were receiving palliative home care in the South of England in 2003. Methods of data collection included semi-structured interviews with 30 purposively selected patients. A topic explored was change in food preferences and what patients found helpful when living with these changes. A secondary content and thematic analysis was conducted on this data about food intake.
Findings: The 30 patients described many changes in their food intake as problematic. Difficulties arose in consequence of change in, 'the desire to eat', 'taste', 'texture' and 'smell'. Collectively the patients were able to suggest different ways of adapting to and living with altered preferences for food. This paper will present these as 'tips on eating for patients with advanced cancer'.
Conclusions: The research has collated patient experiences to develop the first package of tips on eating for people with advanced cancer. Further research is needed to find out if this information, when offered as support to patients, helps them to self-manage any eating difficulties they experience.

Reference

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Abstract number: 491
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Session: Symptoms

Review of endovascular venous stenting in palliative care patients (work in progress)

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Introduction: Palliative care patients presenting with lower limb oedema are often assumed to have either a Deep Vein Thrombosis (DVT), congestive cardiac failure (CCF) or lymphoedema. Venous obstruction is another common cause of lower limb oedema either Inferior Vena Cava (IVC) compression (hepatomegly or retro peritoneal nodes) or iliac vein obstruction (direct tumor or nodal compression). Venous obstruction can be relieved with an endovascular stent which is a straightforward procedure undertaken by the interventional radiology department. We have used this procedure successfully in a number of patients and review our practice in order to highlight the use of this technique.
Methods: We completed a retrospective chart review on patients referred for endovascular IVC or iliac vein stenting over a 9 month period. Data recorded included demographics, primary diagnosis, procedure undertaken and documented clinical response.
Results: 14 patients underwent venous stenting- 8 female 6 male. All patients presented with unilateral or bilateral leg swelling. 11/14 patients got good to full resolution of lower limb oedema.
Conclusion:

- Lower limb swelling which is assumed to be lymphoedema may actually be dual pathology-both venous and lymph obstruction
- Computer Tomography scan can ascertain whether venous obstruction is present
- Venous stenting is a straightforward procedure. It is well tolerated and effective (Survival was short for a number of patients (4 patients died within 3 weeks) however their oedema improved and their quality of life was enhanced for their remaining time (Image 6 pre-stent and Image 7 post-stenting). This highlights the need for early referral
- Local radiotherapy is not an contraindication to venous stenting
- This procedure can be considered in the paediatric palliative care population.

Abstract number: 492
Presentation type: Poster
Session: Symptoms

The role of corticostheroid treatment of Home Hospice patients

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The goal of the study: Estimation of frequency of applying, indications and the complications resulting from applying corticostheroid treatment for Home Hospice patients.
Material and method: Patients with advanced cancer being in care of the Home Hospice of Lower-Silesian Oncology Centre in Wroclaw. Analysis of disease history as of 14.09.2005.
Results: Out of 130 of patients of Home Hospice, 54 (30 women and 24 men) on the day of the analysis were taking the glucocorticosteroids. For 19 the persons the glucocorticosteroids had been applied before to the patients were admitted to Home Hospice, and for 34 persons it was recommended during the time of hospice care. The principal indications to use the glucocorticosteroids were: dyspnoea(14), raised intracranial pressure (13), hepatomegaly (11), neuropathic pain (7), obstruction of alimentary tract (6), lack of appetite (5), weakness (4), mood (4), obstructive lymphandenopathy (3), adverse effects of radiation (3) and others. 15 patients had more than one indication to start taking glucocorticosteroids. The maximal daily dose of dexamethason was 16 mg, and minimal-2 mg. Average 24 hour dose dexamethason this 5 mg.
Conclusions: Corticostheroid treatment was applied for 41,5% of the ill being included in the care of Home Hospice. Indications to inclusion glucocorticosteroids are very diversed, predominating: dyspnoea (25,8%), raised intracranial pressure (24,0%), hepatomegaly (20,3%), neuropathic pain (12,9%), the obstruction of alimentary tract (11,1%). Side effects of corticostheroid treatment were observed for 27,7% patients. The most frequent were: poststeroid diabetes (12,9%) and oral candidiasis (7,4%).

Abstract number: 493
Presentation type: Poster
Session: Symptoms

The assessment of insomnia during first time consultations by palliative care (PC) physicians

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Introduction: Insomnia affects up to 50% of patients with cancer, but it remains underdiagnosed and undertreated. Lack of documented assessment is one of the reasons why this occurs.
Objective: To determine the frequency and correlates of insomnia assessment by palliative care (PC) physicians at the initial consultation.
Methods: We reviewed 48 medical records at first consultation in a PC clinic during April-July 2005. We compared two groups. Group 1: patients with insomnia registration in medical history (difficulties to fall asleep, maintaining sleep, early morning awakening and/or nonrestorative sleep). Group 2: without insomnia registration. We also assessed insomnia as a symptom with the ESAS.
Results: 30/48 (63%) patients were from Group1 and 18/48 (37%) from Group2. 90% were assessed through the ESAS. All had advanced disease. 46% had sleep difficulties. Mean age (SD) 62 (13,58) 66 (13) p = 0,87. ECOG 1–2 en 21 vs 6 y 3–4 en 9 vs 12(p = 0.019). Table 1 Difference in ESAS Group 1 (n = 29) Group 2 (n = 14) Pain 7 (5–8) 8 (5–9) p = 0,79 Fatigue 5 (2–7) 8 (7–9) p = 0,008 Nausea 0 (0–0) 0 (0–5) p = 0,1 Depression 5 (0–8) 3,5 (0–7) p = 0,67 Anxiety 5 (0–8) 5 (3–7) p = 0,77 Drowsisness 0 (0–5) 2 (0–6) p = 0,43 Lack of appetite 5 (0–6) 5 (3–6) p = 0,78 Dyspnea 0 (0–3) 0 (0–5) p = 0,59 Insomnia 3 (0–8) 0 (0–4) p = 0,1 Well Being 6 (4–8) 6,5 (5–8) p = 0,47 Results were expressed by median (Q25–Q75).
Conclusion: We consider the 63% reading of patients with insomnia as acceptable, taking into account that the unregistered group, showed worst PS, greater level of pain, fatigue and delirium, and lower level of insomnia. More severely symptomatic patients are less likely to undergo insomnia assessment. Because of its high frequency insomnia should be routinely assessed in all patients undergoing a first PC consultation.

Abstract number: 494
Presentation type: Poster
Session: Symptoms

Do cancer patients' expectations of complementary therapies match changes in quality of life, symptoms and functioning? A questionnaire survey

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Background: Some one third of cancer patients use complementary therapies (CTs) during their illness. Understanding whether their expectations of benefits yielded by CTs are actually achieved is therefore important.
Aim: To explore patients' pre-therapy expectations of CTs and compare these with pre to post therapy changes in quality of life, symptoms and functioning.
Methods: Questionnaire survey of cancer patients using CTs at three centres in North West England (two community based and one in an acute care setting). Patients' pre-therapy expectations of CTs were explored. Quality of life (QoL), symptoms and functioning were assessed pre and post therapy using the EORTC and HADS.
Results: Data reported here are for all three centres combined. 107 patients returned both pre and post therapy questionnaires (mean age 54 yrs, SD 11.3; 88 female). Pre therapy, the main issues/symptoms that patients considered amenable to CT were relaxation 98 (91.6%), general well-being 88 (82.2%), anxiety 88 (82.2%), stress 87 (81.3%), emotional well-being 80 (74.8%) and muscle aches/tension 75 (70.1%). HADS data showed pre-post therapy reductions in anxiety (p = 0.01) and depression (p = 0.002). EORTC data showed no statistically significant pre-post CT changes in overall QoL, physical, cognitive, social or role functioning, but significant changes in emotional functioning (p = 0.002). 78.5% (N = 84) reported that CT helped them with the issue/symptom they most hoped it would, with 86.9% (N = 93) stating that it met or exceeded expectations.
Conclusions: Patients' expectations of benefits from CTs focused primarily on psycho-social issues and these areas showed greatest improvement pre-post CT. The data suggest a good match between patients' expectations of CTs and the benefits yielded. These data could help to better identify the potential contribution of CTs in cancer supportive and palliative care.

Abstract number: 495
Presentation type: Poster
Session: Symptoms

Palliative care and palliative chemotherapy

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Introduction: The PC Service of Trento (Italy) is an autonomous Operative Unit (OU) of the District. We provide for home assistance and care per year approximately 300 patients (pts) suffering from oncological pathologies that cannot be cured (more that 50% of oncological related deaths in the district). The hospital oncology OU has treated in different moments approximately 75% of these pts, and has kept on treating 43% of them during the palliative phase in 2005. Pts that continue to be under the care of an oncologist, continue treatment for their disease, with consequences that are difficult to evaluate about the following aspects: 1) physical 2) psychological, 3) economical.

Purpose: in this perspective study, we gathered data regarding patients that were assisted by the PC OU and deceased during 2005, with the aim of evaluating the number of pts that continued ct and up to which point ct was continued in the palliative phase. The study also evaluates if there were any significant differences regarding the symptomatology in the last days of life or in the way in which death occurred between pts that were treated with ct or not.

Materials: Data gathered 194 pts. Gender was male56% and female 44%; median age was 76 (range 30–94), with a difference between the treated with ct or not (64 vs 76). Ct treated: 38%. Lifespan after the last ct: 1–7 day 9%, 8–21 day 16%, 22–60 day 19%. Presence of illnesses or ailments in the last 5 days in ct treated vs not: anxiety 43% vs 33%; pain 57% vs 50%. There were no significant differences in the necessity of sedation, but significant differences in the death place between ct or not (at home: 67% vs 82,5%; at hospital 19% vs 10% at hospice 14% vs 7,5%).

Results: Leaving out the economic and psychological aspects, which we didn't analyse, our study didn't evidence any advantage for the patient treated with ct in the last life days.

Abstract number: 496
Presentation type: Poster
Session: Symptoms

Quality of life of cancer patients during the last year prior to death: A prospective study

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When cancer has advanced to a stage in which cure becomes very unlikely, quality of life becomes an important goal of treatment. We studied the quality of life of cancer patients during the last year prior to death. We followed 128 patients with incurable lung, breast, ovarian, colorectal, or prostate cancer. Every three months, patients filled out a questionnaire about their quality of life (EORTC-QLQ-C30). We used data about functioning and symptoms of 99 patients who had filled out one or more questionnaires in the year prior to death. During the last year of life, quality of life deteriorated gradually, that is a decline in functioning on various domains was going together with increasing scores on symptom scales. This deterioration in quality of life was most outspoken in the last months of life. Our data give no indication of differences between various types of cancer, except that dyspnoea was typical for lung cancer. Patient characteristics did not seem to determine the quality of life in the last months prior to death. Quality of life scores in these last months were strongly related to quality of life scores at the previous measurement. We conclude that a gradual decrease of quality of life during the last year of life with acceleration in the last months is typical for patients with these different types of cancer.

Abstract number: 497
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Session: Symptoms

Symptom burden and quality of life impairment in advanced cancer patients

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Patients with advanced cancer experience impaired quality of life (QoL) due to variety of symptoms acting together. Understanding of symptom interference with a patient's QoL provides the basis for better cancer outcome measurement. The goal of this research was to study symptom burden in advanced cancer patients with different grades of QoL impairment. A total of 250 advanced cancer patients (mean age 57.4 (SD 14.5); male/female 66/184) with different malignancies were accrued. SF 36 and M.D. Anderson Symptom Inventory were used for patient reported outcomes assessment. The grades of QoL impairment were determined by the Integral QoL Index calculated for each patient by the method of Integral Profiles. As a result, the distribution of patients by the grades of QoL impairment was different across the disease groups. Most of the patients who exhibited no QoL impairment (no decrease as compared with population norm, PN) were observed in breast cancer (23%), followed by lymphoma (21%), gastrointestinal (11%), and gynecological (8%) cancer. Only 4% in myeloma group had no QoL impairment while the largest proportion of myeloma patients (76%) had critical QoL impairment (>75% decrease as compared to PN). The number of patients who experienced 5 or more moderate-to-severe symptoms simultaneously differed significantly between the malignancies (chi-square = 20,11; df = 8, p < 0,009). The smallest proportion of patients with moderate-to-severe symptoms was seen in breast cancer patients (61%), followed by lymphoma (64%), gastrointestinal (70,5%), and gynecological (74%) groups. The greatest number of patients (90%) with moderate-to-severe symptoms was observed for myeloma. In conclusion, our findings demonstrate heterogeneity of advanced cancer population in terms of QoL impairment. Each malignancy in advanced stage is characterized by unique combination of symptoms differing in their severity, number and, thus, in their impact on QoL.

Abstract number: 498
Presentation type: Poster
Session: Symptoms

The Development of Standards and Guidelines for the Mangement of Seizures

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Introduction: Seizures are an unfortunate complication of primary or secondary brain tumours and can have a significant impact on the patient's quality of life. Anti-epileptic drugs can successfully prevent the occurrence of seizures, but there is a paucity of information relating to use of this class of drug in cancer patients.

Objectives: 1) To review the current management of seizures in patients with primary or secondary brain tumours by palliative care specialists 2) To develop standards and guidelines for the use of anti-epileptics in the palliative care setting.

Method: In order to ascertain the current management of seizures, this retrospective study examined the management of cerebral malignancies that presented to a district general hospital in addition to investigating the use of anti-epileptic drugs within a hospice in-patient unit. Over a twenty month period, the investigators completed a proforma for each patient with a diagnosis of either a primary or secondary brain tumour. The proforma recorded patient demographics and pharmacological therapy.

Results: Proformas were completed for 21 (hospice) and 15 (hospital) patients respectively. Half of the patient population (50%) presented with primary tumours. There was wide variation in the drugs used to treat seizures, with no standard regimen being evident. There was little consideration for drug interactions and inadequate knowledge of potential side effects.

Conclusion: This study, along with a review of the literature, has led to the development of standards and guidelines for the management of seizures which have been disseminated across the network.

Abstract number: 499
Presentation type: Poster
Session: Symptoms

Palliative symptom control in an acute hospital: How do ward staff manage nausea and vomiting?

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Aim: To evaluate management of nausea and vomiting in palliative care patients at first referral to the Hospital Palliative Care Team (HPCT) using established regional guidelines as a benchmark.
Method: 100 consecutive referrals to the HPCT were audited prospectively. The investigator obtained information from the HPCT about the assessment, the severity of nausea/vomiting, any investigations carried out and antiemetic prescribing by the ward staff. Management by ward staff was compared with recommendations in the Lothian Palliative Care Guidelines and the HPCT assessment. Variances from the Guidelines were noted and reasons for these elicited. Barriers to improving generic palliative care through use of guidelines were explored by interviewing twelve ward staff from a wide range of disciplines. Minitab and NVivo software aided data analysis.
Results: These symptoms were identified in 36 patients. Poor assessment by the ward staff led to not detecting the symptoms in 11% and failing to elicit the cause in 53%. Prescribing problems included no regular or inappropriate antiemetics in 81%, inappropriate route of administration for regular and as required antiemetics (39%, 58%), and illogical antiemetic combinations in 22%. Complete resolution of nausea and vomiting occurred in 66% and 85% of cases within three days of assessment by the HPCT, with a significant reduction in severity scores (Wilcoxon Signed rank test $p = 0.000$ for nausea and $p = 0.023$ for vomiting). Despite having the Guidelines available, ignorance about them amongst new staff, and ready access to the HPCT for specific advice emerged as factors inhibiting their use.
Conclusion: Evidence informed guidelines are being used increasingly as a method of improving management of palliative care problems by generalists but need to be supported by proactive education. Palliative pain management has been emphasised, but other distressing symptoms deserve more attention.

Abstract number: 500
Presentation type: Poster
Session: Symptoms

Non-invasive ventilation (NIV) reduces dyspnea in end-stage solid cancer patients with Acute Respiratory Failure (ARF)

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In a pilot study performed in a selected group of patients with (ARF) and end-stage solid cancer, we have previously shown that NIV have a success rate of about 55% (Cuomo et al Palliative Medicine 2004;18:602–10). In the present study we have applied NIV in 32 consecutive patients with solid tumor needing only palliative care (16 lung, 5 stomach, 4 breast, 3 gut, 2 bladder, 1 head and neck, 1 melanoma) undergoing an episod of ARF due to a potential reversibile cause (13 COPD exacerbations, 9 pneumonia 7 cardiogenic pulmonary edema 3 pulmonary embolism) with the aim to verify in a "real life situation": 1) the tolerance to ventilation 2) the changes in dyspnea score and 3) short and long-term surivival. 8/32 patients (25%) did not tolerate NIV and were therefore excluded from further statistical analysis. After 1 hour of NIV dyspnea score, measured with the Borg scale, significantly improved from $6.2+1.6$ to $2.4+1.1$ ($p<0.05$), while 19/24 of the "tolerant" patients reduced their breathing frequency from $31+12$ b/m a $20+14$ ($p<0.05$). Hospital and 3 months mortalities were 15/32 (47%), and 25/32 (78%), respectively. 10 of the hospital survivals were finally discharged home. In conclusion, despite the tolerance to NIV was lower in end-stage cancer patients than for other pathologies, as previously reported in the Literature (25% vs <15%, respectively), this mode of ventilation was associated with a significant and rapid decrease in dyspnea and respiratory rate in the "tolerant" patients. Hospital and 3 months mortalities were relatively high, considering the potential reversibility of the causes leading to the episode of ARF, but most of the patients were discharged at home. Further randomized controlled studies are mandatory in patients undergoing palliative treatment for end-stage solid cancer, to assess the efficacy of NIV vs oxygen therapy alone, in improving dyspnea score and eventually reducing the need of morphine.

Abstract number: 501
Presentation type: Poster
Session: Symptoms

The influence of fatique on the quality of life in hospice patients

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The purpose of the present investigation was to investigate the influence of age, sex and diagnosis in patients with terminal malignant disease on chronic fatigue and quality of life.
Patients and methods: In the period May 2000 to May 2003 114 patients, 78 females and 36 males, were subjected to a structured interview concerning the influence of fatigue on their quality of life, their coping strategies and their opinion on the importance of various social factors in relation to their relatives. Fifty-two percent had gastrointestinal or pulmonary cancer, 11 percent gynaecological cancer. Fatigue was defined according to Piper (1).
Results: No difference in coping strategies was found between patients with cancer in the gastrointestinal tract and the lungs and we could demonstrate no influence of age and sex. In all patients fatigue had a substantial negative influence on the quality of life and statements as "I could cry or scream from my tiredness, and it fills my whole day" were typical. The patients used various methods to cope with their tiredness ranging from small rests with music to long rests with quietness in their room. The interviews showed the importance of a well structured day, planned in corporation with the nurse, and a strict planning of the length of visits from the relatives to minimize the negative effects of fatigue.
Conclusion: We had expected that demographic data and diagnosis had an influence on the patients' experience of fatigue, but the present interviews demonstrated the opposite. Patients admitted to a hospice with terminal cancer are beyond such factors and we stress the importance of the nurses' ability to detect, recognize and individualize the treatment and care in these critically ill patients, preferably in a multidisciplinary regimen.

Reference

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Abstract number: 502
Presentation type: Poster
Session: Symptoms

Chemosensory Changes in Cancer Patients Receiving Chemotherapy

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Background: Few studies have explored patients' experience of chemosensory changes when receiving chemotherapy. Conducted studies found that 46%–77% of the patients undergoing chemotherapy report taste changes and 35%–64% report changes in sense of smell. Issues like what chemosensory changes mean, how they affect the daily life of patients, and how patients respond to chemotherapy- induced chemosensory changes are important to address systematically.
Aim: To explore experiences of chemotherapy-related chemosensory changes among a heterogeneous group of patients with cancer.
Method: The study had a qualitative longitudinal design. Semi-structured interviews were conducted with 14 women and 7 men who reported smell and taste changes to cancer nurses. These participants were followed monthly until chemosensory changes ceased or for up to 6 months. The inductive analysis was inspired by Thorne et al's Interpretive Description.
Results: There was great individual variation in terms of patterns, intensity and impact of smell and/or taste changes. While not all participants found the reported changes 'bothersome', those who did, reported mainly emotional and social consequences. Smell and taste changes were said to be influenced by or influence other symptoms, e.g. appetite, nausea and oral problems. Chemosensory changes were said to impact emotions as well as meals, both nutritionally and socially. While the participants said they lacked

ways to manage the situation, a number of specific coping strategies were described including: more frequent oral hygiene, trying to find food that could be tolerated, relying on smell and taste memory or just accepting the situation.

Conclusions: Smell and taste changes should be addressed in oncology care. The great individual variation in chemosensory changes makes these side-effects especially challenging for nurses to assess and alleviate.

Abstract number: 503
Presentation type: Poster
Session: Symptoms

Fatigue in patients with advanced cancer is not caused by muscle weakness

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Introduction: Fatigue has been described as a multidimensional phenomenon with physical, affective and cognitive features. In a prior study we found that physical functioning was more impaired than motivation and mental functioning in patients with advanced cancer. Because advanced cancer often causes cachexia with subsequent loss of muscle mass, we hypothesized a relationship between muscle strength and physical fatigue but not with motivation and mental functioning.

Methods: 95 patients with advanced cancer were studied within 72 hrs after admission to a specialised palliative care unit. Fatigue was measured with the Multidimensional Fatigue Inventory, a validated questionnaire measuring the dimensions General Fatigue (GF), Physical Fatigue (PF), Reduced Activity (RA), Reduced Motivation (RM) and Mental Fatigue (MF). Using a hand held dynamometer muscle strength was measured in two sets of proximal muscle groups; flexors of the hips and abductors of the shoulders, and one set of distal groups; flexors of the ankles. Values were expressed as percentages of normal.

Results: GF, PH and RA scored almost maximal on a 4–20 scale. Median proximal and distal muscle strength varied between 65 and 83% of normal values. Proximal muscle strength did not correlate with the various fatigue dimensions. Distal muscle strength was only correlated with RA.

Conclusion: In patients with advanced cancer suffering from severe physical fatigue, muscle strength is seriously impaired. Muscle strength is unrelated to physical fatigue, which suggests that patients' experience of physical fatigue and measured muscle strength are different phenomena.

Abstract number: 504
Presentation type: Poster
Session: Symptoms

A systematic review of patients' feelings of being a burden to others at the end of life

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The burden of providing care to a family member at the end of life is well documented in the literature. However, in spite of the fact that caregiving occurs within the context of the caregiver-care recipient relationship, little is known about the care recipient's feelings about creating burden (self-perceived burden), or the consequences of these feelings. Yet recent evidence suggests that feelings of being a burden to loved ones is a significant problem faced by considerable numbers of patients at the end of life. The present study set out to systematically review literature addressing patients' perceptions of burden. Using recognized systematic review methods, databases, journals and the grey literature was searched for information in palliative care and related fields for relevant literature. The review revealed that the vast majority of research was in the literature examining euthanasia/physician-assisted suicide in individuals with advanced disease. Self-perceived burden also emerges as important to outcomes relevant to quality end-of-life care, such as dignity, quality of life, and suffering. Furthermore, concern about burdening others is also a factor that is considered by some individuals when making decisions about place of care at the end of life and treatment decisions. The review heightens awareness of an important existential issue that has been underestimated, and consolidates what is currently known about self-perceived burden. Furthermore, relevant literature and theories from other areas are drawn upon to expound understanding of the construct. In particular, social psychology theories that address imbalances in social interactions, since these may explain how disparity in the caregiving relationship contributes to self-perceived burden. The review serves to direct research aimed at identifying individuals for whom self-perceived burden is a problem and the development of interventions to alleviate the problem.

Abstract number: 505
Presentation type: Poster
Session: Symptoms

Sedation in the imminently dying patient – an observational study in savignano sul rubicone's hospice

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Background: Sedation is a clinically important therapeutic intervention in the imminently dying patients (pts). At the end of life symptoms are progressively more difficult to manage and may become refractory to standard medical therapy.

Method: On May 2004 in Savignano sul Rubicone's Hospice we started an observational study regarding sedation in the last 72 hrs of life of consecutive patients who died in hospice during a year. The parameters of investigation included demographic characteristics, need and indication for using sedatives, patient's or oncologist's request for sedation, state of consciousness and communication abilities during sedation. This study valuated Morphine cloridrathe, Prometazina and Cloropromazina i.v. is the most common medication prescribed to achieve sedation.

Results: Our data show: sedation was given to 51 out of 134 (38%) pts died at the hospice: 33 male, 18 female, median age 68 years old (range 31–91); 14/51 patients received sedatives for more than 72 hours, 4 for < =72, 10 for < =48, 12 for < =24, 3 for < =12, 6 for < =6 hours. The most common of these intractable symptoms are been dyspnoea in 31/51 pts (61%), agitated delirium and confusion in 48 pts (95%), pain in 3 pts (6%), existential and psychological distress in 7 pts (14%). In 7/51 pts "14% sedation was administered continuously. The effectiveness of sedation in relieving refractory symptoms was judged complete in 43 pts (85%), and moderate in 8 pts (15%).

Conclusion: Palliative sedation is an effective symptom control strategy for pts suffering of intractable symptoms at the end of life.

Abstract number: 506
Presentation type: Poster
Session: Symptoms

Comparative views of patients, health care professionals and therapists on complementary therapies within cancer supportive and palliative care

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Background: Use of complementary therapies (CTs) in cancer supportive and palliative care continues to increase, highlighting the need to understand why this is the case Aim To explore attitudes towards and expectations of CTs from the perspective of patients (pts), health care professionals (HCP) who refer to CTs and complementary therapists.

Methods: Questionnaire survey across three CT services in North West England exploring patients' (pre-therapy, n = 280), HCPs' (n = 1255) and therapists' (n = 72) perceptions and expectations of CTs.
Results: 171 (61%) of patients (mean age 55), 292 (23%) of HCPs and 51 (71%) of therapists completed questionnaires. 70% of patients (n = 114) and 76% of HCPs (n = 222) regarded CTs as 'something extra'. However 61% of therapists (n = 30) regarded CTs as 'integral' to care. Overall attitudes to CTs (scale 1–5) were comparable in patients and HCPs with more committed than uncommitted (pts = 3.9/5, HCP = 3.6), accepting than sceptical (pts = 3.9, HCP = 3.7), curious than indifferent (pts = 4.2, HCP = 3.9) and positive than negative (pts = 4.2, HCP = 4.0). The patients five main expectations of CTs were improved general (89%), emotional (82%) and physical (74%) well-being, a pleasant experience (83%) and enhanced coping (81%). HCPs expected improved emotional (92%) and general (91%) well-being, reduced symptoms (90%), enhanced coping (87%) and 'always wanted to try one' (82%). Therapists expected enhanced coping (98%), pleasant experience (88%), reduced symptoms (88%) and improved emotional (90%), general (86%) and physical (86%) well-being.
Conclusions: Patient and HCP views on the role of CTs and their overall attitudes towards CTs contrasted in some respects with those of therapists. Patients and HCPs shared emphasis in their expectations of improved well-being, whilst therapists considered that CTs benefited a wider range of issues. Work to facilitate the harmonisation of perspectives is needed, to inform the delivery of future services.

Abstract number: 507
Presentation type: Poster
Session: Symptoms

Home based palliative care evaluating a community complementary therapy service

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Aim: To evaluate a community complementary therapy (CT) service, delivered to patients with identified palliative care needs in their own homes.
Background: CT's are increasingly seen as integral to palliative care, claiming to offer a range of benefits including improvements in symptom control and quality of life (QoL). A hospice community CT service was initiated to provide one form of palliative care to under represented groups (e.g. black and minority ethnic communities) living within an area of social deprivation in Manchester, UK. However, there is currently a lack of evidence to support the application of CT's within this context. Methods Postal questionnaire survey of patients in receipt of CT's (aromatherapy, massage, reflexology) assessing expectations from and perceived improvements in symptoms/issues and QoL, together with attitudes towards and satisfaction with a home based service.
Results: 104 patients were referred for CT (mean age 63 (31 to 90), female:male 2:1, ethnicity 41% from BME groups. 83 (80%) patients received at least one CT (mean 5.2, 1–10). 25 (30%) patients returned completed questionnaires. All patients perceived at least one of their symptoms/issues to have improved after CT. 22 (88%) of patients also perceived improvements in their overall QoL (mean 2.94, scale 1–5). None of the patients (except one) would have wished to receive their therapy at the hospice. 62–71% of patients also felt that it would be difficult physically to attend and to travel to the hospice, and that they would feel safer at home.
Conclusions: Patients perceived that their CT had improved both a range of symptoms and overall QoL. Findings also suggest that delivering a home based service is targeting a hard to reach palliative care patient population who may otherwise not access such services. Further research is required to inform the development of appropriate and equitable services for such patient populations.

Abstract number: 508
Presentation type: Poster
Session: Symptoms

The edmonton symptom assessment system as a screening tool for depression and anxiety

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Purpose: Mood disorders are among the most important psychiatric problems in patients with cancer. However, they are frequently underdiagnosed and therefore under-treated. This may lead to difficulties with symptom control, social withdrawal and poor quality of life. This study was conducted to evaluate the screening performance of the Edmonton Symptom Assessment System for depression and anxiety, as compared to Hospital Anxiety and Depression Scale.
Methods: We retrospectively reviewed and analyzed ESAS and HADS data, which were collected from previous three clinical trials conducted by our group. The diagnosis of mild, moderate and severe depression and anxiety were made when patients presented a score of 8–10, 11–14 and 15–21 in the HADS questionnaire for anxiety and/or depression, respectively. The sensitivity, specificity, positive and negative predictive values for ESAS were calculated.
Results: ESAS and HADS data from 216 patients were analyzed. The median (range) score for depression was 2 (0–10) and anxiety 3 (0–10) using ESAS, and 6 (0–16) and 7 (0–19) using HADS, respectively. A cut off of greater than or equal to 2/10 and greater than or equal to 4/10 in the ESAS gave a sensitivity of 77% and 83% with a specificity of 55% and 47% for depression and moderate/severe depression, respectively. A cut off of greater than or equal to 2/10 and greater than or equal to 4/10 in the ESAS gave a sensitivity of 86% and 97%, and a specificity of 56% and 43% for anxiety and moderate/severe anxiety, respectively.
Conclusion: The ideal cut-off intensity of ESAS for the screening of depression and anxiety in palliative care is greater than or equal to 2/10. More research is needed to define ideal cut-off point for screening depression and anxiety.

Abstract number: 509
Presentation type: Poster
Session: Symptoms

Comparison of effectiveness of decongestive lymphatic therapy in breast cancer patients with and without prior lymphedema treatment

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Objective: Upper extremity lymphedema can occur in approximately 12–25% of breast cancer patients post treatment. Decongestive lymphatic therapy (DLT) is a conservative and effective treatment, but it is not clear whether DLT will be effective in those patients who had previous treatment for lymphedema. We compared the effectiveness of DLT in breast cancer patients who had prior lymphedema treatment to those who did not.
Methods: After IRB approval, we retrospectively reviewed the charts of 95 patients who received DLT for postmastectomy lymphedema at The UTMD Anderson Cancer Center in Houston, Texas. The DLT were performed by licensed physical therapists that were certified in lymphedema treatment. An optoelectronic limb volumeter was used to measure limb volume. We excluded patients with bilateral upper extremity lymphedema and patients whose affected upper extremity was not more than 150 cc larger than the unaffected extremity at baseline. We compared the percentages of volume reduction, age, gender, number of axillary nodes dissected, and radiation therapy in the two groups by using Student's T-test, the chi-square test or the Fisher exact test.
Results: Among the 47 patients included in our study, 33 patients (33/47, 70%) received postoperative radiation. Of a total of 47 patients in our study, 28 (60%) did have any prior treatment (group 1), whereas 19 patients (40%) had received DLT or compression sleeve previously (group 2). Age, number

of axillary nodes dissected, radiation therapy, the number of DLT sessions were not significantly different between the two groups ($p = 0.49$, 0.91, 0.88, and 0.55 respectively). The mean arm volume reduction is 17% in those patients who did not have previous DLT, while 19% for those who previously had DLT or compression sleeve ($p = 0.8$). The majority of patients completed 12 treatment sessions.

Conclusions: DLT can lead to reduction in limb volume, even in patients who had prior treatment for arm lymphedema.

Abstract number: 510
Presentation type: Poster
Session: Symptoms

Massage: An advantage for the patient?

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Introduction: In palliative care and pain management, the care teams are faced to patients who suffer, but express more or less their needs. We, a group of nurses from the pain and palliative care consultation teams of the University Hospital of Geneva (HUG), developed in collaboration with the care units a new approach through massages after individual training. This care is described in literature as being pleasant and soothing. Aim of our study was to describe real advantages for the patient.

Methods: First we reviewed the literature that broached the concept of palliative care and Toucher-Massage®. Second we completed for each patient an evaluation chart and a data basis of the massages during the years 2003 and 2004.

Results: Approach through massages reduced in 94 patients a bothering symptom to a tolerable level by leading to more relaxation and well-being: 44% anxiety, 17% pain, 5% lack of breath, 20% changing in well-being. Four patients refused massage after the first session. The duration of treatment was adapted to the patient's need with a mean time of 20 minutes spent per session. The main body parts massaged were the feet (26%), the legs (19%), the back (17%), and the hands (16%). The sort of body contact brings about a relational enrichment, increases the quality of care and allows the communication and the expression of emotions related to a severe disease. Sometimes it's more soothing than any words could be. Conclusions, perspectives The massage is a complementary and positive approach, ready to hand, which reassures and relieves the patients. It's also a first step to communication. This work allowed us to confirm that this kind of massage is a privileged tool to be used in the setting of pain and palliative care. It's also a part of the independent role of a nurse. The development of this approach by body contact represents an advantage for the whole care team. It allows to rethink and to improve the nursing.

Abstract number: 511
Presentation type: Poster
Session: Symptoms

The clinical use of gabapentin and pregabalin in palliative care

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Background: Gabapentin has been introduced as an adjuvant drug for neuropathic pain in non-cancer patients, but its use has spread to patients with cancer-related pain.

Aims: The aims were to study the clinical use of gabapentin and pregabalin in everyday palliative care.

Material and method: PANIS, the palliative care research network in Sweden, was established in 2002 aiming at a national coverage. In total, 42 units participated in the survey during October 2005. Data were reported through an internet-based tool, which enabled the physician in charge to respond to 27 specified items regarding the patients.

Results: (preliminary results-about 60 patients remains to be analyzed) 1537 patients were recruited (83% in an advanced home-care programs), of which 90% had a cancer diagnosis. Mean age was 68 years, 55% were female. In total, 104 (7%) were on gabapentin ($n = 78$) or pregabalin ($n = 26$) medication, in 85% the indication was a neuropathic pain component. The mean daily doses were 975 mg for gabapentin and 200 mg for pregabalin. An effect on pain was seen in 67% of the treated patients, of which 29% were perceived as "moderate" and 38% as "good", by the respective physician in charge. In the remaining cases the effect was poor or not possible to distinguish (in multi-modality treatment situations). The reported frequency of side-effects was low: distinct side-effects (tiredness, vertigo, other neurological side-effects) were accounted for only in 13% of the patients. 97% were on opioids, 28% on NSAIDs, 49% on steroids and 18% on tricyclic anti-depressants, as concomitant medications.

Discussion: The large number of patients ($n = 1537$) recruited via a web-based survey generator, enables descriptive studies of less frequent issues. The drawback in its current design is that effects and side-effects are estimated by the physician, not the patients, which may result in both under- and overestimations. Still, it gives a picture of the present clinical situation.

Abstract number: 512
Presentation type: Poster
Session: Symptoms

Oral health in palliative care and cancer

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Background: Patients with cancer are at high risk of oral ill-health, which can bring great physical, psychological and social distress. Despite this oral care is often suboptimal.

Aims: This study was undertaken to assess the quality of oral care provided to palliative care patients and to promote best practice in palliative care professionals within a palliative care network of 2.3 million people in the northwest of England. Method Hospice, hospital or community-based palliative care professionals prospectively completed a questionnaire for new patients seen over a three month period. Patients who had chemo/radiotherapy within four weeks and those in the dying phase were excluded.

Results: Data for 139 patients was collected 93% had initial oral examination, 81% received basic oral care at least daily and 50% of those with dentures ($n = 30$) received denture care twice daily 53% had xerostomia, which was present most or all of the time in 77% and 54% had two or more of dysgeusia, dysarthria, dysphagia, or difficulty chewing 47% were prescribed three or more xerostomic drugs, primarily opioids, steroids, PPIs and NSAIDs 58% used water. The new treatment most prescribed was saliva orthana (35%). Overall treatment success was 36%, partially in 45% and unsuccessful in 7%, 34% had oral candidosis, causing two or more symptoms in 60%. 83% received nystatin or fluconazole 70% had a full or partial clinical response to treatment. Only 17% had a mouth swab taken for C&S 9% had oral cavity ulceration and 10% a sore mouth. Mouth washes, Gelclair, systemic and topical opioids and other treatments were prescribed. 75% of these patients had a full or partial response.

Conclusions: Oral ill-health, causing multiple problems is common in palliative care patients with cancer. Correct diagnosis and management of oral ill-health can provide significant clinical improvement. Further therapeutic options need to be developed for refractory patients.

Abstract number: 513
Presentation type: Poster
Session: Symptoms

Fatigue and laboratory parameters

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Fatigue is one of the most frequent symptoms impairing the quality of life of palliative care patients. Anaemia, hypothyreosis, vitamin deficits, infections as well as cachexia or high cytokine load may cause fatigue. We evaluated retrospectively the relationship of laboratory parameters and self-assessment of sedation and weakness. In the Department of Palliative Medicine laboratory parameters were assessed for 209 patients. Detailed fatigue laboratory parameters were assessed for 21 patients (FL). Patients assessed fatigue with 4-step categorical scales for sedation and weakness in a symptom checklist. Patients with less than slight intensity (NO) were compared to patients with more than moderate (HI) intensity. Hypoproteinaemia was seen in 65% of patients, low haemoglobin in 75% and high leucocytes in 45%. In the FL-patients Erythropoetin was low only in one patient (5%), but elevated in 47% of patients. IL-6 was high in 95%, TNF-a in 62%. Vitamin B6 was reduced in 35% of patients. Patients in the HI-weakness group ($n = 41$) scored lower serum protein concentration, transferrin levels and FT4 as well as higher CRP concentrations and leucocytes compared to the NO-weakness group ($n = 73$). Patients in the HI-sedation group ($n = 44$) scored lower serum protein concentrations and higher CRF concentration than the NO-sedation group ($n = 60$). Haemoglobin, sodium, potassium and calcium did not show any differences between groups. Difference for Erythropoetin, ACTH and Cortisol, FT3 and TSH, IL6 and TNF- a as well as vitamin B1, B6 and B12 did not reach significance due to small patient numbers in the FL-group. In a retrospective review on the laboratory findings we found only general markers of progressive cancer disease such as hypoalbuminaemia and high CRF as significant factors related to sedation and weakness. Investigation of specific fatigue laboratory parameters should be repeated with a higher number of patients.

Abstract number: 514
Presentation type: Poster
Session: Symptoms

Affect of eating disorders on quality of life of patients with advanced cancer

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Objectives: To study the affect of nutritional problems (NP) linked to advance Ca, on patients'(pt's) quality of life (QOL). Aim: To explore the interactions between eating difficulties and demographic, health, emotional, physical, social, and cognitive factors, and to examine the impact of this whole complex on QOL.

Sampling & Methodology: 61 advanced Ca. Pts of both genders were interviewed in their mother tongue, using 2 questionnaires: Nutritional, QOL.

Statistical analysis: It consisted mainly of descriptive statistics, including%, means and SDs, as well as indices of association including correlations and non-parametric statistics (Chi Square).

Results: A reduction in QOL was an outcome of the NP that the Pts suffered as a consequence of progressive Ca. When total QOL was examined against demographic indices, gender appeared to be an important factor. Women deal with NP better than men, particularly men with GI Ca. The most pronounced effect on total QOL was due to a complex of eating difficulties, including unsavioury sensations, quality of food & stage of disease, resulting in neg emotions& influence on self control. Eating difficulties & pain were correlated significantly ($p < 0.001$). Health worries were considerably affected by nausea, while pos emotions by various types of eating disorders ($p < 0.01$). In addition we found that vomiting had a direct effect on self control & neg. emotions; vomiting & nausea neg affected the relationships within the family & reduced pos. emotions. Links are shown to be were found between normal eating features, self control & positive emotions.

Conclusions: The majority of advanced Ca Pts suffer from NP, which neg affects QOL. Correcting NP is effective in improving QOL of advanced Ca. Pts. Early attention should be given to NP in order to maintain Pt wellbeing.

Abstract number: 515
Presentation type: Poster
Session: Symptoms

Long-acting release octreotide may have a role in the treatment of malignant bowel obstruction

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Introduction: Malignant bowel obstruction (MBO) is a complication in advanced abdominal or pelvic cancer. Management is challenging and controversial. Nasogastric tube (NGT) often represents the better and only treatment.

Methods: From February to September 2005, twelve neoplastic pts with documented MBO, entered the study and received long-acting octreotide 20 mg by i.m. injection. We recorded the volume of gastric drainage in the presence of NGT before administration of octreotide (T0), one day after (T1), two days after (T2), three days after (T3), four days after (T4), five days after (T5), eight days after (T8), and one day before death (TE). In pts without NGT, we recorded episodes of vomiting and severity of nausea according to NCI CTC criteria version 2.0. We also monitored side effects potentially related to octreotide LAR.

Results: Octreotide LAR was administered after the failure of a more conventional treatment. In eight pts with NGT, octreotide LAR was able to reduce early and consistently the secretions, with volumes of NTG secretions maintained constant until patient's death. In one patient, it was possible to remove the NGT after three days from T0. Administration of octreotide LAR also reduced episodes of vomit and severity of nausea in all four pts evaluated for these symptoms: the better control of emesis was maintained during days. The only relevant toxicity observed in two patient few hours later the injection of octreotide LAR was an increased abdominal pain eliminated by an i.m. injection of NSAI.

Discussion: The combination of agents with different mechanisms may have a synergistic effect in controlling symptoms of MBO. The LAR formulation of octreotide may represent an excellent partner of more consolidated drugs. The potential activity of octreotide LAR in controlling MBO symptoms deserves more studies, as the comfortable schedule of LAR formulation could confirm the role of octreotide in combination for medical treatment of MBO.

Abstract number: 516
Presentation type: Poster
Session: Symptoms

Nursing responses to the psychosocial needs of palliative patients: An ethnographic study of a hospice ward

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Aims: Psychosocial support is considered an essential element of everyday palliative care. However, there is little evidence about how this concept is operationalised. This study examines practice on one hospice ward, and is the first to explore empirically: how nurses respond to patients' psychosocial needs; what sense patients make of these responses; why variations occur in psychosocial nursing; and whether, and how, nurses record and report their psychosocial care.

Methodology: Data was collected by observing nursing practice (including multidisciplinary meetings); interviewing patients and nurses about observed interactions (taking into account the other interviewee's responses); and documentary analysis. Triangulating the data sustains a case study approach whereby all aspects of care are analysed in relation to each other, and in relation to organisational constraints.

Analysis: 39 cases, recorded over a 6-month period, are being analysed. Analysis is both within and between cases, following an ethnographic text approach, using NVivo software, and qualitative comparative analysis

(QCA). Analysis has been ongoing since the commencement of data collection, and takes into account the researcher's impact (as a participant observer) on the field of study.
Results: Analysis so far has shown that nurses' responses to patients' psychosocial needs can be assigned to four categories: dealing with the need; adjusting the need to something the nurse feels comfortable dealing with; deferring dealing with the need; and failing to acknowledge the need. The comparative analysis, which is underway, will determine what factors are associated with these responses, and what leads to increased patient satisfaction.
Conclusions: Understanding the nursing repertoire in palliative care, and the contextual factors associated with different ways of responding to psychosocial need will, enable palliative care practitioners to provide more effective support for their patients.

Abstract number: 517
Presentation type: Poster
Session: Symptoms

Constipation measurement & palliative care patients' views on management

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Background: Constipation may cause more distress than uncontrolled pain in patients with terminal disease and is common in palliative care patients. There is no objective validated constipation assessment tool. Bowel scores calculated from frequency and consistency of stool have been reported but little data exists on patient preference in constipation management.
Aims: To determine the proportion of palliative care patients taking laxatives who feel constipated – To compare subjective constipation with two objective bowel scores – To identify patient preferences regarding treatment – To explore side effects of treatment.
Method: A convenience sample of palliative care in- or out-patients were invited to complete a questionnaire: Generic questions about bowel habit, treatment preferences and 2 different bowel score calculations ('3 day' and '7 day') – Specific questions about patients' current treatment (form, taste, effect, side effects) Results were analysed using SPSS V12.
Results: 44 questionnaires were completed – Bowel habit 23% of patients felt they were constipated objective incidence of constipation was 23% (3-day score) and 45% (7-day score) – Feelings of constipation the strongest correlation with feeling constipated was ease of passing stool consistency and frequency of motions were not significantly correlated with feelings of constipation – Medication preference most patients did not mind taking laxatives (64%) and preferred a once-daily dosing regime (82%) – Rectal intervention no patients liked rectal interventions, 46% of patients didn't mind having suppositories and 39% didn't mind enemas – Side effects were rated as either none (58%) or few (33%) commonest side effects were flatulence (29%) and loose motions (27%)
Conclusions: Ease of passing stool is most important to patients – Side effects and patient preference may be more important to patients than effectiveness.

Abstract number: 518
Presentation type: Poster
Session: Symptoms

Characteristics and frequency of antimicrobial therapy on a palliative care unit

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The incidence of infection in terminally ill patients is between 40–55%. Despite the lack of guidelines and outcome criteria, antibiotics given empirically are amongst the most frequently used agents in palliative care. We conducted a retrospective analysis of the frequency of infections and the use of antibiotics on a palliative care unit during two years. Of 366 patients treated on the palliative care unit in the years 2003 and 2004, 169 (46,2%) were treated with antimicrobial agents 95.8% of these patients had a malignant disease and approximately 50% had an estimated and revealed life expectancy of a few weeks. As the presumed focus of infection, the urinary and the respiratory tract was clinically identified in one third of the patients each, others were abdominal, skin and catheter associated infections. In 92 patients (54.4%) antibiotic treatment resulted in clinical response, symptom control or improvement of laboratory parameters indicating acute infection. 42% of all inpatients treated with antibiotics died on the palliative care unit despite successful anti-infective therapy in 45.1% of these patients. The most frequently administered antibiotics were quinolones (53%) and beta-lactam antibiotics (40.2%). Main application route was parenteral (61.6%), in 26.7% of these patients antimicrobial treatment was switched to oral. Overall, we observed a clinical benefit from antimicrobial therapy in half of the patients, 50% of whom were assessed to achieve a possible life-prolonging effect due to antimicrobial treatment. However, almost half of the patients were treated without reaching the aim of palliation or life prolonging. This resulted in additional treatment burden and increased expenses. Prospective studies are required to identify patient characteristics and clinical parameters facilitating treatment decisions in terminally ill patients regarding antimicrobial treatment at the end of life.

Abstract number: 519
Presentation type: Poster
Session: Symptoms

Pre-emptive breath-therapy in combination with relaxation therapy at terminally-ill oncologic patients in a hospice

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Introduction: During the last six weeks, 70% of the terminally-ill oncologic patients are suffering from respiratory problems. To prepare patients and caregivers to cope with the symptom dyspnoea, a standardized learning program was developed. The purpose of the study was to evaluate the efficacy of this program.
Method: In a hospice 68 patients and their caregivers followed an instruction program by the physiotherapist concerning breath therapy, relaxation therapy and specific individualized measures. The incidence of respiratory problems was registered and compared to the incidence figures mentioned in literature.
Results and conclusions: The incidence dyspnoea and other respiratory problems during the last days of life amounted 53,8%. The reported incidence in literature of these symptoms was 70%. Pre-emptive breath therapy may result in an increased quality of life by better breathing and energy consumption.

Abstract number: 520
Presentation type: Poster
Session: Symptoms

Sleep disturbance (SD) is reported by patients with cancer and their carers, but there have been few attempts to systematically investigate the problem

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Aims: To determine the prevalence of SD in a cohort of patients with advanced cancer and their carers.
Methodology: Open study in a random sample of patients with advanced cancer attending a cancer centre in the UK. Objective &

subjective measures of sleep were undertaken in patients/carers over a seven day period. Patients/carers were each fitted with an 'Actiwatch', a validated device to provide a measure of sleep efficiency and daytime sleepiness. Validated tools were completed for physical & psychological symptoms.

Results: 49 patients and carers have completed the study.48% of patients and 45% of carers reported that they did not sleep well Of patients who reported this, 39% stated they had SD prior to their cancer diagnosis, 11% felt SD was related to their cancer and 39% reported a combination of both. Of carers who reported poor sleep, 27% stated they had SD prior to the patients cancer diagnosis, 33% felt SD was related to the patient cancer diagnosis and 27% reported a combination of both. Actigraphs revealed $<90\%$ sleep efficiency in 39% of the patients (12/24 that reported SD, 7/25 that did not report SD) and 41% of the carers (8/22 that reported SD,12/29 that did not report SD). Patients had significantly more daytime naps than their carers ($p<0.05$). Epworth sleepiness scores were significantly higher in patients than carers ($p<0.001$). Patients/carers that subjectively reported SD compared to patients/carers that did not report SD, had significantly higher HAD anxiety scores ($p<0.001$ & $p<0.05$).

Conclusion: Objective assessment demonstrated that sleep problems are common in patients and carers, but did not necessarily correlate with patient/carer subjective assessment. In patients/carers that report SD, we should have a high index of suspicion for anxiety, which may be playing a significant role and should be addressed

Abstract number: 521
Presentation type: Poster
Session: Symptoms

A double-blind, randomized, placebo-controlled comparison of subcutaneous hydration with and without human recombinant hyaluronidase

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Background: When parenteral fluid administration is needed, such as for hydration, subcutaneous (SC) infusion has advantages over intravenous (IV). Nevertheless, concerns for flow rate and discomfort limit its

clinical use. Hyaluronidase hydrolyzes the major SC diffusion barrier, hyaluronan. SC Hylenex (recombinant human hyaluronidase) increases local dispersion and absorption. This volunteer, randomized, double-blind, placebo-controlled trial compared the flow rate, tolerability, and safety of SC-administered Lactated Ringer's (LR) Hylenex.

Methods: Fifty-four subjects had 24-gauge angiocatheters placed subcutaneously in both upper arms. Each arm received 1 of 3 doses of Hylenex or equal volume saline placebo. Immediately, 400 mL LR was gravity-infused from a 100 cm height. In a pilot phase of the study, 5 subjects also received an IV infusion under similar conditions. Flow rates, tolerability, and safety were assessed.

Results: Hylenex significantly reduced edema and edema recovery time. Both infusions caused only mild discomfort, but Hylenex significantly reduced discomfort while achieving faster flow rates. 92% of subjects and clinicians globally preferred Hylenex SC infusions. Adverse events were equally distributed. There were no serious adverse events.

Conclusions: Hylenex enhances gravity-driven SC infusion rates ~4-fold. Clinically useful volumes and rates (~500 mL/hr) can be delivered subcutaneously with Hylenex without a pump in a well-tolerated manner. Additionally, since SC catheters are easier to administer and entail less risk of thrombosis and systemic infection than IVs, these observations may support the widespread use of Hylenex-enhanced SC infusions for patients requiring parenteral hydration.

Abstract number: 522
Presentation type: Poster
Session: Symptoms

Healing narratives in people with advanced metastatic cancer

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Identifying mental health problems in people with advanced cancer involves interpreting peoples' accounts of their experiences in light of diagnostic criteria. However narrative medicine approaches suggest we need to focus on how individual narratives not only reveal, but also shape health experiences. Our aim was to investigate whether understanding of individual narratives offers new insights into the management of emotional health problems in patients with terminal cancer.

Methodology: Semi-structured interviews were conducted with a purposive sample of 19 adult patients (8 men) with advanced metastatic cancer identified from Liverpool GP lists. Transcripts were analysed using the phenomenographic method which seeks to explain inter-personal variation in experience.

Results: The impact of illness on a person's narrative of themselves living their lives was intimately associated with emotional health experiences. Three categories of experience were identified. The norm was a continuity of both a narrative and sense of self, associated with emotional wellbeing. Flow was supported by flexibility of understanding of both the self and the world. However maintenance was at times an emotionally draining process. Relief came through emotional release, reflection and the development or maintenance of a shared narrative. Some people experienced a negative disruption of their narrative of self, precipitated by physical and emotional exhaustion as well as isolation and leading to profound emotional disturbance. Healing came through both emotional support and restoration of a shared narrative. The third group described a change in the sense of self as a result of terminal diagnosis which brought a new positive emotional outlook.

Conclusion: This study demonstrates the need to focus on both the narrative and emotional aspects of the self in the support of people with terminal cancer. Future work should focus on the role of health staff in maintaining a shared narrative.

Abstract number: 523
Presentation type: Poster
Session: Symptoms

Palliative cancer patients experiences from a physical exercise program. results from a pilot study

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Background: Physical function (PF) is an important component of quality of life in general and also in palliative patients. In a recent study our group showed that palliative patients are willing and able to participate in group exercise program to maintain PF. There is limited knowledge about how palliative patients experience such programs.

Purpose: To evaluate the patients' subjective experiences and opinions after completion of a six week physical exercise group program tailored to the individual patient's PF. Patient population: 34 palliative cancer patients with life expectancy below one year completed the program.

Methods: Immediately after completion of the program, the patients' experiences was registered by a self-reported questionnaire (SRQ) designed for this study. Additionally five randomly chosen patients were interviewed in a semi-structured open approach 7 months after completion of the physical exercise program.

Findings: From the SRQ most patients (73%) reported extreme satisfaction in attending the program, 77% voiced a preference for group exercise intervention as opposed to individual follow up, 80% wished to continue in

the programme and 55% reported increased energy, physical endurance/muscle strength and relied more on own physical abilities. The five interviewed patients highlighted participation in the group as a commitment and it provided a setting for coping both physically and mentally. In addition motivation and empowerment to improve their physical and mental well-being and a change of focus from illness to health was reported. One patient expressed: "Exercising brings out the healthy side of me. You feel you're in control and a little more healthy than before".
Conclusions: The patients reported the individually adjusted exercise program to be effective, it gave them a sense of improved coping and well-being. It is a need for larger scale studies evaluating various types of training programs in several patient sub-cohorts.

Abstract number: 524
Presentation type: Poster
Session: Symptoms

Blood transfusions in palliative care

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Background: Blood transfusions can be used to palliate symptoms in the presence of anaemia. Little is known about effect on physical function or survival in terminally ill patients.
Aims: Calculate prevalence of transfusion use §Study an objective measure of physical function post transfusion §Investigate survival post transfusion.
Method: A retrospective survey was undertaken to collect data on all patients transfused in a year at 8 palliative care inpatient units. Demographic, transfusion and survival data were collected. Survival was calculated as time from first transfusion to death. From the largest hospice we collected additional information on physical function using the modified barthel score. A sub-set of 30 transfused inpatients were compared with 30 non-transfused inpatient controls for change in barthel score a week post transfusion/admission and survival.
Results: From 8 units (2460 admissions): §164 patients received 650 units of blood on 230 occasions §83% of transfusions were as an inpatient §5.7% of all hospice inpatients received a transfusion §Most transfusions were of 2 (39%) or 3 (37%) units §71% of patients had a single transfusion overall §Mean (SD) survival post transfusion: 75 (82) days, median 42, range 0–436 days. Post inpatient transfusion: 68 (77) days, median 36, range 0–353 days. Post outpatient transfusion: 120 (103) days, median 104, range 3–436 days §No significant difference was found between transfused inpatients and controls for change in physical function ($p = 0.42$) or survival ($p = 0.43$).
Conclusion: Only 5.7% of 2460 palliative care inpatients were transfused despite the known high prevalence of anaemia and fatigue in palliative patients. Blood transfusion made no difference to physical function assessed by barthel score and compared to a control group. 50% of patients died within 6 weeks of a transfusion, shorter if an inpatient (5 weeks) and longer as an outpatient (15 weeks).

Abstract number: 525
Presentation type: Poster
Session: Symptoms

A practical spiritual tool in the palliative care unit

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A practical spiritual tool in the palliative care unit Lucas Lissnijder[1] (pastor), Lut Rubbens[1](palliative nurse), Johan Menten(MD Ph.D) and Carlo Leget[2] (Ph.D)[1] Palliative CareUnit University Hospital Leuven, Belgium[2] Radboud University Medical Centre Nijmegen, Netherland.
Correspondance:lut.rubbens@scarlet.be
Background: Spirituality, the fourth pillar of palliative care, is the least developed area in theory and practice. Aim Developing a practical tool for spiritual care, both open to patients with different backgrounds and that enables the integration of spiritual care in interdisciplinary approach.
Method: Since May 2003 six nurses and the pastor of the Palliative Care Unit of Leuven were working at the development of a practical tool for spiritual care by an interaction of observation, conceptual clarification and daily care practice. Firstly words, sentences and statements of terminal patients have been collected in order to circumscribe the spiritual domain. Subsequently scientific literature on spiritual care has been consulted in order to interpret the own clinically collected data. Since October 2004 a self-made spiritual checklist is used that is based on the 5 themes, described by Dr. Carlo Leget in his book: "Ruimte om te sterven". Later, this spiritual checklist was further adjusted en completed.
Result: A spiritual checklist which is present in every patient file and statements are registered by the team members.
Conclusion: The spiritual checklist helps caregivers to become aware of the spiritual dimension in palliative care. It provides a shared terminology and framework, it is an important tool for interdisciplinary deliberation and results in more continuity in palliative care.

Abstract number: 526
Presentation type: Poster
Session: Symptoms

Diabetes mellitus in adult palliative care: A literature review and management proposal for hospice inpatients

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There is paucity in the literature on this subject. Papers were reviewed and information collected, to aid in writing clear guidelines for management. The management proposal will be implemented with a concurrent running audit to inform amendments in future. Other local hospices will be invited to participate in implementation, to increase patient numbers in the audit. Literature search All papers elude to the difference in approach around managing diabetes in the palliative care setting. Recurrent themes are: Complicating factors (causing hypo- or hyperglycaemia), Important distinctions (where in disease trajectory, Type 1 vs. Type 2), Aims of treatment (and rationale for these), as well as – The ethical side around end-of-life decisions and communication with the patient and family. The literature lacks clear guidelines on managing specific scenarios. Management proposal Guidelines were assimilated from available literature, as well as from local experience, and grouped into: 1. Pre-existing diabetes, not in terminal phase 1.1 Type 2 diabetics on oral hypoglycaemics 1.2 Type 2 diabetics on insulin 1.3 Type 1 diabetics (with specific reference to recognising DKA) 2. Pre-existing or recently diagnosed diabetes, in terminal phase 3. New diagnosis diabetes, not in terminal phase 4. Hypoglycaemia 5. Corticosteroids and diabetes Each of the groups is summarised into a flowchart and aims to be as prescriptive as possible on managing specific scenarios that might arise in each group. An adapted Actrapid insulin sliding scale that is used in our setting is introduced and potential uses discussed. This sliding scale presents a low, moderate, high dose, then patient-specific scale, on the same chart as blood sugar monitoring and insulin administration for ease of use. It has been trialled in our unit with good results.

Abstract number: 527
Presentation type: Poster
Session: Symptoms

The use of subcutaneous omeprazole in the treatment of dyspepsia in palliative care patients: Case reports and literature review

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Introduction: Dyspepsia is a common symptom, which has multi-factorial aetiology in advanced cancer. Therapeutic intervention includes targeting acid secretion, and proton pump inhibitors are the medication of choice. Maintenance therapy is necessary to prevent recurrence of symptoms. However, in the palliative care population, oral administration may not be possible. Rectal omeprazole and subcutaneous ranitidine have been described, however we postulate subcutaneous omeprazole would be more efficacious and better tolerated.

Methods and results: A medline search for the period of 1966 to 2005 was undertaken to identify the efficacy of various methods of acid suppression and alternative routes of administration. All the references of the papers identified were also reviewed for papers not retrieved by the medline search. A discussion of the literature and 4 case studies of successful use of subcutaneous omeprazole in difficult symptom management are made. The method of administration of omeprazole was by diluting 40mg of intravenous omeprazole formulation in 100 mL of normal saline and infusing over 3 hours via a subcutaneous Saf-T-IntimaTM line.

Conclusion: Treatment of dyspepsia can be difficult when swallowing and conscious levels are impaired. Acid suppression forms a key part of symptom management with the literature supporting the superiority of Proton Pump Inhibitors (PPIs). The subcutaneous route of administration of medications is often preferred over the rectal route by patients and intravenous cannulation causes increased patient discomfort. The cases reported demonstrate that discontinuation of oral omeprazole can lead to symptom relapse, and that good symptom relief is obtained with omeprazole subcutaneously. Further prospective studies are needed to delineate this further.

Abstract number: 528
Presentation type: Poster
Session: Symptoms

Use of corticosteroids in palliative patients in a tertiary swiss hospital: A retrospective study

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Introduction: Corticosteroids (CS) are frequently prescribed in palliative medicine in order to relieve both specific and non specific symptoms. Evidences about their real effectiveness lack in the medical literature. Long term use of CS has a high incidence of adverse effects. The aim of this study is to collect the type and modality of prescription of CS in patients of a tertiary hospital who were followed by a palliative care consultant team (PCCT) and died in hospital.

Method: patients followed by our PCCT who died in hospital over a 12 month period (July 2004 to July 2005) were first selected. We then analyzed retrospectively data of patients receiving systemic CS. Details were obtained on the type, the dosage, the route of administration, the indication and documented adverse effect of CS. Demographic details and diagnosis (cancer/non cancer) were also obtained.

Results: 207 charts were reviewed. The total number of patient receiving CS was 49 (24%). 43 patients (88%) had a cancer diagnosis. The mean duration of hospitalisation was 23 days. Indication for CS was specific in 53% (n = 26). The most common specific indication was cerebral metastases (n = 11), while pain (n = 12) was the most common non-specific indication. 47% of patients (n = 23) were already taking CS at hospital admission. CS prescribed in hospital was dexamethasone (n = 30), prednisone (n = 10) and methylprednisolone (n = 6). The mean duration of CS use was 14.2 days (range 2–40). The percentage of patients who received CS until day of death was 65% (n = 32). Documentation of adverses effects was clear only for 27% of patients but the two most frequent ones were hyperglycemia and oral candidosis.

Conclusions: both specific and non specific indications for CS are well documented, but modality of prescription varies from one medical team to another. Documentation of adverse effects is insufficient. A more rigorous and prospective trial is warranted

Abstract number: 529
Presentation type: Poster
Session: Symptoms

Terminal cancer patient's hydration at the end of life: A multicentric prospective study in lombardia (Italy)

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Introduction: Subcutaneous or intravenous hydration in terminal patients often presents clinical and ethical dilemmas and there is no agreement on the clinical procedures.

Aims: To know and compare the effective use of terminal cancer patients' hydration taken care from the Palliative Care Units (PCU), in different settings, during the 15 days which precede the exitus.

Patients and methods: A prospective, descriptive study of the hydration at the end of life was undertaken in nine PCU: data were collected from 320 patients over three months period. Patients were followed in the last fifteen days, until death, in different settings: home, hospice and hospital; in order to compare the choice criteria, the quantity and the quality of the infusion treatment and the eventual interruption. Data were registered on a computerized, specially designed, chart listing 36 data in three items: patient and pathology features, infusion's type and duration, patient and care-giver's clinical and psychological motivation.

Results: 96 of 320 patients (30%) treated in 9 PC Units (44% Hospice; 55% at home, 1% Hospital), received parenteral hydration at the end of life for mean 8,4 days. Mean 850 ml/die fluids were injected by CVC (25%), subcutaneous (21%) or intravenous injection (53%). The patients more frequently hydrated were: 50% affected by throat cancer, 43% affected by colon-rectum cancer and 35% haematological patients. Hydration was carried out in order to control: vomiting, dehydration and delirium. Nearly 30% of treatment was influenced by patient's or caregivers' psycho-emotional needs.

Conclusion: In spite of different settings, 70% of patients isn't treated by hydration during last 15 days of life. The treatment is the same in every different PCU. The kind of cancer defines the need of hydration at the end stage of life. These data are useful to plan hospice and domiciliary assistance at the end of life; it's also useful improving our knowledge about these data.

Abstract number: 530
Presentation type: Poster
Session: Symptoms

Subcutaneous antibiotic infusions: a preliminary experiment

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Introduction: Interest exists in expanding the subcutaneous (SC) route to administer parenteral antibiotics. A preliminary investigation was planned to investigate the toxicity of antibiotics administered via SC infusion.

Method: The author, underwent periodic infusions of antibiotics using standard intravenous (IV) butterfly needles placed in a SC abdominal site. All infusions utilized standard hospital pre-prepared IV bags of the antibiotics with the recommended parenteral fluid. The author alone placed each SC site and administered each infusion utilizing an IV pole, standard IV tubing and gravity infusion. No infusion pump was used. Observations of the SC site and recording of SC site pain scores (0–10) were performed for all infusions.

Results: A total of 12 antibiotics were administered. Nine infusions were completed with minimal discomfort (0–2/10 pain) and no erythema occurring. Infusion times ranged from 6–60 min. for volumes ranging from 50–100 ml. These infusions included: Cefazolin 1 g, Cefuroxime 750mg, Cefoxitin 1 g, Ceftriaxone 1 g, Ceftazidime 1 g, Cefepime 1 g, Ampicillin 1 g, Clindamycin 600 mg, and Pipercillin 4 g. Three antibiotic infusions were not able to be completed due to local pain. These included Penicillin G 4 million Units and two infusions of Cloxicillin (500 mg and 1 g). These infusions caused pain scores of 5/10 (Pen G) and 4/10 (Cloxacillin infusions) and local erythema. No tissue necrosis, abscesses, other soft tissue complications or allergic reactions occurred from any of the infusions.

Discussion: It appears that many antibiotics may be well tolerated as a single SC infusion. Further study is needed to determine the toxicity from a course of treatment utilizing SC antibiotic infusions. Other limitations of this experiment include the use of a single healthy volunteer, pain reporting without blinding, and absence of pharmacokinetic data reporting serum antibiotic levels.

Abstract number: 531
Presentation type: Poster
Session: Symptoms

Parancentesis: Its feasibility and complication during home hospital treatment

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Introduction: Home Hospital Treatment of terminal cancer patients (pts) makes it possible to carry out invasive procedures in the patient(pt)'s own home. We evaluated the feasibility and risks of complications in paracentesis in the pt's home.

Methods: In a retrospective observation study from January 2004 to September 2005 we studied 26 pts with malignant ascites. We noted the number of days of home treatment, the average amounts of fluid evacuated, the use of albumin and complications.

Results: We performed and evaluated 73 paracentesis at home in 26 pts. 1 was excluded due to a diagnostic error. The patients' mean age was 66.4 years. Only 1 paracentesis was ultrasound assisted; 2 others were performed in hospital because of confined ascites. 18 pts (72%) died at home, and 7 (28%) in hospital. 14 pts underwent only 1 paracentesis, 9 pts from 2 to 6, 1 pt 14 and another pt 15. We performed 1 paracentesis for every 29 days of assistance (2135/73). The average amount of fluid evaluated was 3200 ml (range 100–9000) in 73 paracentesis. 1 paracentesis was stopped immediately due to blood loss and 2 were stopped after 200 and 1800 ml respectively because of chylous fluid. For the 14 pts with only one paracentesis albumin was never used; for pts with 2–6 paracentesis 100 ml of 20% albumin was used, in each case, in 4 pts; in pts with 14 and 15 paracentesis albumin was administered during paracentesis and during the intervals between. There were no surgical or medical complications.

Conclusion: Paracentesis at home was carried out in 73 of 75 cases (97.3%), was not associated with any significant complications, reduced hospital costs, and involved hospitalisation only when death was imminent. Of the 7 pts who were hospitalised the average number of days spent in hospital was 4, compared to an average of 85.4 days (range 7–627) in home assistance. The study also shows that the use of albumin in malignant ascites is indicated only in the case of repeated paracentesis.

Abstract number: 532
Presentation type: Poster
Session: Symptoms

Cachexia: Lives, bodies and loss. the social impacts of cachexia induced weight loss in advanced cancer patients

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Background: Cachexia occurs in patients with cancer, particularly hormone insensitive malignancies. Weight loss, anorexia and poor performance status characterise the syndrome which leads to an increasing 'skeletal appearance' Social understandings of weight loss and self-image in palliative care are largely unexplored.

Aim: To critically explore the social impacts of cachexia induced weight loss in advanced cancer patients. Sample: 12 purposively sampled patients (6 men, 6 women: 49–86 years) with advanced cancer and weight loss ranging between 8–43% were recruited via 2 palliative care teams

Methods: One hour in-depth interview. Topic guide was developed following literature review and theoretical synthesis of Bury's (biographical disruption) and Charmaz's (loss of self) work. Interviews were recorded, transcribed verbatim and checked for accuracy.

Analysis: Readings of transcripts for familiarisation. Inductive generation of original codes via content analysis. Deductive concepts identified from theoretical framework and existing literature. Findings contextualised within existing literature to aid generalisability.

Results: 1) Physical self: awareness of altered body shape. Reduction in body size, strength and energy and perceived attractiveness compound negative feelings associated with prognosis. 2) Psychological self: lowered self-esteem and increased social anxiety. 3) Social self: awareness of reactions from others and development of strategies to reduce social rejection.

Conclusions: Cachexia related weight loss negatively effects body image and sense of self. Perceived negative attitudes from others compound the effects. Practitioners need to be aware of the multi-faceted impacts of cachexia related weight loss as well as developing psychological support for patients and their families/carers. Body image across palliative conditions needs to be further understood and social theory is a useful vehicle to achieve this.

Abstract number: 533
Presentation type: Poster
Session: Symptoms

Olanzapine in the management of nausea and vomiting in palliative care

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Introduction: Several antipsychotics are used to treat nausea and vomiting in palliative care. Olanzapine is an atypical antipsychotic which is an antagonist at D1, D2, D4, 5HT2A and 5HT2C receptors and also binds to H1, muscarinic and alpha1-adrenergic receptors. Passik and colleagues reported a phase I trial of olanzapine for vomiting associated with chemotherapy (1). Its use for nausea and vomiting in palliative care has been less commonly described than that of other antipsychotics.

Aim: To describe the effectiveness of olanzapine for control of refractory nausea and vomiting in an acute hospital setting.

Methods: We retrospectively studied the notes of five patients who had received olanzapine for refractory nausea in an acute hospital setting (February-July 2005).

Results: 4 patients with haematological malignancy (2 ALL, 2 AML; including 3 on cyclosporin) and one with chronic pancreatitis received olanzapine for refractory nausea and vomiting. They had previously tried at least two of the following antiemetics: metoclopramide, cyclizine, haloperidol, levomepromazine and ondansetron, but had persistent nausea. 3 experienced excessive sedation with levomepromazine. Olanzapine was effective and well tolerated by all 5 patients at doses from 2.5mg twice daily to 5mg twice daily. In particular, the patients who had experienced intolerable sedation on levomepromazine found that olanzapine did not cause undue sedation.

Conclusion: Olanzapine can be a useful oral antiemetic, particularly in patients with intractable nausea for whom first line antiemetics are unsuccessful and for whom levomepromazine is too sedating.

Reference

1. Passik SD, Navari RM, Jung SH, Nahy C, Vinson J, Kirsh KL, Loehrer P (2004) A phase I trial of olanzapine (Zyprexa) for the prevention of delayed emesis in cancer patients: a Hoosier Oncology Group study. Cancer Investigation, 22(3): 383–8.

Abstract number: 534
Presentation type: Poster
Session: Symptoms

Falls of patients hospitalized in palliative care ward

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Objective: To compare falls of patients (pts) in a palliative care ward with those occurring in general geriatric wards.
Method: Retrospective analyses of falls questionnaire reports during the year 2004.
Results: 148 patients were admitted in the palliative care unit and 69 reports were completed about 42 pts. 24 were males and median age was 76.5 ± 11.5. 40 pts had end stage cancer and 2 terminal cardiac illness. 67% had no previous history of falls. Factors associated with falls were misjudgement of pts' own capabilities (75%), delirium (67%) and poor general condition (54%). Concomitant medications included neuroleptics (43%), benzodiazepines (32%) and diuretics (17%) 35% of pts were totally dependent for ADL and 11% required walking aids. Information about risk of falls was present in the medical file in 55% of cases and preventive measures were taken in 35% 87% of falls occurred in patient's room and 10% in the toilets. Comparison with 653 falls that occurred in geriatric units during the same period showed significant differences ($p < 0.001$). 161 pts were males and median age was 86.1 ± 6.7. Falls mainly occurred in pts with previous history of falls and better mobility, less delirium and better general condition. Pts were receiving more diuretics but less neuroleptics. Falls occurred more frequently outside pts' room and poor lightning was regularly implicated.
Conclusion: Characteristics of pts' falls in a palliative care ward markedly differs from those in geriatric wards and this must be taken into account to improve on preventive measures. Available data about falls in the elderly may not be applied to palliative care pts without additional and specific precautions.

Abstract number: 535
Presentation type: Poster
Session: Symptoms

Day time sedation under an oral opioid therapy with morphine or hydromorphone and its treatment with stimulants: A prospective, comparative evaluation of 120 patients with cancer pain

Stefan Wirz, **Hans christian Wartenberg**, **Joachim Nadstawek**, University of Bonn, Bonn, Germany, **Uwe Junker**, Sana Clinics, Remscheidt, Germany

Introduction: Aim was the evaluation of patients with strong sedative effects under an opioid therapy either with oral morphine (m) or hydromorphone (hm). After identifying a subgroup suffering from sedative effects, a therapy with stimulants was induced.
Methods: and patients After ethical approval of the local ethics committee and patients written consent we enrolled 120 cancer pain patients into this prospective comparative, observational study. Using standardized interviews and questionnaires we assessed sedative effects as day time sedation and dizziness by Numerical Rating Scales, beside demographic and medical data. Patients with an NRS-Score (sedation and/or dizziness) of higher than 5 received a therapy with stimulants. Data were analysed descriptively.
Results: Cancer diagnoses were lung cancer, gastrointestinal and urogenital tumours. 22 Patients revealed NRS scores (sedation or dizziness) higher than 5, indicating a stimulant therapy. All patients received a high dose therapy of m (462,9 mg/d) or hm (morphine equivalent (394,4 mg/d) with similar NRS for pain. Day time sedation (NRS 4.2 hm, 7 m) and dizziness (NRS 1.8 hm, 2.4 m) were more severe with morphine than with hydromorphone. The administration of stimulants improved sedative effects and dizziness, especially of morphine, (NRS sedation 5.6 m, 4.2 hm) (NRS dizziness, 1.5 m, 2 hm).
Conclusion: Sedation is common in cancer patients with an opioid therapy. Stimulants can control this symptom. In this study, sedation as a symptom that indicates a stimulant therapy, was less severe with hydromorphone than with morphine.

Abstract number: 536
Presentation type: Poster
Session: Symptoms

The dyspnea and interference of function in advanced cancer patients

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Dyspnea can be a dominant and incapacitating symptom in advanced cancer patients. It is an independent predictor of will to live. It is not well understood and less well managed, due to dearth of research on this subject in advanced cancer patients. Dyspnea as a lonely symptom or in association with other parameters is a prognostic indicator of survival. In our recently concluded descriptive study of dyspnea in advance cancer patients to characterize and find the correlates of dyspnea, we have also analyzed the interference of dyspnea with general activity, mood, ability, normal work, relations with other people, sleep, enjoyment of life. These questions were adopted from Brief Pain Inventory.
Results: The analysis was done using analysis of variance, The ANOVA procedure. Dyspnea was categorized based on mild, 1–3, ($N = 14$), moderate,4–7 ($N = 37$), and severe, 8–10($N = 19$) on a 0–10 scale. General activity was found to be significantly related to dyspnea, $p = 0.0276$. In the mild category the mean score of interference of 3.142. in moderate category,4.51, and in the severe category, 6.05, Walking ability was significantly correlated with dyspnea, $p = 0.0081$. in mild category, the interference mean was 5.21, in moderate category, 5.86, in severe category, 7.89. Normal work, including work outside and housework, was significantly correlated to dyspnea, $p = 0.0506$. In mild category the mean interference was 6.50, in the moderate category, 4.52, and in severe it was 6.75. Mood, relationship with other people, sleep, and enjoyment of life were not significantly correlated with dyspnea.
Conclusion: Dyspnea is a devastating symptom in advanced cancer patients. We found a strong association of dyspnea and physical activity domains, interfering with daily functions and hence quality of life in these patients, but was not associated with sleep, mood, and relationship with people, and enjoyment of life.

Abstract number: 537
Presentation type: Poster
Session: Symptoms

Surgical palliation of advanced gastrointestinal tumors: Results from the decision and outcomes in palliative surgery (DOPS) trial

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Introduction: Patients with advanced gastrointestinal tumors suffer progressive symptoms that decrease their quality of life (QOL). Surgical palliation and its effect on QOL in these patients is poorly studied. This prospective study seeks to measure the effect of operative interventions on symptoms and QOL in patients with advanced gastrointestinal malignancies.
Methods: Patients undergoing WHO-defined palliative operations were prospectively followed by research nurses with monthly Quality of Life (QOL) and Distress Thermometer surveys until 6 months postoperatively. Comparisons were made between preoperative and 3 month postoperative data. Parameters of physical, psychological, social, and spiritual QOL were measured on a scale of 0 (worst) to 5 (best). Frequency of occurrence and degree of distress caused by that specific symptom were scored from 0 (rarely/not at all) to 5 (most of the time/severely).

Results: Thirty-five patients had gastrointestinal cancer. The median age was 56 years. The most common symptoms were pain ($n = 13$) and obstruction ($n = 8$). In 17 patients, this was the first operative procedure. Thirty-three operations were abdominal. Six patients experienced complications and 3 required reoperation. Ultimately, 34 patients (97%) were discharged home. When preoperative data was compared to 3 months postoperative, the frequency of the primary symptom improved by 2.22 ($p = 0.001$) and the distress it caused decreased by 1.82 ($p = 0.004$). Over the study duration, physical QOL decreased by 0.60 ($p = 0.009$), psychological QOL decreased by 0.50 ($p = 0.015$), social QOL decreased by 0.48 ($p = 0.017$), spiritual QOL decreased by 0.42 ($p = 0.008$), and overall QOL decreased by 0.57 ($p = 0.012$).

Conclusions: Because of the unrelenting nature of gastrointestinal tumors, QOL over time will inevitably decrease. Palliative operations effectively improve symptom frequency and distress without greatly affecting the expected decline in QOL parameter.

Abstract number: 538
Presentation type: Poster
Session: Symptoms

Randomized, double blind, placebo-controlled trial of docusate for preventing and treating constipation in advanced cancer patients

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Introduction: Constipation has been recognized as a highly prevalent and troublesome symptom in advanced cancer patients. Docusate is a stool softener which has been widely used for management of constipation in Canada, based on inadequate evidence. The need for further investigation has been identified.

Research aim: To assess the effectiveness of docusate in preventing and treating constipation in advanced cancer patients who are admitted to a hospice with a life expectancy of less than two months.

Methods: Randomized, double-blind, placebo-controlled trial to compare current standard treatment (docusate with sennosides) to sennosides alone. A total of 70 patients (35 patients in each group) will be recruited from a hospice unit in Edmonton. Patients must be on opioids chronically and able to take oral medication. Duration of treatment will be 10 days. The main outcome measures will include frequency and consistency of stool, other interventions required in order to maintain bowel movement at least once every three days, difficulty defecating, and sense of inability to evacuate completely. Recruitment began on 12 December 2005. The total number of patients admitted is 21, as of 27 January 2006. Five patients met the criteria, and 3 patients agreed to participate. Data from the first patient was removed due to protocol violation. Currently, two patients are on the study phase. So far, recruitment has been hampered by restrictions in admission to the hospice because of a caregiver shortage and an infectious disease outbreak. Recruitment at a second hospice is planned.

Implications: This study will provide insight into the role of docusate in management of constipation in advanced cancer population, although recruitment of patients at the end of life has been challenging. If docusate is found to not be effective, then the study has the potential to enhance care by reducing the number of medications taken by these patients and the associated clinical and economic burden.

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The effects of Aroma self massage in hands on pain, depressive mood and anxiety in breast cancer patients

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Aroma therapy is one of the alternative medicine. It was well known to have an analgesic, antidepressive and anxiolytic effects. This study is designed to investigate the effect of aroma self hand massage on vital signs, pain, depression, anxiety and stress in breast cancer patients. 32 female patients over 20 years old were divided into two groups by non-blinded randomized controlled method. Patients in the aroma group ($n = 15$) massaged their hands twice a day using aroma oil by themselves in their home for 2 weeks. However, those in control group ($n = 17$) had not received any intervention during study periods. Pain intensity, state anxiety, depression and stress of subjects were evaluated three times (0, 1, 3 weeks) using Visual Analogue Scale (VAS, 0–10 cm), State Trait Anxiety Inventory (STAI), Beck Depression Inventory Scales (BDIS), Brief Encounter Psychosocial Instrument (BEPSI revised edition). Pain Intensity decreased in the aroma group compare with control group. (VAS changes -0.83 ± 1.01 vs 0.38 ± 0.86, $p = 0.005$). The numbers of accompanying symptoms ($p = 0.044$), depression score ($p = 0.001$) and anxiety score ($p = 0.008$) significantly was decreased in aroma group, while in control group increased after 2 weeks. However, the stress score showed no significant changes in both groups (0.05 ± 0.85 vs 0.04 ± 0.20, $p = 0.1519$). The depression, anxiety and stress score showed negative correlation with compliance of aroma massage, but statistically no significant. The systolic blood pressure was a little increased in aroma group (4.53 ± 14.43 vs 0.0 ± 7.22, $p = 0.026$), but clinically was not significant. Aroma self massage during two weeks in breast cancer patients alleviates the pain intensity, depression and anxiety significantly.

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